

Opinion

ENGAGEMENT AND PARTICIPATION AS A PART OF THE MENTAL WELFARE COMMISSION FOR SCOTLAND

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ABSTRACT

An account of the work of the engagement and participation officers with lived experience as users and carers in the MWC, showing: the history of user and carer involvement in the Commission, the reason for the employment of the present workers and the creation of the department of engagement and participation. Told from the perspective of lived experience of using services, describing the development of the roles to date, the activities carried out to date, especially those connected with mental health law, capacity, and the role of the NPM in safeguarding against cruel and degrading treatment and torture, some assessments of the impact of these activities and a presentation of the personal perspective of using lived experience as an integral part of a professional role.

For a scholarly journal this will be a slightly unconventional article. I'm going to tell you a story. I am going to muse and reflect on why having people with direct experience of mental ill health or direct experience as carers is so important to an organisation such as the Mental Welfare Commission for Scotland. There is a more detailed description of the Commission elsewhere within the journal's pages but—to put it simply—we are there to uphold and protect the rights of people with a mental disorder in Scotland. In fact, we are one of the many organisations that make up the UK National Preventative Mechanism—an institutional framework prescribed under the auspices of the UN Torture Convention—that exists to ensure that people with a mental illness, personality disorder, autism, dementia, learning disability and related conditions are not treated badly, are not abused, and are not trampled on by an uncaring society.

We visit people in hospitals, including the secure hospitals. We visit people at home. We monitor the mental health and incapacity legislation that applies to us. We carry out investigations, promote good practice and influence policy. We keep records of people detained under the Mental Health Act. We do all sorts of things. These are all aimed at ensuring people are not badly treated, while at the same time helping to establish and further promote good practice that lead towards a better quality of life.

We have a network of practitioners who are assigned to different areas of Scotland. They are psychiatrists, social workers and mental health nurses, all of whom use their detailed expert knowledge of policy and practice to influence and comment on what they see.

Unlike some organisations we do not have many formal powers. Decisions about detention are more the province of the Mental Health Tribunal for Scotland. We cannot close a ward, or insist on a change in practice. But we can influence, and we can persuade, and we can be very good at doing this.

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When I first came into post as an Engagement and Participation Officer (Lived Experience) three years ago, I met many advocacy groups and, in discussion with them, found out many of their views about the Commission. First of all, many people's initial reaction was of an organisation that is remote, formal, populated by smart professional people in suits, people they would not necessarily feel comfortable with, people they might, indeed, feel wary of. I will talk more about that later. Another theme from groups was that they wished the Commission had greater powers, could close a ward or even a hospital, and that it could insist on changes being made then and there. This resonated with me because I too often thought that way. I felt that an organisation that is there to safeguard the rights of people like me, and others more vulnerable than me, could only ever be tokenistic if ultimately it could not force bad practice to stop.

But I wonder how change happens? How good practice flourishes? I remember being on a Commission visit to a hospital ward that—quite frankly—was not doing too well, but I also remember the sensitivity with which the nurse practitioners pointed out some of the areas that needed improved and the enthusiasm with which the nurses on that ward, some of whom had little training in mental health, embraced that conversation; they fell upon it almost as if they were hungry for the learning and the good practice that they could implement. So, much as I do sometimes want to shout and stamp my feet, and force change to happen—especially when I see the way some of my friends and colleagues with a mental illness are treated—I can also see that change is almost something that we need to be drawn into; that to create change, we need to want that change to occur and that the bluntness of "*You will do this and this and this*" can serve sometimes to create only fear and defensiveness.

I have a similar feeling about my job in the Commission. My Engagement and Participation colleague with lived experience as a carer, Kathleen Taylor, and I are here to create a culture change—a shift in working—a different perspective and a different emphasis.

It is easy to see, when the perspective of lived experience is not a daily reality of an organisation, why people may worry about it, may be hesitant; and very easy when we arrived as new, anxious, idealistic people in brand new posts for us to come with a set of assumptions and beliefs about how people would view us. Looking for a negative reaction can be confirmed in an instant if you look out for it, are poised for a silly comment or an offhand dismissal but it takes me back to how change occurs.

Sometimes change occurs by setting aside worries and preconceptions; and needs people like us to help it along. If I had come along as the person I was some years ago I don't think I would have lasted in post for long at all. But with my carer colleague Kathleen, who is both funny and cynical, and is a wonderful person to confide in, we almost became a feature of the dining area in the Commission offices for a time. Eating our lunches, getting to know people, asking questions, enjoying the new people and experiences about us; and maybe—not quite the same as the peer support our practitioners offered to those nurses I mentioned before, but similar—we offered links and connections. We showed that we had mutual aims and that even when we were desperate for change to occur for the communities we had come from, we were also ready to laugh and giggle and learn.

In that way, some of the hesitation drops aside and we all gain a better understanding of each other; what we are good at and could well do more of, what we need support with, and where we are better not used in certain areas.

And I must admit I do like this approach. If I had joined the Commission full of anger and full of assumptions about the people who worked there, it would have been hard to create partnerships and to share stories, ideas and thoughts about how we could work together.

But first of all, in this story; lived experience is an essential requirement for the work I do. Now that is one of the strangest skill-sets to find on a job description! To be in a professional world where it is a positive advantage to have a diagnosis of schizophrenia; where to be on a compulsory community treatment order not only conveys credibility but equally an expertise other people want to seek out!

These sort of posts, in what is really quite a formal organisation, need to be set within context, and part of the way I will do this is to do just what my job demands and be open about my lived experience and its place in what might be called the 'user movement'.

I was first referred for psychiatric help when I was 17 and first admitted to hospital when I was twenty or twenty-one.

Middlewood, 36 years ago, was an asylum scheduled for closure. It was a dark forbidding place on the outskirts of Sheffield, set in beautiful grounds but frightening. I remember my bewilderment about being taken there, after an overdose; both at the holes in the walls and the smashed furniture. Some of the bare rooms were just floorboards and dust. The beds crammed next to each other, the noise at night; but also the nurses—friendly, not in uniform—taking us out to the pub in the evening. And then of course the less attractive sights; the nurse who was assaulted, the patient who was then leaped on by about six male nurses—jagged in the bum—who screamed and screamed through the night before he was taken away. The old ladies from the long-term ward above us who sometimes escaped and rushed into our room; desperate to get at the fag ends we—the more fortunate patients—had left in the ashtrays. The man with no belt, who walked around having to hold his trousers up; he was so emaciated and died not long after I was discharged. The friend I made who had learning disabilities and alcohol problems, who the nurses took to the pub and discharged when he took a drink there; who the next time I saw him was in a homelessness shelter: just two rooms with bare floorboards; the men's possessions piled in bin bags and the corners of the room. A young man kneeling on the floor rocking backwards and forwards while we tried to speak to each other.

That is the setting which drew me into activism and trying to make the world a better place for people like me with a mental illness. In our country there are now hardly any of the old hospitals left and fewer of the bad practices. But these experiences are not some antiquated aspect of care, some curiosity.

Many of the older people who still go into hospital, nowadays, will have both good and very bad memories of treatment in what now seems like a different age—but is actually a scant few years ago—and of course so will many of the staff. The changes that have occurred to combat some of the abuse of the past are, in many ways, recent; the possibility that life will change for the worse again, not an impossible idea.

However, in that setting, when I left hospital in my twenties, I received some very puzzling and mostly silent psychotherapy as follow up. I found, for me, a slight sense of liberation. Here was something clearly unjust, here was something to change, and here was a cause to believe in.

So I became a volunteer in a halfway house for young people with mental health problems, where we met support workers and community development workers who schooled us in the works of RD Laing,¹ Asylum magazine,² and that whole area of alienation and oppression we were just becoming aware of.

We set up a new organisation imbued with many of the values we had been taught. We established a drop-in centre for young people with mental health problems (McMurphys); created, run by and developed by young people with mental health problems. We were intensely suspicious of officials and professionals, and only reluctantly agreed to speak to some of the people in the Council and Health Board who might fund us; refused to allow professionals access to the building, and maybe that anger was justified. Maybe that search for identity, a voice and control, was what we needed; it certainly helped me.

I moved to Scotland, where again with some of the more radical people in the third sector we set up Awareness³, one of the first advocacy groups for people with mental health problems in Scotland. From that, after an interlude as a yacht skipper, followed work with CAPS Independent Advocacy⁴, where I worked to set up advocacy groups across Lothian, helped establish a National user voice for our country, a series of user conferences and also a National user written magazine. We were still strident; dead set on having our voice, not having it adulterated by carers. In fact suspicious of carers. In many ways we still saw people who worked in the NHS as the enemy, with only the occasional allies. We were deeply suspicious of compulsory treatment, aggrieved by our experiences of hospital.

It was in Edinburgh that I had the first of my major hospital admissions. There, I had to line up in a queue for medication, and get stitched up without anaesthetic when I harmed myself.

Then 24 years ago I moved to the Scottish Highlands where again I set up an advocacy group called HUG⁵ (action for health), and here my views shifted both because of my treatment and because of the people I met.

All of my work so far had been mainly with radical social workers, progressive planners and policy makers; we sort of knew what we all thought and were expected to think. But in the Highlands, I met with service users who had not been educated and had their consciousness raised. Here I found, when Craig Dunain, Highland's Asylum was due to be shut that many people who had been patients in it did not want this to happen. That if there had to be a new hospital, that they wanted it in the same isolated patch of beautiful

¹ Nick Crossley, 'R. D. Laing and the British anti-psychiatry movement: a socio-historical analysis' (1998) 47 (1) Social Science & Medicine Volume, [877-89]

² Now published by PCCS Books asylummagazine.org/

³ Oor Mad History, Community History and Arts as Advocacy Project based at CAPS

⁴ capsadvocacy.org/

⁵ www.spiritadvocacy.org.uk/about-us/who-we-are

countryside on the edge of town. It was here I met people who said that they were kept alive by medication and that far from being a chemical cosh, it gave them a new life; and also people that had no problem with getting help from a chaplain or going to church to find peace.

A far and hugely liberating cry from the fairly rigid ideals of liberation and oppression that I had grown up with, in my career to work with people with a mental illness to make change for the better for that community.

And that is also where my personal perspective changed, I was admitted a few times to hospital—nearly always under a section—and although there were very clearly times when practice was not as it should be, I also had my own en suite bedroom, had things to do and met people who genuinely seemed to care for me and—much as I still wonder if it was for the best—had my life saved on a number of occasions. Then later, when life became particularly bad, I met a succession of psychiatrists and CPNs who I got on well with and who I found I could trust with aspects of myself I couldn't with anyone else. I met and helped create a community motivated by giving back and providing mutual support where anger was not the driving force for speaking out but creating connection and belonging and finding solutions to what often seemed like insoluble problems. Where the issues we addressed were the ones we found important and not necessarily the emotion laden aspects of treatment that other people thought we should address and lastly where we found that by working together—with professionals, schools, businesses, arts projects—we could often create a change that would never have happened if we had remained in separate and mutually suspicious camps.

And that is why I am now with the Mental Welfare Commission. As I mentioned, I have been sectioned a number of times and know that those sections keep me alive. I am fairly sure that my ten years on a CTO does likewise, and am fascinated and honoured to hear the different stories of my friends and colleagues on that subject; and still slightly surprised at how conservative our community is when you peer beyond the radicalised activists and community of which I used to be and to some extent still am a part of.

I am no longer filled with a harsh anger at my personal treatment and can feel slightly awkward when I meet people with lived experience who, with a straight face, can say that no medical professional can possibly feel empathy with a person with a mental illness.

It seems to me, that as part of that user movement that made the involvement of people with mental health problems in policy and services an everyday expectation, I am now learning that, what may have once needed to be a separate and distinct voice; one which reclaimed its own power has, to some extent, a need to recognise that it is also sometimes an artificial voice and on occasion an unfair one. That most people who work in mental health do so from a personal commitment to improving our lives – most would hardly do it for the money! That it is just as common for a doctor or a social worker or a nurse to develop mental health problems as anyone else and to deliver the very services, we sometimes say, do not acknowledge the lived experience we have. That the need to critique and display our anger sometimes excludes those people who are grateful for and happy about the treatment they have received.

That was a very long introduction to my life and to my motivations, but it is important to set the involvement of people with lived experience in context. The idea of engagement, participation, advocacy, has come from the combined efforts of service users, carers and their allies. It has a rich history and will develop in a variety of ways. For me and many of my friends, that development is about partnership and shared values—whilst I know that for some others the only credible voice rests in a distinct identity and a distinct way of interpreting distress and which often rejects the very concept of mental illness.⁶

Thirty five years ago, we would have been bewildered to be told that the involvement of people with a mental illness in an organisation like the Commission was now a legal consideration – it would have been inconceivable.⁷

And yet over the last few years since the creation of the Mental Health (Care and Treatment) Scotland Act 2003, it has been a requirement in law to have people with lived experience as a part of the Commission. Initially this started with the people with lived experience joining the Commission's Board of Directors and Advisory Committee, and also the employment—for a few days a year—of people with lived experience to take part in some of the Commission visits. Five years ago, following direction from the Commission Board, a Department of Engagement and Participation was created with an executive director employed to create strategies and manage both the present Engagement and Participation officer (lived experience) and the Engagement and Participation officer (lived experience as a carer) posts. The director sits alongside the other directors of the Commission and it is an essential requirement of all staff in this department that they all have personal lived experience. She also has other more general responsibilities within the Commission.

And now for what we actually do in the Commission: what we achieve. How having someone like me at the Commission and someone like Kathleen does, in reality, make us better at safeguarding people with a mental disorder from abuse. This means that the worst aspects of the old asylums will hopefully remain as stories and tales we are happy to have moved on from.

I remember when I worked for HUG and was part of the Millan Committee⁸ (chaired by The Rt. Hon. Bruce Millan) which paved the way for the current Act in Scotland. While my verbal contributions in the meetings were not as they would be now, my presence was an important milestone. In fact, I was rather bewildered by the language, procedure and manner of my fellow committee members, and could never keep up with what ended up as around fifteen bin bags full of dense and complex reading materials in just a couple of years. But I do remember that I was visible, and it was that presence which created a dignity to the process of developing and modifying legislation that justifies the detention of people like me.

In any sphere where it is possible to see people and communities as 'other', when we place them in the societies where decisions are made for and about them— sometimes without

⁶ Helen Spandler, Jill Anderson and Bob Sapey, *Madness, distress and the politics of disablement* (Bristol, The Policy Press, 2015)

⁷ Schedule 1 Mental Health (Care and Treatment) (Scotland) Act 2003

⁸ Scottish Executive, *New Directions: Report on the Review of the Mental Health (Scotland) Act 1984* (SE/2001/26)

their consent or knowledge—it is incredibly hard to perpetuate that difference, that alienation when the person you are alienating is sitting next to you. When you share a train journey, a coffee, a story of how your children are doing.

And so—much as I regret that lack of skill this could imply—being in the Commission, having my post created where it is a matter of public record that I have lived experience creates the same imperative. I now know that many people who work in the Commission have had their own problems and that even more have friends and relatives that they are very close to those who have mental health problems or learning disabilities or dementia. But where that might once have been a private thing, almost something that is obscured by the role of a worker, now it is celebrated and highly visible in Kathleen and myself.

I would like to say that this is a simple awareness raising exercise that doesn't take any effort; that it just occurs and creates change purely because Kathleen and I are visibly in post—but actually it does carry a burden.

It is a burden I willingly carry, and would not have any other way, as a large part of my identity rests in my experience of mental ill health and the services that treat me. But keeping that high profile can be hard and it can be easy to misinterpret reactions from other people.

I come from a tradition where we expected—and experienced—our presence and voice as being something unwelcome; where we saw barriers to everything we were trying to achieve. These barriers were and to an extent are still real, but they can make me hypersensitive. I can worry intensely what people think of me and worry that when I use my personal experience that I am too intense, too inward. I can worry when something I put forward for the intranet or internet does not appear that it is because of my failings or because I have lived experience or because I am incompetent.

Within this is a whole host of issues; the very existence of my post makes this feeling slightly inevitable as our perceived difference is highlighted as a condition of work. The fact that there is no career path, no qualification that I can use to justify my skill base can make me anxious in a work environment with highly qualified professionals. The fact that there is sometimes probably some degree of this perception of 'otherness' coming from our fellow workers, that they may perhaps sometimes be slightly confused by the boundary issues that might potentially exist when working with people who at another time would likely have been their clients and the fact that I do have anxieties and paranoid and worries that seem to be part of my condition which can make me think that people are talking about me, or looking at me negatively or avoiding me. Makes for a possibly heady mix of potential problems.

This is an inevitability that will occur when people are put into jobs like this; but it does not mean that it is wrong to have such jobs or that the worry we have about other people's reactions to us are realistic. I am constantly having people from the Commission reaching out to me and speaking to me and praising me. When my book *START*⁹ was published, at least ten members of the Commission came to the launch; that is over a fifth of our organisation took time out of their social life to celebrate an achievement of mine.

⁹ Graham Morgan, *START* (Fledgling Press, Edinburgh 2018)

In this story I have laboured that sense of otherness; it is a real problem but sometimes it comes from within. Sometimes when we have grown into our roles from a sense of alienation, we can occasionally see evidence of hostility that does not exist and neglect to recognise those everyday gestures of welcome that routinely occur each time we come into the office.

Having a line manager who herself has lived experience has also been invaluable for dealing with the anxieties and worries that both Kathleen and I initially had when we came to the Commission.

Some time ago I talked about my role in the Millan Committee, said that my value to some extent just rested on my visibility, but I also remember a reunion of the Committee many years ago where one of the Committee members said that a speech that I gave at an away day completely transformed her ideas around detention and the Mental Health Act.

And that aspect is a wonderful part of my job; there can be few roles where just reflecting on what you have been through in your life—especially when it has been harsh and traumatic—has been prized and sought after. Invariably, when I give speeches, I employ a personal perspective, but equally try, as far as I can, to include the different viewpoints of the Communities and people I work with.

This has been especially the case with some of our national and international work around detention and supported decision making.¹⁰ We have involved a few hundred people in discussions around both our freedom and our capacity and ability to make decisions or be supported to make decisions; as well as just what would avoid decisions being taken out of our hands. This work has very clearly shown that, at least in Scotland, people with lived experience do not easily subscribe to the pronouncements of the UNCRPD around compulsory treatment;¹¹ in fact a considerable majority are opposed to its general comment.

This can be confusing and difficult because there is also a very loud and angry minority of people completely opposed to compulsory treatment.

Balancing these views can be difficult. But to be honest, when I have addressed the United Nations or a number of international conferences it can be a relief to deliver my own personal perspective knowing that it reflects the mainstream opinion in my country; if not in other parts of the international community or user and survivor movement.

¹⁰ See eg: Mental Welfare Commission for Scotland (MWCS), *The views of people with lived experience on supported decision making: Service users and carers information* (2019); Mental Welfare Commission for Scotland, *Seeking Your Views consultation Capacity, Detention, Supported Decision Making and Mental Ill Health* (2019); Craigie, Bach, Gurbai, Kanterd, Kim, Lewis, Morgan, *Legal capacity, mental capacity and supported decision-making: Report from a panel event* (2019) (62) *International journal of law and psychiatry*, [160-8]; Jill Stavert, *Good Practice Guide – Supported Decision Making* (Mental Welfare Commission for Scotland, 2016)

¹¹ Committee on the Rights of Persons with Disabilities, *General Comment No 1 (Article 12: Equal recognition before the law)*, CRPD/C/GC/1, 19 May 2014.

There is, however, a balance to be achieved in telling a personal story; I have recently delivered a speech on care planning at an event we ran to develop good practice.¹² I used my personal experience of care planning to illustrate the fact that so many people I have consulted with seem to feel only a passing connection—or indeed interest—in their care plans, and then used the experience of the people we consulted to finish the talk; there is a power in the real story. That narrative in a speech has an authenticity, but when the final report on our consultation with service users and carers is produced¹³ it will just contain their opinions and not my personal preferences and thoughts.

This is where the other aspect of being a Participation Officer is so important. The majority of my time I am visiting lived experience advocacy groups, self-management and support groups, and also groups of peers using services. At these meetings we find out their opinions on anything from seclusion¹⁴ to legal representation,¹⁵ from the definition of stigma, to the purpose of hospital¹⁶ to the degree of autonomy we want in our lives¹⁷ or carers' experiences of interacting with services¹⁸.

These meetings occur throughout Scotland; in inner city areas, hospitals, remote rural and island areas, in community halls and services and it is here that we are able to both involve people in the Commission's work and find out their views on what we are doing—but also find out their voice on key issues around such things as freedom and detention, right to life, and respect for personal and private life¹⁹ that are of concern to both us and the people we speak with.

We check all our notes with the groups and people we meet with— and from this create papers reflecting the views of carers and people with lived experience. In this situation my role is more specific; I am there to get the discussion going, to record the discussion and to make sure that the final paper is an accurate record and reflection of the meetings that we have held. Although it is not research and is instead a record of a consultation, we have had help from our research officer in the Commission in qualitative analysis of the results of what we do, and do check with people with lived experience that the final report does as far as it can, reflect their views and of course, as part of this, I bring in the decades of experience I have had in facilitating group meetings and in encouraging the diverse range of views that our communities have about their treatment and identity.

Some of the reports we have created around supported decision making have been commented on by various Universities and some have influenced other bodies such as people reviewing the English legislation. Increasingly these reports will become public

¹² Mental Welfare Commission for Scotland (MWCS), *Person Centred Care Plans: A Good Practice Guide* (2019)

¹³ MWCS, *Care plans: how people with lived experience and their friends and family want to be involved*, Service users and carers information (2019)

¹⁴ MWCS, *Use of Seclusion: A Good Practice Guide* (2019)

¹⁵ MWCS, *The views of people with lived experience of mental ill health on legal representation* (2019).

¹⁶ MWCS, *The views of people with lived experience on the purpose of a psychiatric hospital*, Service users and carers information (2019).

¹⁷ MWCS, *How much we want to keep our autonomy when being cared for*, Service users and carers information (2019)

¹⁸ MWCS, *Carers' experiences of interacting with services* (2020)

¹⁹ Universal Declaration of Human Rights (United Nations [UN]) UN Doc A/RES/217(III) A, UN Doc A/810, 71, GAOR 3rd Session Part I, 71

documents on our website in a section likely to be called 'What people tell us'; hopefully they will increasingly influence our own work and wider policy arenas.

Now that we are beyond the purely personal perspective, there are a number of other areas where we try to include the voice and ideas of people with lived experience. Some examples include work around advance statements²⁰ and around our rights.²¹

These were both projects that we, as engagement workers, have been involved in. With advance statements terms of reference, we worked alongside advocacy groups and others to consult on why people so rarely have advance statements; despite governments and Advocacy groups generally saying they are a 'good thing' when we are at risk of having decisions taken out of our hands when we are very ill.

Our report on people's views informed the Commission, but in addition we contributed to the final leaflets that were produced and recruited and supported people with lived experience to be filmed speaking about advance statements in films that were later placed on our website. Now that the advance statement guidance has been produced, we have worked alongside user groups and people with lived experience to deliver training on the subject.

In similar vein, when we are about to be admitted to hospital we can be bewildered about what is happening to us; we can be frightened, confused, anxious but above all we can be ignorant—not knowing what we can do, what we can't do and what can and can't be done with us. In the midst of all this our rights are very important. But at the same time, we may not be in such a position that we either recognise or indeed act on those rights. In order to make some difference in this area, we ran a consultation event aimed primarily at service users and carers to find out what things are important to us during these times—and from this came a project where we created a 'Rights Care Pathway' which related and contrasted particular issues we may experience prior to, during and after admission to hospital to the relevant legislation—nationally and internationally—that applies to us. This can vary from anything from the right to have our pets cared for while we are patients, to our right to advocacy or to appeal a section. The Rights Care Pathway was a visual guide. There was also a more detailed report produced on the subject and a series of films created from a lived experience view-point and professional view-point. We also had a few hospital wards piloting projects around improving recognition of our rights when in hospital and distributed the Rights Pathway throughout Scotland, as well as creating a 'Learn Pro' module for professionals. As engagement workers we helped consult service users and carers, were a part of the Planning Group, recruited people to be filmed and recruited people to speak on rights at a launch event. Though we took the pathway and films around user and carer groups these were aimed primarily at professionals. A reflection that rights should be as much or even more of a concern for them when carrying out their job as they are for us; particularly when we do not have them upheld. Generally speaking, the groups we have visited have been enthusiastic about the Rights Care Pathway; feeling it is a very valuable document to use when we are very vulnerable and also of great use to the advocacy projects and groups that they might be a part of. But there is also a degree of cynicism which maybe reflect just how far we have to go and how important the sort of

²⁰ MWCS, Good Practice Guide: Advance Statement Guidance: My Views, My Treatment (2017)

²¹ MWCS, Rights in Mind: A pathway to patients' rights in mental health services (2018)

awareness raising and voice of people with lived experience can be. Some people—watching the enthusiasm some of the nurses had on film, for our rights—said that it was great but not something they witnessed in their treatment. Other people commented that it may be great to know what our rights are and to know they are legally enforceable but that actually making them real, in a time of cuts and austerity, was less easy to contemplate.

The Commission has now produced guidance around care plans and seclusion. We consulted people with lived experience and their carers across the country and held two large consultation meetings attended by some users and carers but mainly by professionals where we presented the findings of our meetings with people with lived experience. Despite the large number of people with lived experience who have only a hazy notion of care plans we had little difficulty in finding out views on this and were greatly helped by one of the people with lived experience's paper on how she had taken ownership of her care planning.

With seclusion we had more difficulties. While a massively important subject, it is rarely used and indeed where it is practiced it is sometimes not known as seclusion, so although we were able to get a broad selection of views about how we might feel or how a loved one might feel if they were subject to seclusion; we only managed to get a few concrete examples of what people who had actually experienced it felt about it but did gain more information from Carers in carer groups where the experience of seclusion by family members unfortunately is sometimes a common event.

This is another aspect of the role; the examples we gathered were from people we had built up a good relationship with over the years. This creates a degree of trust in which to be able to talk safely about experiences that can be both traumatic and humiliating and rests to some extent on the links we have established with the user movement.

All these areas of work are around good practice. They are based on rights and legislation and concentrate on times when we may be at our most vulnerable—but they remain guides that we hope will encourage professionals to uphold and promote people's rights, and also for people with lived experience to become aware of.

Slightly more focussed on practice is our visiting program. The Commission routinely visits every psychiatric ward in the country, as well as some other services. The team meets service users, carers and staff, and has access to all the paperwork on the ward. We carry out both announced and unannounced visits and produce public reports with recommendations which we expect wards and hospitals to implement.²² As engagement workers we are a full part of the visiting team, although there is a practical limit to the number of visits we can go on. The combination of practitioners and engagement workers can be very powerful. From a personal perspective, knowing what it is like to have someone within arm's reach of you for week after week, remembering the indignity that can occur when having to share dormitory space, or the sheer boredom that can occur on a ward, gives us a perspective that most practitioners do not have. It also gives us an opportunity. While many patients are happy to talk to practitioners, there are occasions where a connection can be more easily established if a patient knows that we also understand what it is like to be a patient—or know what it is like to have a loved one in hospital. This

²² For local visit reports, see: www.mwscot.org.uk/publications/local-visit-reports/

connection can make conversation much easier and information about issues on the ward easier to find out. It adds another dimension to our visiting program. We are often used where the team is keen to have as much contact with patients as possible; perhaps because of worries that have been raised prior to our visit. There is sometimes a perception that certain patients are more likely to talk and confide in us than in other people.

An additional aspect of this is our regular round of meetings with user and carer groups. In these meetings we can become aware of particular concerns people have of a certain ward, which has led to further action from practitioners.

We can also be asked to meet with advocacy groups and projects, prior to a visit, in order to check just what exactly the key issues are that we should be looking at. Key to this, has been the work we have carried out with user and carer groups to develop a relationship with them and give the belief that there is some point and value in letting us know when they have worries about a hospital.

This is greatly helped when we can point out areas of work which we know have come about as a direct result of the voice of people with lived experience and their carers—and has led to some very productive and enjoyable meetings with people; despite the difficult subject matter that is being raised and discussed.

As with all our work, being able to contribute both from a lived experience and from a sort of outsider status helps the Commission get a breadth of view and perspective. Being part of a culture that exists in many ways to challenge the status quo—and having had experiences of treatment for mental ill health that have on occasion highlighted just how we should not be treated—is an important complement to the perspective of practitioners; who though professionally critical are nevertheless a part of the very professions that they sometimes scrutinise.

The expertise and depth of experience of the Commission's practitioners is undoubted, as is the power of peer mentoring and critique. But equally, we can come from a perspective where we may highlight issues—and aspects of treatment and ways of seeing people with lived experience—that are not immediately obvious.

In addition, there is considerable variety in how people and communities view mental illness and mental disorder. As Engagement Officers we consciously reach out to try to understand perspectives and experiences that do not fit within a conventional model of how mental distress is viewed. Some of the communities and people who are treated for a mental disorder have had deeply damaging experiences at the hands of the mental health system and in consequence may have such a different understanding of their experience that they become deeply resentful—and maybe antagonistic—towards not only the mental health system writ large, but of organisations such as the Commission. As Engagement Officers, we try—as far as we can—to reach out to such people and communities. Trying to acknowledge that some forms of behaviour and conduct are an inevitable consequence of poor treatment can, on occasion, be difficult; but it is extremely important to us that we take in, as far as possible, the wide variety of voices and perspectives of people with lived experience that exist.

Separate to visits to psychiatric wards are themed visits where we look at a particular issue affecting a particular community or service. We may have been made aware of this issue through calls to our advice line, or through our wider visiting program. Increasingly—through our contact with people with lived experiences—we are being made aware of current issues that, under any system of evaluation, merit deeper investigation.

We are a part of every themed visit and contribute a lived experience perspective to the planning, and the visit itself. We have been involved in visits to medium and low secure hospitals,²³ to acute wards,²⁴ and have played a major part in visits around the experience of people who are homeless and have mental health problems,²⁵ people with dementia in community hospitals²⁶ and people with a diagnosis of Borderline Personality Disorder or EUPD.²⁷ Again our perspective is useful; both in establishing a connection and trust with people, but also in having some idea of what issues people may be facing.

Lived experience, however, does not necessarily mean that we have lived experience of everything people go through and does not—in itself—mean we will be immediately and automatically approachable. For instance, I have never experienced homelessness or incarceration in a secure unit. But just as practitioners may have an expertise in issues that they have no personal experience of, we may have some idea of the issues people experience through our past work with those who have lived experience—people who are carers. One of the things that we concentrate on in themed visits is finding out from people what their priorities are for us to look at in the first place. So when we carried out our visit around people with EUPD, we met with over thirty people—with the diagnosis—initially just to find out what issues were important to them so that we could focus our visit around this and likewise with people with eating disorders or those who experience homelessness and currently with people with experience of prison and mental ill health, or dual diagnosis of mental illness and substance misuse issues.

Our networks that we have established, both in the past and in our current posts, can also be invaluable ways of both advertising a themed visit and of gaining access to people on the actual visit. Increasingly we are now part of the write up of the final report of the visit itself.

These are the main elements of our involvement in the Commission, with particular emphasis on our role in safeguarding the rights of people with a mental disorder. There is talk of involving us in some of the formal investigations that the Commission carries out into failings in care; though we are not involved in casework, apart from by alerting practitioners to issues they might need to know about and follow ups. We are not involved in the advice line, guardianship visits or in leading particular areas of work—although our line manager is a director at the Commission and routinely carries out much of the high level work we have less connection with.

²³ MWCS, Medium and low secure forensic wards: Visit and Monitoring Report (2017)

²⁴ MWCS, Adult acute themed visit report: Visit and Monitoring Report (2017)

²⁵ MWCS, Themed visit to homeless people with mental ill health: Visit and Monitoring Report (2017)

²⁶ MWCS, Themed visit to people with dementia in community hospitals: Visit and Monitoring Report (2018)

²⁷ MWCS, Living with Borderline Personality Disorder – The experience of people with the diagnosis, families and services in Scotland: Visit and Monitoring Report (2018)

Briefly referred to earlier, is the bit about culture change. We are expected to raise issues that encourage everyone in the Commission to routinely involve people with lived experience—including their carers—in the everyday work they carry out; to respect the differing experiences, views and backgrounds people come from, to recognise what is easily forgotten, that we are working in effect for people with a mental disorder. We may have varied expertise and qualifications but ultimately, we are working to promote the rights of people with a mental disorder and are in many ways accountable to them; just as we are also accountable to Parliament and to our Board of Directors.

Culture change is a complex and difficult aim; the Commission is not aiming to become a user-run organisation per se but is aiming to have lived experience at the centre of what it does. Just as it wants to be an organisation that would want professionals to turn to whenever they have concerns about the rights of people, so does it hope that ultimately people with lived experience feel a sense of belonging and ownership of the Commission. Our presence across Scotland is helping with this, but it is a complicated; just as professionals can mistreat and prejudice against service users and carers so can we, as service users, feel anger and anxiety about people seen as professionals. We may refuse to speak to social workers or psychiatrists, and this is where, as Engagement Officers we bridge a gap; by being people that certain groups are willing to speak with, in contrast to some of our other staff.

Hopefully as time goes by this occasional mismatch in perception and expectation will begin to reduce; why else have these posts if we are not aiming for that? But just as there will always be necessity for an organisation like ours when society sanctions the detention of people—who haven't committed a crime—so too will there always be the possibility of suspicion and conflict when an organisation that is here to protect our rights is run by some of the people who when acting as professionals can take away our freedom; even if this is in the name of providing us with that fundamental right—the right to life.

Our presence challenges the idea that everything is about a power imbalance and that mental health services are inevitably about oppression and restriction. We tread a ground where we acknowledge that there are many, many, different perspectives when looking at mental disorder. That there is definitely abuse and poor treatment and even more definitely, the potential for poor treatment and abuse. But where, in the past, I would have thrown my hands up at this and said 'We will have nothing to do with a system in which we have had such bad experiences', now I feel that the solution to such issues is by dialogue and cooperation and by learning together. It means that I recognise the expertise of professionals and also recognise that the practitioners in the Commission can have a greater understanding of legislation and the rights contained in it than I ever will, but equally that without my voice—and the voice of people like me—the Commission will always run the risk of being a tokenistic gesture. That we need the feedback that Kathleen and I gain from service users and carers and need to act on this, that we need the blog posts and comments I put up on the intranet to remind us all of a lived experience perspective—and the numerous speeches and reports, not only on issues to do with detention but on issues like our rights in the benefits system or experiences in rural areas, or views on restrictions on smoking in hospitals.

I said earlier that nowadays I like the idea of dialogue and co-operation and learning because that is how change happens; but I also said that service users can get frustrated

at our inability to insist on change. The legislation that underpins our organisation makes it a legal requirement to have people with lived experience in the Commission and the last four years have been spent in making it a reality rather than a token gesture—though I think there is still an incredible amount to do. But I can also see the point sometimes of reflecting that legal requirement on our internal working with perhaps correspondingly more powers in the actual work the Commission does. It is a debate that is maybe beyond me, but sometimes—when I witness what some of the people with lived experience go through and what their friends and family experience—there are times when it does seem sad that we can only point out to a Health Board, or Local Council/Authority that they are acting improperly; maybe it would be better if we could require them to make changes, just as service users and carers have told us.

There are of course, lots of issues around this; it would need more resources, it would need legislation, and above all it would need that increased debate about creating change through example and dialogue—and the power of argument—as opposed to telling another organisation that a certain course of action will not be permitted.

Already I swither, I can see the point of both ways of looking at rights and the services we receive. But more than anything, I can see the point of having people like myself and Kathleen in the Commission to raise discussion about issues like this, to wonder if we have enough people with lived experience on our Board of Directors, to wonder if the Advisory Committee is diverse enough, to question the level at which we involve our contacts in the Commission, think always 'Is this being done with the right motives and ethics or is it something that just looks good?'

And do we—as people with lived experience—make a fundamental difference around such things as detention, rights and freedom? I think we do. We have an experience that most people do not, we have a perspective that is essential in any organisation such as this, and the capacity to build connections and create bridges and in some circumstances have a role that cannot be found elsewhere – our discussions on detention and supported decision making really needed to be rooted in and informed by lived experience—just as it can be immensely helpful having a lawyer or psychiatrist influencing national and international practice, it can also be incredibly important to have people whose role it is to help people with direct experience of some of the worst aspects of life; to give expression to that experience and on occasion use their own experience to influence and create what we hope will be a better world for people with a mental disorder.

Just as a small summation of our work, between 2017 and 2019 we have met and reached out to at least 1500 people; attending well over 120 user and carer groups, visiting well over 20 hospitals, and playing a role in more than 40 themed visit events. We have also delivered over 65 presentations—varying from user and carer group meetings to International conferences—contributed to six commission reports and created ten of our own reports documenting our engagement activities.

A few quotes to finish with:

From Commission staff:

'Still sitting at my desk because I started reading your paper and couldn't put it down...I'm completely blown away by your honesty and how you've managed to describe your experience with such heart-rending clarity. I hope in difficult times you realise how much you are valued here too - even if we don't show it and seem a bit stiff compared to former colleagues!! I think the dilemmas you describe – both personally and for others – really get to the heart of what's important and cut through the political speak we seem to tie ourselves in knots with when we start to talk about these rights.'

From advocacy groups:

The new post has contributed directly to Carers feeling more involved with the Commission and more confident to approach it.

Face to face meetings with a number of Carers who are individually or collectively facing very complex issues have been particularly valued. Carers report feeling listened to and understood in a way they had not experienced before

Thanks so much for last night It seemed to me that they appreciated being asked about their experiences on acute wards, and that maybe that was the first time that anyone has taken an interest (which I should've asked, in hindsight!) Hopefully this will be the first of other things to come - it was really inspiring in terms of my own project, and gave me some ideas about what we, as a group, could think about in terms of challenging some of the issues that were raised

From outside agencies:

"Informative and hugely inspirational talk about lived experience. Really beneficial to hear about the experience and impact of detention in reality, the restrictions and differing viewpoints. Really warm and enjoyed listening to you."

Your reports look excellent to me – I really think the focus on supporting people to make their own decisions has great potential to improve people's experience of services and, as you suggest, reduce the need for compulsory intervention. A theme, which is in your report, which we also found to be really important was time – people saying that they felt pressured to make decisions and that more time would have eased that – I've attached the most recent draft of our report too. It's still a draft but I think it reinforces many of your findings.