CAPS Independent Advocacy

Lived Experience Led Collective Advocacy and Education

Introduction to the organisation

CAPS is a long-standing **Independent Advocacy** organisation who amplifies the voices of **vulnerable people in Edinburgh**. We provide Individual Advocacy to a diverse range of adults and children in East Lothian and Midlothian as well as facilitating seven different collective advocacy groups which are all mental health related and accessible to **people who live anywhere in Lothian**.
The depth of our work and our reputation as a trusted independent organisation who works with people in a trauma informed, non-judgemental way means that our advocacy projects act as a safety net for people from marginalised groups, who often have no other safe place to turn, when they find themselves at risk.

Independent Collective Advocacy for **people with mental health issues** is a statutory right under the Mental Health Care and Treatment (Scotland) Act 2003 and further expanded upon in the Mental Health Bill 2015. https://www.gov.scot/publications/new-mental-health-act-guide-independent-advocacy-information-service-users-carers/
The entitlement is to **collective advocacy** as well as individual advocacy and applies to people living in the community as well as in hospital.

CAPS Collective Advocacy workers listen to people's views, and what is important to them, and highlight relevant information to inform the many policy and planning forums of Health and Social care that we have a place at, ensuring **the voices of lived experience** are able to **contribute to the design and improvement of services** in future. True co-production in action.
Practitioners and service providers also learn from people's lived experience by attending free training events facilitated by CAPS and led by people themselves, contributing to a **better educated and compassionate workforce.**

Lived Experience-Led Collective Advocacy and Education Figures 2024 – 2025

753

current collective advocacy group members

459

people attending experience led training

For every £1 funded

£9.96

of social value delivered*

Value of free training delivered

£ 45,900

(@ £100 per attendee)

*See Page 9 for calculations using 'Social Value Engine'

Additionally, research published in Jan 2025 by 'Social Finance' https://www.socialfinance.org.uk/assets/documents/Independent-advocacy-for-independent-lives.pdf calculated that for **every £1 spent, independent advocacy generated benefits worth £12** (savings of approximately £7 to the National Health Service and £5 to the local authority). This was because of savings made by avoiding the need to use more expensive services: Independent-advocacy-for-independent-lives.pdf

Introduction: Lived Experience-Led Collective Advocacy and Education

These projects provide essential lived experience input to service planning, design and education helping the Edinburgh IJB fulfil its statutory obligations.

These projects are designed to provide collective advocacy to marginalised groups of people who identify with specific conditions or 'labels', providing not only unique spaces to allow them to have their voices heard but additionally providing safe, trauma informed, authentic peer spaces.

These projects support several of the IJB's priorities in areas such as:

- Early intervention and prevention
- Protecting our most vulnerable
- People supported under the Mental Health Act:
- People affected by Health Inequalities
- Using our resources effectively

All our projects are underpinned by the national Principles of Independent Advocacy, led by the participants, and support several of the IJB's responsibilities to deliver the national health and wellbeing outcomes:

- People are able to look after and improve their own health and wellbeing and live in good health for longer
- People who use health and social care services have positive experiences of those services, and have their dignity respected
- Health and social care services contribute to reducing health inequalities

Within this funding allocation there are six distinct projects:

- Oor Mad History
- Experience of Eating Disorders – Seen but not Heard
- Experience of Personality Disorders – Much More Than A Label
- Lothian Voices
- Experience of Psychosis
- Experience of Trauma

1. Oor Mad History

This project was one of the first Collective Advocacy projects for CAPS Independent Advocacy in 2008. It began as a group of interested people along with a community history worker. After following the Mad Studies ‘Ryerson course’, online from Canada, our worker, along with a group of people took this learning and created **the first Scottish Mad People’s history and Identity course**. This was then delivered in conjunction with Queen Margaret University. Since then, the Oor Mad History project has grown and expanded into a thriving mental health community history collective, providing access to the **stories of people with lived experience of mental health**.

Key activities and highlights

There are currently **148** people involved in this project

- **Presented on Mad Studies** at several conferences - Durham, Lancaster, keynote speaker at Cork “mad studies conference”
- Audio **recordings of people’s experiences produced on DVD’s** alongside the first OMH book 2010
- **Collectively wrote 2 books -** 'Oor Mad history' & 'Ten years on'
- **Mad People History & Identity (MPHI) course** QMU ran from 2014 to 2023
- Building and curating an **Oor Mad History archive** which currently holds over **20000 records** and is hosted in the Lothian Health Services Archive.
- Building a **digital archive** of the material we hold to increase visibility and accessibility.
- Through an initial objective of Oor Mad History to be involved in the Scottish Mental Health Arts and Film Festival, our **Arts as Advocacy project and Out Of Sight Out Of Mind exhibition** developed.
- A **Mad Matters community course** for people across Edinburgh and the Lothians was developed and supported by CAPS by a group of people who’d studied MPHI in 2016

OOR MAD HISTORY and TEN YEARS ON

The creation of the first 'Oor Mad History' book came from a desire to capture the work that the group had been undertaking with their development of an archive of 'The mad movement' to make this available and accessible to others. The purpose would be to **"archive, celebrate and promote the history of the mental health service user movement in Lothian."**

The book gathered experiences from across Lothian to give a voice to the changing treatments and attitudes to Mental Health. It was an empowering project that produced a work that has been **and continues to be educational to people in the community, academics and decision makers.** You can read the first book here

The group were keen to continue the success of the first book and so came together again 10 years later to write another book chronicling the developments of the **10 years since the first book.** Download the book here.

Some people that were involved in the first book returned to be involved along with new people coming to the project for the first time.

This book was also published and widely distributed across Edinburgh and the Lothians for the education and information of current and future generations of people in the menta health world, to hear from people with **lived experiences in their own voice.**

ARCHIVE

The Oor Mad History archive is a **live community history archive** that has been growing and expanding for 16 years. The physical content is shared across CAPS Independent Advocacy offices and the **Lothian Health Service Archive housed at Edinburgh University Library.**

The archive currently contains over **90 oral history interviews** along with reports, posters, other written material as well as t-shirts, badges and many other items.

This **was Scotland's first Community Mental Health archive** and remains a vibrant and important resource in the Lothians for information on Mad History. Over the last few years CAPS Independent Advocacy have supported and overseen huge developments with the archive that have allowed us to continue the work that previously ran out of Queen Margaret University by combining a **free educational workshop**, with our archive material at Edinburgh University. We now run a four week **'Understanding Oor Mad History'** course within Lothian Health Services Archives that draws on the material in our archive as well as highlighting other topics in 'Mad Studies' such as Intersectionality, Treatment and Confinement and Activism.

The development of a **digital archive through a dedicated website** has catapulted our project into the 21st century. This will mean that practitioners, academics and researchers across Edinburgh, the Lothians and beyond will have **immediate access to the 20,000, and growing, items in our archive.**

2. Experience of Personality Disorders – Much More Than A Label

This project began in 2009. It was developed in recognition that there was little understanding and even less services available for Personality Disorder in Edinburgh and the Lothians.
The purpose of the project was **to create a toolkit of information for people with Personality Disorder** (specifically Borderline Personality Disorder) that would **"promote better understanding and support for people with experience of personality disorder diagnosis."** Along with producing the toolkit the project has been involved in local and national strategy and networks and has designed and delivered Lived Experience workshops to a wide variety of audiences.

Key activities and highlights

There are currently **108** people involved in this project

- **Toolkit**
- Input into Women with "**Multiple with multiple and complex needs" agenda**
- Poster presentation at NHS Scotland's Research Conference
- **2-day workshop** - extensively delivered across Edinburgh and the Lothians - Universities, social workers, nurses, psychiatrists etc
- Panel members on Mental Health Nurse evaluations Napier University
- **3 hour workshop** - extensively delivered across Lothian
- Presented at Scottish Personality Disorder Network (SPDN) conference and initiated **Service user members of the SPDN steering group for the first time.**

TOOLKIT

The toolkit that CAPS Independent Advocacy supported a group of people with lived experience of attracting the diagnosis of 'Borderline Personality Disorder' to create, was **unique and groundbreaking** and remains to this day to be **one of the few resources available linked to this diagnosis.** It is cited as one of only two resources available in https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr214.pdf?sfvrsn=ed59144_2
.When the group first designed the toolkit they hoped it could have a variety of purposes, they wanted it to be a starting point **for discussion amongst staff working with people who had this diagnosis**, a way for people to find out what was helpful

and unhelpful to people who had lived experience of this diagnosis along with being a useful tool to people to use with workers as a way to explore their experiences and **promote better working relationships**.
The toolkit has been distributed throughout Edinburgh and the Lothians in Hardcopy and is available online through our website. https://capsadvocacy.org/collective-advocacy/experiences-of-personality-disorder/

WORKHOP

Following the development of the toolkit the group undertook a consultation, with over **130 respondents**, to discover what people would want to include in a **workshop educating people on the lived experience of people who attracted this diagnosis.** From the responses and their own lived experience they developed a **two day training course** in collaboration with the Royal Edinburgh self-harm nursing team. This training was delivered to **hundreds of students, nurses, statutory services, third sector workers and people with their own lived experience** over a period of 8 years pre-covid 2019 lockdown. The group continued to deliver a reduced version of the course during lockdown and have since continued to deliver this **workshop in person and remotely across Edinburgh and the Lothians to hundreds more people.**

SPDN

Amongst other presentations the group presented their work to the **Scottish Personality Disorder Network conference** and were able to highlight that there was a lack of lived experience representation in the network and **successfully initiated service user members of the SPDN steering group for the first time.**

WOMEN WITH MULTIPLE AND COMPLEX NEEDS

The group were **asked by NHS Lothian to be part of the stakeholder group for the Lothian Matched Care Model for 'Women with multiple and complex needs',** as part of the NHS Lothian's Joint strategy for improving mental health and wellbeing – "A sense of belonging".
Members of the group, supported by CAPS Independent Advocacy, attended the steering group meetings and **contributed lived experience voices to the development and design of this care model.**

CAPS
Seen But Not Heard

3. Experience of Eating Disorders – Seen But Not Heard

This project began in 2013 in response to calls for more information about eating disorders and a successful application to the Butterfly Bursary to create a **film about people's experiences of eating disorders** to use in raising awareness and reducing stigma. Following this, two volunteers involved in the film came forward to support a further application to the Butterfly Bursary in 2014 to take the film into **schools to raise awareness of eating disorders amongst young people** as an early intervention tool. The project was able to secure further funding in 2015 from the Butterfly Bursary to make **a film in collaboration with CAMHS specifically about the experiences of young people** and continue to take this into schools as part of their PSE programme. In addition to this work a large scale survey of people's priorities led to the project successfully receiving funding from See Me to **produce 2 booklets about Eating Disorders** – one for people who identified as having an eating disorder and one as **a resource for GPs** to use when dealing with patients who presented with difficult relationships with food. The project has designed **lived experience workshops** that are delivered across Edinburgh and the Lothians in many diverse settings and have collaborated with other CAPS collective groups to provide joint training to hundreds of people over several years.

Key activities and highlights:

There are currently **131 people** involved in this project

Since its inception the Seen But Not Heard Project has worked on a number of key issues around eating disorders and has designed, created, delivered and presented in a variety of ways. They have:

- **Created two films,** one specifically around young people's experiences of eating disorders
- **Produced resource booklets for GPs** and for people identifying as experiencing eating disorders
- **Designed and delivered workshops** that have been delivered in high schools across Edinburgh and the Lothians as part of the PSE programme as well as universities, hospitals and community venues.
- Been heavily involved in the **redesign of Eating Disorder Services in the Lothians**

- Helped **rewrite two books in the 'Overcoming' series of books** written as self-help guides using cognitive behavioural techniques
- **Campaigned successfully for the creation of a new book** in this series on the subject of binge eating, which they are **co-authoring.**
- Published an **article in the International Journal of Mad Studies.**
- Undertaken lived experience research on the topic of **Men and Eating Disorders**

FILMS

The two films produced by the group have been used widely in a huge variety of settings. Throughout Edinburgh and the Lothians the **'Spilling the Beans'** film co-created with CAMHS has been screened in **more than 15 different high schools across the 4th, 5th and 6th year pupils** over a number of years. This work has had a huge impact on not only pupils but parents and teachers as well.

> *'My mother has an eating disorder and I never really got it. I thought it was her just trying to be really skinny and not liking food or something. It really frustrated me because I didn't understand why she was not eating when she was already thin. I get it a bit more now, it's not really to do with food or weight, it's how she is feeling.'*

> *"The film was great – The experience of people with eating disorders speaks louder than information on leaflets or posters that I might have in the past ignored"*

GP BOOKLETS

One of the key messages that the group heard from people was that people's **interactions with GP's were not positive**. There seemed to be a lack of information about how to manage difficulties with eating, a significant proportion of GP's were **unaware of specialist services that were available**, in order to refer people and there was a general feeling that GPs were not comfortable or equipped to talk with people about this topic.

Following a large survey amongst GP's that gathered a wealth of information about their current knowledge, the group created **two separate booklets** as companions to each other. One that could be used by people who had there own questions about their relationship with food or a diagnosis they had been given: https://capsadvocacy.org/wp-content/uploads/2021/10/Living-with-an-Eating-Disorder-What-you-need-to-know-2015.pdf

and one that **was distributed to every GP surgery in Edinburgh and the Lothians** as a resource for them to have good conversations with patients who were diagnosed or had questions about eating disorders. https://capsadvocacy.org/wp-content/uploads/2025/06/See-Me-GP-info-booklet-blue.pdf

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Lothian Voices

4. Lothian Voices

This project developed in 2013, around a time when significant consultation had been carried out across Edinburgh to **identify people's priorities around what was important to them in the services they received, and how they influenced them**. It was highlighted that people felt that there were no 'protected' spaces for them to talk to peers about what they needed from services and what was important to their mental health. CAPS Independent Advocacy introduced the **'People's Conference' as a way to engage with people in a safe environment that was exclusively for people who identified as having lived experience of mental health issues**, where their voices could be heard in the way that they wanted them to be.

Over the years the project has run **11 People's Conferences** on a wide variety of topics, along with presenting their findings to decision makers, **responding to consultations** from a lived experience perspective and been active members in Cross Party Parliamentary groups, focus groups and working groups in Edinburgh and the Lothians.

Key activities and highlights

There are currently **151** people involved in this project

- **People's Conference** for 11 years
- Presented people's views at **5 years of Taking Stock & twice at Thrive conferences**
- **Members of CPG** for Mental Health for 4 years until dissolution
- Input the **voice of lived experience** into strategy consultations across Edinburgh and Nationally
- Members received **Edinburgh Volunteer award**

PEOPLE'S CONFERENCE

The People's Conference has provided a **unique space for people with lived experience to come together** to discuss and decide what is important to them, and to plan an event that highlights people's voices about the topic, and **to present the day's findings to decision makers**.

The first People's Conference was an attempt to ensure that people were able to feed into the NHS strategy at the time - 'A Sense of Belonging'. People gathered to discuss what was available in their local area, what worked well for them and **identified where the gaps were.**

Following the event and a report being produced by the steering group, supported by CAPS, they presented their findings at the **NHS annual conference – 'Taking Stock'.**

This revolutionary process started a unique collaboration between people with their own lived experience and the people who commissioned services that **ensured that the voice of lived experience was heard in decision making and policy development across services.**

Over the years the People's Conference has tackled topics such as **– The Housing Crisis, Welfare Reform, parity of service provision across physical and mental health services, lived experience involvement and many more.**

The group continued to present their findings at the Taking Stock event, and latterly the Thrive conference.

> *"Felt empowered and listened to, and that my experiences and opinions were valued and listened to."*

CPG & CONSULTATIONS

The group have expanded their activities throughout the years and have been part of **two different Cross Party Parliamentary Groups**, responding to calls for evidence of topics, speaking at oral evidence sessions and campaigning for Lived Experience to be recognised as a required agenda item at all CPG's.

The group have been active in **responding to local and national consultations, such as the Mental Health Law Review and the National Care Service strategy.**

They have been part of focus groups for assessments of the now devolved disability benefit – ADP (Adult Disability Payment) and many other local strategy groups such as the **Place to Live steering group**.

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Experiences of Psychosis

5. Experience of Psychosis

The need for this project was identified in 2010 and was intended to find out about the experiences of people who have had psychosis in order to **inform NHS training** for staff and improve the experiences of people with psychosis when receiving support and treatment. It formed NHS work on **Early Onset Psychosis and CAPS** Independent Advocacy were invited to gather the views of people to inform this work. The project intended to:

- **Consult with people who had had psychosis about their experiences**
- **Work with people with experience of psychosis to develop training materials**

Key activities and highlights

There are currently **83 people** involved in this project.

The experiences of Psychosis project throughout its tenure has been steadfastly **committed to having a place in education,,** be that through their own lived experience workshops they have designed and delivered, to being involved with National Education Scotland in **reviewing and contributing to training resources**. They have:

- Gathered the **views of people with Experiences of Psychosis across Lothian** through surveys and interviews to feed into strategy
- Presented at **NHS conferences**
- Designed and **delivered Lived Experience Workshops** that have been delivered to hundreds of students and workers across Edinburgh and the Lothians.
- Produced a **series of films clips** showcasing people's stories of experiences of psychosis, launched at the **Scottish Parliament**
- Input into the **National Education Scotland** training programme for workers dealing with psychosis
- Members of **the Early Onset Psychosis steering group** with NHS Lothian
- Members of **the APEX (Edinburgh University)** psychology students entry and training panel of experts

6. Experience of Trauma

This project begun in 2015 with a **request from NHS Lothian to gather views of people who had lived experience of Trauma** to inform the redesign of the Rivers Centre – Lothian's centre for psychotherapeutic clinical services for people with past experience of trauma. CAPS Independent Advocacy was part of the Public Social Partnership and was **engaged throughout the relocation and design of the new centre at Fountainbridge Library**.

Key activities and highlights

There are currently **135 people** on the mailing list for this project.

The experience of trauma group has been involved in several different projects involving **embedding trauma informed practice** into workplaces and community settings. They have integrated several different trauma initiatives into their own lived experience workshop including the **ACE Aware Scotland campaign** and the **NES transforming psychological framework**. The group have always been passionate about supporting the agenda **of educating the public on the strengths and resilience that can come with experiences of trauma**. They have:

- **Been a member of the Rivers centre PSP**
- Input into National Education Scotland – transforming psychological trauma framework and training plan – **evaluated Level 1 training**
- Lived Experience input into the **pilot site (Midlothian) for the rollout of NES trauma training.**
- **Lived experienced workshop** designed and recently delivered for the first time

Financial Value of Social and Emotional Benefits

The Social Value Engine is used to illustrate the social value of Collective Advocacy and experience led research.

Using Social Value Engine, **four outcomes** have been selected, and a **conservative estimate** is achieved by reducing the total numbers of people who benefitted to 75%, 50%. & 33% respectively. See Appendix 2 for numbers of people benefitted.

Outcome	Mental Health Proxy	Cost per person	No.of people	75% of people	Value with 0% deflators
Increasing the capability of people to have a say over decisions	Average cost of advocacy	£2150	753	565	£1,214,750
Outcome	**Mental Health Proxy**	**Cost per person**	**No. of people**	**50% of people**	**Value with 0% deflators**
People enabled to fully participate in their community	Value of Participatory engagement	£400	753	377	£150,800
Outcome	**Mental Health Proxy**	**Cost per person**	**No. of people**	**33% of people**	**Value after 4% deflators**
People enabled to fully participate in their community	Value of regular attendance at a local organisation	£2334	753	248	£555,678.72
Total Impact Value					**£1,921,228.72**

Social Value Engine requires us to discount the impact value by 3.5%, to allow for any inflationary effect to reach a **"present value"** figure.

Figures 2024 - 2025

Total present value: £ 1853,985.71

Funds allocated 2024/25: £186,162.00

Value Per £1: £9.96

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APPENDIX 1

Oor Mad History Book
https://capsadvocacy.org/wp-content/uploads/2021/10/Oor-Mad-History-Book.pdf

Oor Mad History – Ten Years On Book
https://capsadvocacy.org/wp-content/uploads/2022/01/OMHBookCompleteLoRes.pdf

Personality Disorder Toolkit

https://capsadvocacy.org/collective-advocacy/experiences-of-personality-disorder/

Living with an eating disorder – What you need to know

https://capsadvocacy.org/wp-content/uploads/2021/10/Living-with-an-Eating-Disorder-What-you-need-to-know-2015.pdf

Eating disorders what you need to know – a resource for GPs.

https://capsadvocacy.org/wp-content/uploads/2025/06/See-Me-GP-info-booklet-blue.pdf

Trauma Service Redesign

https://capsadvocacy.org/wp-content/uploads/2021/10/Trauma-Service-Redesign-2016.pdf

Mental Health Law Review – Lived Experience

https://capsadvocacy.org/wp-content/uploads/2021/10/Mental-Health-Law-Review-Peoples-Response-2021.pdf

People’s Conference Reports

https://capsadvocacy.org/about-caps/publications-and-reports/