

Issue 4
Sept 2026

Regional Mental Health Service (RMHS) Service User and Carer Edition



Health and
Social Care



Department of
Health

An Roinn Sláinte
Máinnystrie O Poustie

A Service User's Perspective

By Cathy Malcolm

I am going to share with you my perspective on why Service User involvement is so valuable, not just to the system, but more so to me individually.

I want to try and shine a light on why it's so important, and how it has played such an important part in my recovery from poor Mental Health.

We are all aware of the pressures on the system currently, and the lack of resources can leave us feeling like we possibly don't matter, or that we are just a number. The frustration, feeling like we aren't being listened to, not included in decisions, is all too familiar and the endless dark days that I thought were never going away.

Yes, I had some really positive experiences with Recovery Teams, a fantastic CPN, and medication at various times, but what really made a difference was finding my voice and starting my involvement journey; 12 years later I have been involved as a service user, and am starting to feel valued and listened to. I am learning that I can bring my lived experience to the table, and help influence some real and meaningful change.

I have had some amazing opportunities that have seen me sit at a very strategic level, alongside directors and chief executives and senior policy stakeholders. These experiences allowed me to develop and grow as a person, gaining knowledge and skills that have helped get to me where I am today.



I have become more confident, gained experience in public speaking, delivering presentations, attending workshops and training and reviewing various policies. I loved every minute and this was reflected in where I have got to with my mental health. Yes, I still have my struggles, but the experiences I've had by getting involved have helped me cope better.

A Service User's Perspective Cont.

And the best thing is; you decide what you do.

There is no pressure to become involved at that very strategic level.

There is a 'menu of opportunities' that you can use to become involved; whether that's at trust level, feeding into consultations, being involved in a working group with something that you have lived experience with, training opportunities, workshops and that's just to name a few.

It's all at your pace, and comfort level, and with endless support and encouragement along the way. And as for me now, the past 10 years of gaining that experience, developing the knowledge and skills I now have, has seen me gaining employment as a Service User Consultant.

My story is an example of not needing statutory services like I used to, because I am now involved in a different way.

I also would like to see more of an awareness, of not just appreciating the value of involvement to the system, but also to us. To finding our voice, to the skills we develop and the experiences we have; which have, in some ways, done so much more for me in my recovery!

We as service users aren't here to complain or criticize, but we are here to connect and compliment.

Connect with you as professionals to help make our mental health services a better experience for everyone! And here to compliment the fantastic work you guys are already doing!

So let us be part of making it better!



The Art of Rediscovering Hope:

A Journey of Creativity and Healing



About Mad Irish Artist

Hi, my name is Marie.
I have been painting and creating my way through some difficult mental health challenges, using art as a way to process, heal, and keep moving forward.

Finding Hope Through Art

The journey has not always been easy.

At times it has felt vulnerable and challenging, but it has also helped me face my fears and, most importantly, rediscover a sense of hope.



Explore My Work

You can view more of my artwork at madirishartist.com and learn more about how creativity has supported me on my journey. I hope my work inspires you to pursue something meaningful to you, even in the face of adversity.

A Carer's Perspective



My name is Pam Nugent, I am the Co-Founder/Chair of **The Laurence Trust**; supporting men and their families living with an Eating Disorder (ED).



I am also a Mum with a Lived Experience of supporting my youngest son who lived with an ED, and sadly passed away at the age of 24 due to this terrible illness.

As a Mum and someone who, along with my family, was not well enough informed about EDs, I tried to understand how it impacts the person living with it whilst managing the impact it had and still has on our family.

We didn't know this is a serious mental health illness; one of the biggest killers due to not only the ED, but the Mental Health issues it brings (i.e. addiction/depression/stress/lack of self esteem and self confidence – all of which is very difficult for a young man to manage!). We thought Laurence was just being 'Laurence' – particular about his hair, particular about his clothes, worried about what his friends thought about him. He became stressed/paranoid about everything - life was a disaster in his mind.

He couldn't relay this to his Mum and Dad, he didn't want us to know he was suffering; every day we worried. Every day we saw Laurence getting thinner, and thinner, and every day we wanted to talk to him but we didn't know how to do that. We didn't see the eating disorder coming; we were blinded by our own stresses and our worry for Laurence.

We are still feeling the impact of this great loss to our family everyday but you learn how to live differently whilst becoming better informed of what an ED is, you can recover with the right professional support.

A Carer's Perspective Cont.

I co-founded The Laurence Trust, with my son Christopher in 2012, to raise awareness to other families and friends to avoid their loved one becoming a fatality like my son.

- We provide education/information by undertaking presentations to community groups; schools and university students.
- Engaging with various journalists in the media who are raising awareness via documentaries and articles based on EDs.
- Running a website to signpost people where to get support and give them information on EDs /running an information helpline and provide support toolbox literature for people who make contact for support.
- We use social media platforms to reach into people who need support.
- We are a member of The ED Forum NI, collaborating with other ED Organisations and Healthcare providers to improve services being offered.
- We engage with NHSS mainland UK to give presentations to support greater education of the lived experience.
- We are part of a Westminster Taskforce Group for the APPG for EDs supporting the improvement of services and raising awareness of EDs to a wider Parliamentary audience.
- We are a member of the PCC MH Engagement Platform.

I joined the MH Engagement Platform, for three reasons:

1. To raise awareness of male eating disorders and the mental health impact it has on men, their carers and families.
2. To engage and collaborate with people who equally live or have the lived experience of mental health, and who want to improve Mental Health Services in NI.
3. To learn about other mental health illnesses apart from an Eating Disorder that people manage in their everyday life whilst bringing normality to improve their own mental health.

I was not prepared for the amazing people I would be engaging with, who humble me in learning about their lived experiences; how they manage on a daily basis, and how giving they are to working towards securing a better healthcare future for everyone.

Thank you for allowing me to be part of this wonderful informative platform.



A Collaborative Approach to Improving Mental Health Services Across the Southern Area



Story from Lara Sutton
SHSCT Service User Consultant

The Southern Area Mental Health Collaborative (SAMHC) was established by the Regional Mental Health Collaborative Board (RMHC) as an area collaborative pathfinder project to test out, improve and embed a coordinated and integrated approach to mental health service planning and delivering across the SHSCT area.

The SAMHC Mission Statement is : **“We are committed to doing our collective best to plan and deliver services that help support good mental health and wellbeing for everyone in the Southern Trust area”.**



In collaboration with all SAMHC members, I lead on Priority 5 of our workstreams, which is; “Enhancing Families, Service Users and Carers Experience”.

We aspire to ensure people with lived experience and their carers have the support and training to enable their effective contribution to help shape mental health services, locally and regionally. Our intended outcomes in this workstream are timely, meaningful engagement with, and empowerment of, families, service users, carers.

Through meaningful collaboration, we aim for better service design, planning, delivery, and review, informed by family, service user and carer lived experiences and needs.

I also Co-Chair the SAMHC Communications Group with my colleague Elaine from the Mental Health Forum, and together with other SAMHC members, we ensure that there is effective two-way involvement and communications with key internal and external stakeholders, including service users and carers, ensuring their views help shape and enhance key communications and engagement relating to mental health service across the Southern Area.

We recently undertook our first annual review and this clearly demonstrated that SAMHC is performing well internally. Colleagues consistently describe a welcoming, respectful and productive culture and values.

From the perspective of Priority 5 “Enhancing Families, Service Users and Carers Experience”, we will continue to embed involvement of people with lived and living experience (service users, families and carers) in all aspects of SAMHC work.

We will also continue to work on the further development of mechanisms for early and meaningful engagement with people with lived experience to ensure their voices and experiences are heard, and incorporated into all aspects of SAMHC work.

Building a House: Reflections on My First Eighteen Months as Regional Service User Consultant



My name is John Morgan and I currently hold the post of Regional Service User Consultant. I am primarily a carer and service user and having been through the system, an expert by experience. When I was asked to reflect on my first eighteen months as Regional Service User Consultant, I wondered how it could be summed up.

The best way I can describe it is: *We have been building a house.*

I often think about Maslow's Hierarchy of Needs. Before we can flourish, we need a foundation. Many people describe mental distress as a tornado that tears through a house. Afterwards, you try to rebuild but some of the pieces can never be found. For many service users, it can feel as if we were never given a house in the first place. No place. No room. No space where our voices truly belonged.

Can you have good mental health without a home? Without somewhere safe, somewhere you belong?

When I started in this role, there was no blueprint. It was the first position of its kind. The objectives were clear enough: amplify service user voices, promote co-production, influence strategic decision-making and support recovery-focused approaches. But how that would happen remained to be built.

The first eight months were about laying foundations.

More about my journey to Regional Service User Consultant can be found [here](#).

Anyone who has ever built anything knows that foundations matter more than what people can see. I spent much of that time travelling across Northern Ireland, meeting hundreds of groups, organisations, carers, service users and professionals. These conversations were not always visible, but they were essential. Trust was built one conversation at a time. I knew that if the foundations were weak, nothing else would stand.

From those foundations, we began to build the framework.

New relationships led to training opportunities, workshops and strategic partnerships. One of the most significant achievements was the development of the Lived and Living Experience Guidance Framework, co-produced with service users, carers, Trusts, the Department of Health, PHA and many others. It provides practical guidance to ensure lived experience voices are heard respectfully, safely and meaningfully across our mental health system.

Building a House: Reflections on My First Eighteen Months as Regional Service User Consultant Cont.

Then came the walls.

Walls create shape, define space and make it possible for people to belong. Over the past year there has been growing recognition that lived experience has a vital role in shaping services. I have contributed to policy development, legislative discussions and regional programmes. This included influencing the Mental Health Code of Practice, advocating for stronger access to advocacy, and building relationships with MLAs, universities and senior leaders.

Alongside this, partnerships have grown with Queen's University Belfast, Ulster University, Recovery Colleges, Peer Support Workers and community organisations. New opportunities have emerged for education, research and workforce development, helping embed lived experience into places where decisions are made.

Next came the windows and doors.

A house without doors and windows is closed. Recovery requires openness, access and connection.

This has included co-designing and delivering the regional From Experience to Empowerment workshops, involving more than 120 participants from across statutory, voluntary and lived experience sectors. It has involved growing the Regional Recovery College Network, supporting peer support expansion, broadening membership of the PCC Lived Experience Platform and helping ensure traditionally under-represented voices have a place at the table.

Finally, we are putting on the roof.

The roof protects what has been built. It ensures that progress survives changing weather, changing priorities and changing systems.

Regional peer support developments, standardised job descriptions, strategic representation, succession planning, newsletters, partnerships and leadership networks are all part of creating something sustainable rather than temporary.

But a house is not the goal. Home is the goal.

A place where people feel safe, heard, respected and valued.

That, to me, is the true measure of success.

Many service users have expressed the feeling that there is no place on earth for us. Perhaps what we have been building together through peer support workers, Recovery Colleges, service user consultants and lived experience leadership is at least a room of our own.

The tornado may have struck. The damage may be real.
But recovery is not about pretending it never happened.
It is about ensuring that the damage no longer controls our lives.

If you would like more information regarding this, please contact John on RMHService@hscni.net



Q and A with Regional Mental Health Service

Service user Ross in conversation with RMHS Team member Caroline; Ross and Caroline sat down to ask each other five questions about the lived and living experience movement and its impact on mental health services.

Ross asked Caroline:



Do you think coproduction is something that comes a lot more naturally to organisations in the C&V sector, and if so why do you think this is, or isn't?



I wouldn't say that it comes more naturally, however I do feel that anyone working in frontline services, including Community and Voluntary staff have more opportunities to engage with service users regularly. It is more organic than when working in policy or service design as you are dealing with people in real time and have to be more conscientious of doing this important part of the work right. A great example of this is our Regional Service User Consultant John Morgan. It was a conscious decision to have this key post as part of the RMHS team to ensure lived and living experience and co-production is central pillar to all our work.



What difference have you found it makes actively including service users in power sharing, rather than just inviting them into the conversation - and what advice would you give to someone doing this for the first time, on how to navigate the natural power imbalance that will occur between service user and provider?



For me the main difference is that we gain an important insight into the journey a person goes through within the mental health system. The journey is unique to each individual which is why it is important that we engage with a wide range of lived and living experience and create different opportunities to listen to people. The "From Experience to Empowerment" workshop was a fantastic example of this work, which was co-produced and led by those with lived experience. My advice to anyone doing this for the first time is try to have service user involvement in all levels of your work. In the RMHS we have service user involvement at the heart of our work, and it was critical that lived and living experience was and is reflected across all our enabling structures. As a result, we have service users as active members on the RMHS Collaborative Board, all of the Area MH Collaborative's and all our sub-groups. Our Communication and Engagement Sub-group has been positively impacted by having a number of service users (your good self included) to help us drive forward the work of the group.

Q and A with Regional Mental Health Service Cont.

Speaking of the perceived power imbalance, what do you think is important in creating an environment where both service user and provider are both able to feel like they can challenge each other?



I think one of the most important things is spending the time to build relationships so that everyone has a sense of psychological safety when coming together to do the work. When setting up the RMHS Area MH Collaboratives we have spent time working on building these relationships. It is something that cannot be rushed and needs to be given sufficient time to get it right. Trust in relationships is key to levelling out the power imbalance and creating environments of mutual respect and shared decision making. I also think one thing the RMHS have done well is create a shared leadership and within the RMHS structures we do this by ensuring service users and carers have voting seats on all forums and working groups.

Is there a time during your work at RMHS where lived-experience involvement genuinely changed the way you looked at something, a piece of work or a decision being made?



Yes, I would say having worked for over 16 years in the community and voluntary sector I have seen many times where lived-experience involvement has changed how I see things and how I work. However, since coming into the RMHS it has been so refreshing to walk into a team where one of my peers is a service user who is a senior manager and paid to focus on enhancing the voice of service users and carers and ensure this transfers into tangible actions. This works so well in the Mental health system and I can only say I think it is an excellent example to other sectors of the health system to ensure meaningful change.

And finally, if you could change one thing about how lived experience is involved in the design and delivery of services, what would it be?



This is a tough question. I guess if I could I would change some people's perception of working with lived experience. Over the years I've heard some people hold presumptions that working with lived experience is too complicated, too risky or too much work. The fact is, that it can be all of these things and none of them but this is the case when working with anyone. Everyone we work with in lived experience, professional services, volunteers and so on are more than one thing and bring more than one hat to the table. When we take the time to listen and the energy to take the leap of faith we can together achieve so much more. I think that we have to treat lived and living experience as critical partners in our work and not be afraid to listen to listen and reflect on the positive and negative experiences. This is how we learn and co-design services that will meet the outcomes of those that need to access services in the future.

Q and A with Regional Mental Health Service Cont.

Caroline asked Ross:

Do you think that everyone who has been through Mental Health service can/should become part of the service user movement?



I think everyone who has been through Mental Health services can be part of the service user movement. Whether that is something they want to do will be up to them of course. I don't think anyone who's been through the services should feel like they "owe" it to the services to give something back in this way, but I also think everyone should know that the opportunities are there and see the pathways available. Unfortunately, because there are so many cultural and socioeconomic barriers to entry, the voices that we are missing are those whose voices we really need to hear. I would definitely encourage any service user that has thoughts, opinions or ideas to reach out to their local involvement teams and service user consultants for a chat and see where the journey takes them!

What advice would you give to any organisation or team that want to start working meaningfully with lived experience?



Most importantly I'd tell them go for it - and to start earlier than you think you need to. Don't be afraid to get it wrong, nobody does it perfectly, but you will learn and you will see changes. Make sure lived experience is included right from the beginning of the process, from the planning stages - they will see things that you will miss and it will save you time! Also, there are more and more fantastic resources and good examples of lived experience work in practice, both in Northern Ireland and the UK. Finally, I'd suggest reaching out to other organisation's that might be further down the line with the process and consult with some of their engagement teams and service users to help steer the direction of your process. Personally, I've been part of a Coproduction Advisory group with IMPACT UK and organisations reach out to our service user advisory group to help direct their own engagement work. I think it's a fantastic process, using both our lived experience with our own personal healthcare journeys but also our lived experience of lived experience work.

Some people would say they are afraid to challenge service users and carers, what would you say to them?



Relationship building plays a big part in this because I understand why it can feel hard to challenge service users. It's something I've definitely taken advantage of myself when I know I'm working in a space with organisations or people who aren't used to working directly with service users, that I can be a little bolder as I won't face the same pushback. But all of my best and most productive experiences working in these settings has been where people have felt comfortable to challenge me. There's a reason why people go through years of studying to work in healthcare roles! Learned experience is just as important! I see learned experience as the framework, and lived experience as how to apply that framework in the real world. Finally, I would also say it's disrespectful not to challenge us. We come into the space to be treated equally and that includes being challenged and asked to defend why we believe what we do.

Q and A with Regional Mental Health Service Cont.

If we are genuinely moving towards meaningful coproduction do you have a good example of this and how do you think meaningful coproduction was achieved in that work?



I would say there are definitely pockets of meaningful coproduction happening all around the services. I think to me the most meaningful example is the Service User Consultant positions both within the Trusts and with John regionally. Having service users embedded in a position where their role is not just to voice their own opinion and experience, but to be a collective voice and help amplify other voices is integral to creating a working structure and network around coproduction and engagement. To put it bluntly, to see someone on the "inside" working "for us" gives me and others a lot of confidence around how our own personal involvement starts to look. We know there are people with a long history of working in lived experience spaces as a service user, there to help mentor and guide us, but also to protect us and ensure that the coproduction being done is meaningful, and being done correctly. On a personal level working with the whole Regional Mental Health Service team on the "From Experience to Empowerment" was a fantastic experience of coproduction. To have been able to bring the idea to you, to have had full autonomy over the direction, planning and execution of the workshops while having the support of the team and shared ownership over the project was invaluable to me.

And finally, if you could change one thing about how lived experience is involved in the design and delivery of services, what would it be?



I want it to be structured and valued in the same way everyone else involved in the design and delivery of services is. I want it to be organised, I want to see a path for job progression through lived experience representation. I don't want to hear anymore about how much services value lived experience, without actually showing those involved that they value it. Shared ownership, remuneration, training. Diversity and different levels of engagement but all managed within one coherent structure, just like all other areas of healthcare. The person sitting at directorate level meetings within places like SPPG as the lived experience voice, will never be seen as equal in that room until these things are in place. It takes time and learning to understand and be comfortable in those spaces, so we need to be able to see that pathway from someone being involved in their first workshop at a local level as a service user voice, to years down the line being a full time employed service user representative sitting at policy meetings and helping design and deliver service.

Why Involvement?

A Service User Poem



Why is it important to have service users there;
Because we have had the lived experiences, and like you guys, we care.
As service users we want to be heard, and be part of the team,
And work together on similar themes!

Sharing ideas and experiences we have had
Some of which have left us, at times, very sad.
But we want to be involved, to help shape services and promote hope,
And this might help everyone cope.

Being involved allows us to grow,
And helps us come out of a place that is so low.
We find our voice and allows the system to see
That having us round the table really is the key.

The key to making our communities a better place,
We start small and build a strong base.
Building our neighbourhoods and helping us to lead,
Let's start growing that service user seed!

So if you want to try and become involved,
Then check out some links and come help us solve.
Solve how we make the system better for everyone,
So that we can all start having some much-needed fun!!



By Cathy Malcolm

Support

We encourage all stakeholders, HSC staff, service providers, community partners and individuals to sign up [here](#) for future newsletters and updates. This will ensure you are kept informed as implementation progresses, milestones are reached and opportunities for engagement arise.

If you or someone you know has been affected by any of the issues referenced in this newsletter, support is available. Please do not hesitate to reach out to those around you or contact one of the services listed below:

Lifeline: 24/7 Crisis Support Service

People living in Northern Ireland can call Lifeline on 0808 808 8000. Deaf and hard of hearing Textphone users can call on 18001 0808 808 8000. Calls to Lifeline are free.

www.lifelinehelpline.info

Minding Your Head

Information, advice and support to help people in Northern Ireland look after and improve their mental health and wellbeing.

www.mindingyourhead.info

Family Support NI

Information on a wide range of family support services in Northern Ireland.

www.familysupportni.gov.uk

Helplines NI

Vital support services including information, advice, counselling, a listening ear and be-friending for those with health and wellbeing needs.

<https://helplinesni.com/>

CYPSP Youth Wellness Web

Resources to help young people get the support they need, plus local services that can help.

<https://cypsp.hscni.net/youth-wellness-web/>

Find out more about RMHS



RMHService@hscni.net



<https://online.hscni.net>

www.health-ni.gov.uk

Produced by the Regional Mental Health Service Team,
Strategic Planning and Performance Group, Department of Health