

**Ordinary and extraordinary people, acting to make a difference.  
By the Leicester Living with Psychiatric Medication group.**

## **Introduction**

We are the 'Living with Psychiatric Medication' (LWPM) group; a community group meeting in Leicester with an interest in the relationship our society has with psychiatric drugs. Over the five years we have been meeting we have achieved a staggering amount and are continuing to evolve as an active, informed and supportive collective. We will describe how and why we formed the LWPM group, how we have evolved and the work we engage in. We are proud of what we have achieved and want to share this. We would also like to encourage the formation of similar groups and so we will go into some detail about the working of our group, the roles each member takes on and how we situate ourselves in the wider society. One of the most important aspects of our group is that while we are a group of individuals, with different experiences and views, there is something very vital which unites us- the aim of creating a space that is liberating, democratic, respectful and useful.

There are many different voices in our group and we hope that as many of these as possible are heard as we write this chapter together. An important theme in our critical understanding of the world is power and the structures within which it is withheld or asserted. Language is one such structure and we want to draw attention to words that we find potentially problematic, words such as 'patient' for example are therefore put in parenthesis. We use the terms medication and drugs interchangeably as, while we are supportive of Moncrieff's model of understanding psychiatric drugs (Moncrieff, 2009), we also acknowledge that the term medication is more widely used. We hope this invites readers to think about words we tend to associate with distress and how they might impact on our understanding, experience and identity.

## **How and why the group formed**

Our group came into being in 2006 after founder members were inspired by a public discussion evening led by Judy Harvey and Guy Holmes, two members of the 'Thinking About Medication' group from Shropshire. A significant number of people attending felt that there was a lack of information about psychiatric medication available to people taking it, even during our personal medical consultations. We wanted a space to think about alternatives to medication and other activities that can be life improving that do not involve medication for example, going to university, work and taking up hobbies. It was also important for us to create somewhere to challenge and question taken for granted knowledge about drugs. We wanted to share experiences about taking psychiatric medications and ensure that we are not just taking medication without question.

We established an overall aim to create a much needed space for people in Leicester to think, talk and take action on issues surrounding psychiatric medication. When we became independently constituted, in 2009, we developed our mission statement:

The aims of the group shall be to gain knowledge, ask questions, find answers, challenge assumptions and spread awareness about psychiatric medication in a supportive, relaxed atmosphere. We provide a safe environment which promotes us to make our own choices, decisions and thinking critically about living with psychiatric medication.

## **Who are we?**

We are a group of ordinary and extraordinary people with an interest in psychiatric medication. No-one is referred to the group and meetings are open to anyone; people choose to come because they are interested. The group is always open to new members and we believe that all of us live with psychiatric medication in some way (whether as people who take or prescribe medication, care for, or work alongside someone who does). We each hold different experiences of psychiatric medication; some of us used to take psychiatric drugs but no longer do, some have never taken them, some hope to come off, some have been taking them since childhood. While everyone is welcome in our group it is necessary to acknowledge that many of our group have been prescribed psychiatric drugs for many years and have some very important knowledge to share. We have around 10 members who attend regularly and who are involved in the group activities. Our collective has a fluid membership, with some people coming for only a few meetings or who keep in touch with us indirectly and it feels important to maintain this openness.

## **What do we do?**

We want our meetings to find a balance between being structured and flexible and, crucially, to provide a forum for open debate where differences of opinion are welcomed and respected. This is something which we have found to be lacking in many formal mental health services. For example in the relationship between 'prescriber' and 'patient' we have found that many topics are not up for discussion. We are seen as 'patients' whether or not we wish to take on this identity because we are being seen in a clinical context by someone who has been assigned the identity of 'expert.' In this supposed protection of our best interests, we are denied opportunities to explore really important issues, such as why the leaflet that comes with some of our medications lists death as a possible 'side-effect'. Perhaps because there are no easy answers to some of the difficult questions we have, we have experienced a lack of space in which to think critically as adults in an equal relationship with those that prescribe to us. Our group then becomes a vital opportunity for us to have freedom to talk about these issues and to reclaim power by seeking knowledge and solidarity with

others. The group is not exclusively about coming off psychiatric drugs yet similarly we do not suggest that drugs are an answer to our distress; we aim not to prescribe knowledge, but to provoke critical reflection. The group gives all of us an opportunity to explore the complexities of the relationship between distress and the medical model and to be mindful of the social and political issues surrounding a society that gives such weight to pharmaceutical solutions to human problems.

Sometimes our meetings include a speaker who talks about their role in relation to psychiatric medications and offers a question and answer session. We have invited psychiatrists, pharmacists, psychologists, community psychiatric nurses and solicitors for example. This gives us greater access to mental health professionals. Meeting on our territory rather than theirs makes a powerful difference to the kinds of dialogues we can have. We feel able to ask more questions, to be more open and reflectively critical of aspects of psychiatric medications and the process of prescribing that concern us. We see that the professionals who come to our group also react differently in the context of our meetings, seeming more comfortable with these types of conversation. Perhaps this is because they feel less responsible for us as 'patients' in a group setting, they may have more time to listen to our views or feel safer talking to us in a forum where the distribution of power is shared. Importantly, the support and knowledge we develop as a group stays with us as individuals outside of group meetings. For example, we feel more confident in asking questions and expressing a difference of opinion during an appointment with our psychiatrist; there is something about being part of such a strong collective that legitimises our voice as an individual. We have developed good relationships with speakers we have invited to the group, some of whom come back regularly. We have also developed strong links with the Leicestershire Partnership NHS Trust and Network For Change- a local voluntary sector mental health project in Leicester.

Over time our group has changed and seems to have taken a similar journey to that described by bell hooks in relation to the feminist consciousness raising groups of the 1960's and 1970's (hooks, 2000). In the beginning the group provided a forum within which we could share experiences and learn about psychiatric drugs and the pharmaceutical industry. Concurrently we became aware of the multiple ways psychiatric drugs influence our everyday lives. Whilst doing this was crucial, in those early days there was 'little or no focus on strategies of intervention and transformation' (hooks, 2000, p.7). Like the consciousness raising groups, our initial focus was inviting open communication and doing this in a non-hierarchical way 'created a context for engaged dialogue' (hooks, 2000, p.8). Navigating through agreements and disagreements gave us a 'realistic standpoint' (hooks, 2000, p.8) from which to understand the complexity of what it means to live with psychiatric medication and in turn led us to social and political action.

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We feel strongly that our individual experiences and work together should have a wider impact. With this in mind, we have consulted with people around the UK about the setting up of similar groups, we have presented at national conferences, published articles and booklets about the group, held a drug company marketing amnesty and related art exhibition, organized a debate about prescribing psychiatric medication to children and have plans to organize a national meeting about psychiatric medication. We have also forged important links and relationships with other community groups, e.g. 'Brightsparks Arts in Mental Health' group, 'Seroxat User Group', the medication groups in Shropshire and Bradford and the Nottingham 'Mind Medication group'. We all encourage and support each other and it feels important to be part of a growing network of allies.

Consciousness raising is an important aim of our group and we try to engage in actions that will encourage others to think critically about important issues. The public debate about prescribing psychiatric medication to children, organised alongside the Nottingham- based Mind Medication group, became important to us after we had spent some time thinking about the implications of prescribing psychiatric medications to children and whether this should be acceptable in our society. We had discussed and shared our fears and recognized how important it was to keep open channels of dialogue. Organizing a debate was our way of responding to our concerns. We wanted to encourage critical reflection on the lack of alternatives in understanding and alleviating a child's distress. We wanted to explore what this might say about our society and how else we could respond. It was empowering on many levels to organize such an event, we as a group had to learn many new skills as it was the first time we had had the opportunity to be part of such a project. We also received positive feedback from the speakers we invited to present at the debate and those who participated in the discussion:

*The debate finished five hours ago now, and I still feel like I am buzzing from being there.....It has left me wondering about the powerful influence that open public mental health debates (like this one) could have on perceptions of mental health in our society. It would be fantastic if they were to become more regular events.*

*Debate attendee*

## **How We Run Our Group**

We created some 'Ground Rules' at the very first meeting of the group and these have since evolved into a 'Group Framework' which makes them feel more democratic and less dogmatic. They help everyone (group members, new and old, as well as speakers) to know what to expect in the group. The framework is read out at the beginning of each group and is sent to speakers in

advance of the meetings. It also ensures that the speaker and group are not disturbed and keeps the group on track with its ethos. We found that developing our own framework for working together was and continues to be a major part of the evolution of the group. It can be hard to navigate, for example, the dynamics of a difference of opinion, particularly in a context where we are sharing personal and often distressing experiences. The framework grows out of the challenges we come across as the group progresses and gives us a process through which we can sort out the disagreements we may have.

A good example of how the group framework helps us to manage group dynamics is the evolution of one of our agreements. For a long time we maintained a rule that members could not join in the group session if they were late. This was so that we were not interrupted when discussing personal stories or listening to an invited speaker. However, we often found it difficult to balance the tension between respecting the conversations that were already going on and the passion of late-comers to join the discussion. We spoke at length about how this made us feel and agreed to allow existing members (who were well acquainted with our group framework) to come in late if they agreed to come in quietly and not disrupt the discussion. This felt a frustrating and difficult situation for us and we all had different opinions on how to solve the problem. We needed to balance several conflicting concerns such as respecting the speaker by not having their presentation interrupted and respecting the rules we had all previously agreed to. Yet we also did not want to unwittingly become gate-keepers of knowledge and needed to be mindful that there are some appointments we cannot re-arrange or avoid. Appointments with a psychiatrist, for example, cannot easily be changed and their surgeries often run late. While compromising has produced tensions in the group (and could quite easily have led members to leave the group) we are proud of the way we have managed the situation and it feels like a positive challenge that we have worked through together. There have been other positive outcomes from the conflict; for example, it has led us to think about ways in which we can structure the room layout so that speakers are not interrupted when we need to pop out of the room and, importantly, it has led us to learn a little about ourselves and our potential for flexibility. One group member, for example, was surprised at how rule-bound they were and felt it was powerful to think of ways in which they could be more flexible.

We regularly identify particular roles within our group meetings that are important in maintaining our ethos and focus. We feel it is important to share these jobs and for group members to participate in any way they feel comfortable. This may mean taking on a particular job on a regular basis (such as minute taking, updating the website or reading the group framework) but it is also important that we feel comfortable in saying 'no' to taking on a named role and we recognise that this does not detract from the value of our participation as a group member. This breaking down of the facilitation role means that we have become more democratic in the way we uphold our group framework, for

example, the whole group takes responsibility for not speaking over each other. We have a lot of aspirations that are not easily fulfilled in the two hours every fortnight that we meet. Some work needs to take place outside of the group and we each share this; as we only do as much as we can or want to this does not feel like a burden, in fact some of us thrive on it!

To be more specific, some of the interventions that a group facilitator might make that we try to take responsibility for as a group (without allocating them to one person) are:

- inviting other group members to respond to something someone has said
- offering information as material to be questioned, debated and discussed rather than accepted
- respectfully disagreeing
- encouraging group members to take on roles that might make the most of their talents or offer them a structure for their contributions
- reminding people of their own commitment to say 'no' to taking on tasks for the group

When we do not have a speaker booked, we either use sessions to share our own experiences, or we work on one of our projects. For example this might mean jointly writing presentations, adding to our website or responding to emails. Since we became independently constituted, we have been able to apply for small grants which have allowed us to cover the costs of the projects and buy resources such as a lap top, phone and books.

Our collection of books, articles and general resources is now fairly extensive and we find these useful to refer to during our meetings. Group members and speakers also bring and share articles, views and experiences with each other during the session. Holmes refers to this as the 'democratisation of truth' (Holmes, 2010); information about psychiatric medication in Leicester is no longer in the hands of one dominant group.

### **Balancing different roles**

Some of us attending the group also work in mental health services (two voluntary sector, one NHS). Two of us have psychology backgrounds and have been involved since the groups inception, sharing and developing an enthusiasm in Community and Critical Psychology (see for example Kagan et al, 2011) and liberatory group work (e.g. Holmes, 2010). Smail's (1993) analysis would suggest that it is perhaps not a coincidence that two of the workers have psychology backgrounds. Psychologists often work within the statutory mental health system but do not have the statutory powers of other professionals for example to prescribe or administer mind altering substances, to remove children into care or to administer electric shocks or any other 'treatment' without consent. This coupled with their commitment to the importance of relationships in life may make them more acceptable working partners.

Developing independence as a community group has been important for all of us, for example, we regularly review the location of our meetings (currently within a statutory-sector mental health resource centre) in terms of moving somewhere more neutral. Also we periodically talk as a group about whether it is the responsibility of those of us who also work in services to withdraw from the group; to offer facilitation only to the point where the group can continue to evolve without workers being directly involved. This feels like an ongoing process. Members of the group who work in services certainly take less of a lead now than they used to and it feels less and less as though they are essential for the group to run. Nevertheless, we are not sure that we are aiming for a position where workers do not attend the group at all and we wonder whether our experience may call into question the notion that it is always more empowering for paid workers to disengage with groups once a collective has been achieved. Those of us who have paid positions in the mental health services continually reflect on their stake in the group and the extra dynamics their roles may bring for example acknowledging how it might feel for someone accessing mental health services to join a group which includes people who work in those services.

Often we talk of those in professions as though they are at the end point of their learning while, in reality, they have much still to learn. Working alongside community groups can be a rich source of education and liberation for those who work in services and it is vital to acknowledge and appreciate this. While we feel we meet as equals in our group we also need to be aware that our work is situated in a context that is inherently unequal; acknowledging this together can at times feel challenging and confusing. We are used to talking about power in terms of 'Them' and 'Us' and we can find it harder to locate and name the powers that are structurally embedded, particularly in forums which manage to achieve democracy. The need for the paid workers to withdraw from the group is something we talk about regularly for example and this leads to important questions about the difference between varying roles within the group.

These differences need to be reflected on, regardless of how much we enjoy working together and doing this has helped us to witness the shift from paid workers being needed in the group to simply being welcome. It has been important for workers involved with the group to resist the temptation to make their positions as invisible in an attempt to dilute the power they are afforded by their working role. At the same time Holmes (2010) warns workers participating in community group work that because of their position of relative power, their perceived opinion carries a lot of weight. Whilst in our group workers share their personal experiences, there is a risk that, legitimized by the roles they now hold, their experiences, however they are offered, may be heard as positions in relation to other members rather than as personal accounts, saying for example "I managed to stop taking medication, you should too".

There is a balance that we maintain in thinking enough about these dynamics without allowing them to paralyse us and unintentionally reinforce a divide among those that have paid work in and those who receive support from mental health services. Furthermore it can be liberating to deconstruct the structural differences

inherent between service 'users' and 'providers' while at the same time maintaining an equality within the group. We seem to be able to achieve this and have a strong sense of solidarity in our meetings. We are an open group which means, in theory, workers are very much welcome to join us as members. In practise however the workers that are regularly involved in the group are those that were there from the beginning and whose role has needed to shift in terms of sharing the responsibilities of facilitation. For example for the first year or so the two psychologists met in supervision outside of the group to reflect on their role yet this would certainly not be fitting now as the group has developed such a strong collective identity.

The gradual shift of these particular roles are important in considering the ways in which we as individual members also become resources and in countering the risk of reinforcing traditional hierarchies of role division. There are times for example when we have found ourselves looking particularly to the paid workers when a difficult group situation arises despite having developed collective group processes in order to deal with these situations. At these times we need to question the ways in which we naturally assign/take on roles, acknowledging the ways we have been used to being with each other in different contexts and moving towards more mutual ways of working together. However it is similarly important to acknowledge that there are elements of the differences in our roles that seem useful. For example the paid mental health workers amongst us are more likely to be contacted outside of the group for support prior to (sometimes instead of) bringing personal worries about the group to a meeting. It is interesting to consider how the boundaries of the identity of 'paid worker' may serve an important function at times.

In providing a critique of the particular ways in which some of our roles need to be considered we are in danger of expressing a simplistic and false dichotomy between those who work in and those who seek support from mental health services. Some of our group have the opportunity to take on voluntary roles within local statutory mental health services, developing in-patient services for example, and many of us have positions within service-user forums. This is vital in building links, publicizing our projects and working collaboratively with others in our community; we benefit collectively from the work we do as individuals outside of the group. It feels important to acknowledge the benefits that can be achieved when people with different roles work together and reminds us of the concept of 'edge effects' in community psychology whereby alliances between different communities (or those with different roles in the community) provide a "phenomenon of enrichment...energy, excitement and commitment" (Kagan, 2007, p.225). By redistributing, sharing and encouraging each other to make the most of our personal resources we find ourselves investing in something much larger than what we could achieve as individuals- a collective effort which has the potential to engage in transformative change (Kagan et al, 2007).

## **Why we value the group**

We were recently asked, at a teaching session, how we have managed to keep talking about psychiatric medication for five years yet the topic is so pervasive and broad that we have never run out of ideas and projects. We regularly hold reviews and evaluations to make sure that we continue to evolve in ways that are meaningful and useful to us all. Individually, we feel motivated to attend because:

- It's friendly
- We discuss a common interest
- We feel involved
- It encourages a sense of purpose
- It's a place where we can be heard by professionals or get feedback from them
- We spend a lot of time listening to and learning from others and have gained a lot from other peoples' experiences; sometimes just listening to other people's ideas can help validate your thoughts or encourage you to think in a slightly different way- in this sense we are encouraging a 'listening therapy' as well as 'talking therapy'!
- The group is continually evolving

[Drawing]

We also have support from individuals and organisations outside of the group who tell us that our work is very important and they urge us to carry on. Speakers who have come to our group have also told us that our group is unique and much needed. We have the chance to quiz experts outside of the confines of clinical consultations, to gather a wide range of resources and can be creative in a context which is free of vested interests in us taking or not taking medication. We appreciate the support we offer to each other by having respect in the experiences and opinions each of us share and the knowledge that we are all meeting with a common aim. It always feels like an optimistic group, even as we uncover more questions than answers and talk about some very deep and troubling themes. The group is a positive place to get involved; we love the way it buzzes with ideas and we value exploring these in a space in which we don't impose our judgements on each other or dictate how others should act.

We find ourselves making a big commitment to the group, meeting outside of sessions to finish off projects, completing work in our own time to help the running of the group and developing skills (such as working on a computer or chairing a committee meeting) so that we can offer these to the group. We are a proactive group and this sense of momentum feels important; we identify themes that concern us and then we try and do something about them, even if all we can do is to raise consciousness amongst ourselves and others so that some of this knowledge is no longer hidden.

The LWPM group is important because it gives us a space where we are validated and listened to and, for many of us, this is not something we have regular access to. Some of us have been in the psychiatric system for many

years and this is dis-empowering in a number of complex ways. We can find ourselves disenfranchised, for example, by being prevented from entering the job market or higher education. The medication we take can leave us with physical health problems. We feel like we do not always have an equal place in society, that we are shoved to one side and others can find it difficult to understand us or, at times, do not want to know about our distress or label us as 'hard to cope with'. We acknowledge that the mental health system is unique from other frameworks in our society in that we can be subjected to a loss of our human rights as legally legitimized by the state in the name of our best interests. Some of us have had powerful experiences of being coerced into continuing or starting medication regimes we do not agree with because of the possibility of being sectioned under the Mental Health Act. Some of us have memories of the lack of dignity and basic human rights we were offered while we were at our most distressed and in hospital. We also face being perceived by society as a discrete section of the population rather than as diverse individuals. The current rhetoric of the government can feel like a harsh indictment of the many of us who are entitled to welfare and we are subject to the negative stereotypes perpetuated by the media regarding mental health. Experiences like these, and the many more we share with each other, can have lasting legacies.

We value the group because it gives us an opportunity to work together to counter these processes of disempowerment by, for example, making access to knowledge easier through our meetings with speakers and our collection of research literature. It can be very difficult to find out information about psychiatric medications and we have found it empowering to build up a collection of resources, and to establish a more equal relationship with the 'professionals' that work in the field of mental health. We value making use of our space to share and understand our experiences as, for some of us, this group is the only opportunity we have to do this.

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We find that the group opens up choices, opportunities and rights by:

- Inviting open discussion about medication and encouragement to make informed choices.
- Increasing our knowledge, offering a space to ask questions, find answers challenge assumptions and spread awareness about psychiatric medication.
- Giving us confidence in our own lived experience.
- Offering us new opportunities e.g. being an author, a group facilitator, a campaigner, a tutor, a public speaker, a website designer, an accountant; skills that we can also use when we are looking for employment.
- Actively building knowledge that are useful to others and being asked to share these.

- Giving us the chance to do something about the things we are concerned about.
- Engaging directly with the public and working to break down prejudice.

It is important to us that we can be comfortable amongst others who have experiences of psychiatric medication; in other contexts our ideas have been perceived as radical or maverick, but here they are accepted. We all feel proud to be part of the group and to work on our projects we initiate. We have been able to represent and promote Leicester at a national level and have had many people say that they now think of Leicester as progressive and inspirational.

[Text Box]

### **Challenges we face as a group**

It is difficult to write exclusively about the challenges we have experienced because we have almost always managed to transform them into an area of growth for the group which is a powerful positive experience (for us as a group and as individuals). We recently worked alongside a Trainee Clinical Psychologist to evaluate our group; one specific area we considered was what made attending or contributing in the group difficult sometimes. We identified a few themes. Past experiences (such as being put down, punished, bullied or called names) can interfere with our capacity to contribute as much as we would like to the group. Sometimes our experiences are just too painful to talk about.

[Text Box]

Some days, although we want to attend the group because we find it valuable, we don't really feel like contributing. It can be difficult when feeling fragile or in a bad state or when we are suffering from the effects of medication.

We think we need to continue to work hard to make the group an easy space for new people to join. Several of us have been involved for a long time and this helps maintain a collective identity but we do not want this to exclude new comers. It can feel daunting for someone to come into our group for the first time and it can take a while for new members to feel comfortable. It is easier when an existing member knows the new member and can introduce them to the rest of us. We make our group framework and a list of our hopes and fears for the group available to new members and this can help give people some idea of what to expect from a meeting. Despite this there are times when our group meetings are quite busy and intense as we might have deadlines to work towards for our projects. This can be intimidating for new members. For this reason we take turns in the role of 'hospitality and greeter' so that new members

feel welcome and included. Some people only come to our group once or twice and it is not always easy to find out why. This feels OK though and we have several members who only come every now and then. Some of these people have told us that it is important to them to know that the group is there, even when they don't attend. There is a kind of security in the knowledge that debate occurs even for those not directly involved.

It can feel empowering to be engaged in so many projects but this can leave us with little time to talk about our experiences and concerns about our own medication. Our diverse group aims (taking action, inviting speakers to the group, sharing personal experiences) sometimes compete for time and we need to try and achieve a balance. This can be a fertile conflict though, it can keep us motivated, passionate, structured and ever mindful of the need to question what we are doing and why.

There is also the careful balance that all of us have to strike between silence (which can itself be difficult) and talking too much. We recognise that despite the current fashion for 'talking therapies'; talking is sometimes unhelpful, especially if we do not feel listened to or understood and it is not always possible to put into the words the complex and intangible experiences we have. It can be re-traumatizing to bring the things that dis-empower us into a space that is also dis-empowered and while we are proud of our achievements as a group there are things that we cannot change and wrongs that we cannot right and we should not ignore this. For example one of our concerns in the group is the long-term effects of taking psychiatric drugs. For those of us who have taken these drugs for several decades and those of us who do not have an alternative to medication this can be terrifying to think about. It is important that we are all mindful of each other's right to not want to talk about ourselves or our experiences so that each of us consents to the information we share.

We make sure that we share the responsibilities of the running of the group so that each of us are able to take a back seat during a session if we need to. Despite this there is a lot of passion in the group and it is not always easy to decline opportunities to get involved in projects and take jobs on, particularly as our work is so important. Becoming a constituted group is a good example of this as some of us have taken on the more formal roles of 'Chair', 'Treasurer' and 'Secretary'. This feels a big commitment and despite the strong sense of democracy within the group the responsibilities of these structures can be imposing. We manage this by learning about ourselves and our limits so that we can know when it is best to say 'no' and, importantly, to feel this is OK. The group offers a safe and supportive environment for this as we can help remind each other when we might be taking on too much.

When we first started the group we feared that professionals would feel it too risky to talk openly with us about our concerns however, on the whole, this has

not been the case. One notable exception arose when we invited drug company representatives to come and talk with us about their role within the industry and how it was located within mental health services. Two major drug companies were approached, both of whom declined to come and speak with us referring to the code of practice for their industry. They acknowledged the role of drug company representation as promotional and refused to reply even in writing to some of our questions stating that ‘...plentiful opinion exists in the public domain’ (private correspondence). We acknowledged that it would not be right for a representative to come and market their drugs to us, but felt angered that we needed to be 'protected' in this way. The drug companies acknowledged they would have come to talk to us if we were a body of healthcare professionals. We wondered why it was not acceptable to come and talk to us as adults, but it was OK to advertise to us on the pens our doctors write our prescriptions with and the clocks on the psychiatrist's wall. This frustrating barrier led us to become involved in a drug-advertising amnesty. We worked alongside a local arts collective gathering pieces of marketing paraphernalia left by drug reps in the services we use and turning them into works of art. These were then exhibited locally and at a national conference as a consciousness raising exercise.

All of these challenges to contributing and being involved have over the years been addressed by our group framework, and because these are read and discussed at every meeting and reviewed regularly they are always at the forefront of any work that the group does together and this helps us to openly and collaboratively tackle difficulties that we come across.

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### **The future of ‘social action’ groups**

Perhaps it is too early to call our work part of a movement, but there are now groups in Bradford, Leicester, Nottingham and Shropshire. It is interesting how the groups vary, for example, the Leicester Group seems to concentrate on the ways each of us in our society lives with psychiatric medication whereas the Shropshire Group has developed a focus more on coming off medication.

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A pivotal point for our group's growth was becoming independently constituted. However, this also brought with it challenges, especially those arising from group's growing need to apply for funding as an evolution towards independence and action. Applying for funding, receiving it, spending it, accounting for it are all skills we found very difficult and in some ways we resent the time it takes away from the more important work the group does, even though in many other ways it facilitates us being able to do them. It can impose structures on the group that feel less meaningful than the time we spend listening to each other and acting on issues that are important to us.

There is something especially important about being together that we worry is undermined by society's push towards the formalisation of community groups as social enterprises. There is currently much political rhetoric about supporting community groups to have more control over community resources and to have more say about how local issues are addressed. We are fully aware that our views sometimes situate us outside of a mainstream consensus and we wonder whether this can preclude us from some funding pools and therefore how difficult it can be in this context to achieve radical change. There is something very fundamental about the need for us to come together in our communities that is, perhaps, lost by the formal structures encouraged/foisted on grass-roots groups in their aspirations for power.

We are proud of how we have developed as a group over the past six years, and it can be staggering to think of all that we have been able to achieve together over this time. The picture below illustrates some of the ways we feel we have impacted on the world around us through the projects we have taken part in.

We often surprise ourselves at how much we have achieved over the past five years and how much we still want to do. Much of what we do is new to us and it is important to acknowledge our gradual and organic evolution from developing a tentative meeting space to becoming an active, empowered group with a growing sense of agency. Writing this chapter has been useful for us to remind ourselves of just what is possible, ordinary people really can achieve extraordinary things.

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