

# Creating a movement to end exclusion



"If there's anything that the experience in Malawi taught me, and taught many of us, it's that the work of organising and mobilising starts with very small efforts. You know, sometimes it's one woman at a time, talking about the issues that they care about, no matter how small or insignificant those issues might appear to you as an outsider. It's about taking the time to support them through that journey of self-awareness and self-consciousness, that's where it begins, right? Without a sense of self, without a sense of rights, without a sense of 'this is what I'm entitled to as a human being,' you're not going to move."

– Everjoice Win, Action Aid



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Projects can bring about small changes, but to bring about big changes, to change the way a system works you need a movement – with large numbers of people who are prepared to work together to challenge the system. But what if you want to create a movement of people who are excluded two or three times over, whose own sense of self-worth and agency have been severely undermined by stigma and discrimination? Where do you start? How do you support them to believe that by working together they can make a difference? Let's look at a real story and find out.

Back in 2007, despite enormous amounts of money being directed towards HIV and AIDS-related work in Malawi, rates of infection were still rising. Just Associates (JASS, www.justassociates.org), a global feminist movement-building organisation, together with allies at Open Society Initiative for Southern Africa (OSISA) and ActionAid in the region, were concerned that HIVpositive women, particularly poor black women in rural areas, had the least access to treatment, support and information. Not only were they excluded from public discussion and decision-making about HIV and AIDS, they were also stigmatised in their own families and communities. The stories of these women were being used to show the impact of HIV and AIDS to the world and to raise money, but their specific needs were not being addressed and their organisations were not being supported.

## Recognising and building the power within

JASS started by going out to meet and engage with the women, listening to what they had to say. Many organisations had already run workshops to provide information and involve women. These workshops tended to have a set format, be quite formal, and women knew the role they were expected to play in them. JASS wanted to do something different, to engage with women on their own terms. They called their gatherings "get-togethers" and made them fun and engaging. There was food and dance and song. They aimed to create a safe space where women could talk about their lives and not be told what to think and do. Participants were encouraged to laugh and to cry, to share their hopes and fears, to be themselves. They were asked about the challenges they faced and how they were coping with them.

The focus was not just on problems. Through the gatherings, women discovered they had vital knowledge, experiences, ideas and survival strategies to share. They came to realise they weren't alone and they weren't to blame. They began to see themselves as resourceful survivors who deserved to thrive, to have a voice and to be heard. They began to understand how the systems and power relations in society were leading to inequality and exclusion. This they understood as discovering their "power within".

## "Our bodies, our lives"

JASS used a feminist popular education approach – popular education informed by a feminist analysis of power and how knowledge interacts with power. The approach recognises that the dominant patriarchal system influences what knowledge is valued; privileging male experiences and perspectives while excluding the experiences and insights of women. This system underpins the way society works and how it affects women and men. By unpacking this way of looking at things and enabling women to learn from and value their own experiences and knowledge, they begin to see the world quite differently. They see how the system in which they live impacts on their lives, their opportunities and their relations with others. They also see how they can begin to change that.

**b** By unpacking this way of looking at things and enabling women to learn from and value their own experiences and knowledge, they begin to see the world quite differently.



In the first phase of movement-building work, JASS supported women to understand the connection between their individual pain and the systems and structures that excluded and oppressed them. Women felt this in their own lives and in their own bodies.

Rather than ignoring women's experiences of their bodies, JASS used the body as an entry point, as a source of knowledge and political analysis, using a process called body mapping. This activity allowed women to explore and discuss their stories, some of them quite painful, leading to insights about the negative impact of the second-rate drugs the government was currently providing. This put women's lives and bodies at the centre of movement building.

We sat down and thought about what name could really suit this campaign, and we came up with the name 'Our Bodies Our Lives: the Fight for Better ARVs' because what we are fighting for is our own bodies and our own lives.

> – Sibongile Singini, woman activist, JASS Southern Africa In-Country Organiser

## **Body mapping**

Women's bodies bear testimony to the idea that the "personal is political." Oppression and joy plays out in women's lives physically, mentally and emotionally. This simply means that their experiences of the system can affect their health and sense of wellbeing. The body is a symbol and physical manifestation of our experiences of power. In patriarchal systems women's bodies, often do not "belong" to them but are controlled by the men. The body is also a site of contested ownership, internal tensions, and conflict.

#### How does body mapping work?

- Working in pairs, one person lies down on a piece of paper (or fabric) and the second traces her partner's body onto the paper. Participants then fill in their body maps, using different colours, based on the question: what parts of your body give you pleasure or pain? (With pain understood as a way of naming the way our bodies carry experiences, scars and trauma.)
- 2. In plenary, they share their body maps and discuss these with each other. Each woman speaks to her own body. Participants are urged to be open and honest, as this process is an important part of developing trust within the group. In the first part of reporting back women talk about the ownership of their bodies, then the parts of their body that give them pain.

## Women's bodies bear testimony to the idea that the "personal is political."



- 3. In the second part of the activity, women discuss the parts of their body that give them joy and delight; this is a stage of affirmation, of valuing their bodies and, so, themselves.
- 4. At the end of the process, the facilitator reiterates the power of the body, that is, the power of the experience each body carries. She speaks to how the desire to control women's bodies is central to patriarchy and how, as women, our experiences are common and how our personal problems do not need to be, and cannot be, solved alone. We need to work together. She speaks of the need for self-care to reclaim our bodies and wellbeing.

This requires sensitive and thoughtful facilitation. Facilitators must be able to address painful issues which emerge. It is not something that should be done until the women in the group are comfortable with each other.

For a more detailed description: https://werise-toolkit.org/en/system/tdf/pdf/tools/ Heart-Mind-Body-Mapping.pdf?file=1&force=

**Credit:** JASS SNA with Hope Chigudu based on the work done by HIV and AIDS treatment and literacy activists in Southern Africa.

This is the groundwork, the foundation of the movement. It cannot be done quickly or skipped. Take the time it needs. This first stage of movement building cannot be rushed. This is the groundwork, the foundation of the movement. It cannot be done quickly or skipped. Take the time it needs. In Malawi, JASS worked with an expanding circle of women over six years – supporting them in breaking their fear and silence, building trust and community, developing skills and community leadership – until an organising campaign emerged and they were ready to move to a "standing up" stage.

At a certain point, you will know, you will feel, when you are ready for the next stage.

Don't be stressed with project or donor deadlines. This is the women's process, not the donor's process. Crucially, JASS was prepared to put in the time and effort that was needed. Above all, they were willing to listen to what the women needed to move forward and to help them to recognise their own power within and discover power with others.

#### **Power within**

The women had a safe space to talk about their own lived experience. They saw the barriers that were facing them and the ways in which they had been coping with and overcoming them. They saw that their experiences were valuable in identifying where change was needed and that they had resources within themselves to change their lives. They had agency, the will to act, and they felt that agency and celebrated it.

For how to create safe space go to: https:// werise-toolkit.org/en/system/tdf/pdf/tools/ Creating-a-Safe-Space.pdf?file=1&force=



The women were encouraged to take action in their own communities. They gained confidence by implementing their own ideas, running their own projects, individually or in small groups. While they had small successes, there was no single issue that united them and while they made small gains, they could not individually tackle the system that was oppressing them. They needed a movement and to create the movement these individual efforts needed to be connected.

## Making the connections to create the *power with*

The JASS sessions created opportunities for women to explore working together to develop the "power with" – the power that comes from working collectively. However, during this exploration, cracks emerged between them: they started to form allegiances and cliques based around their differences, rather than looking at what bound them together. How did this happen? The social messages, which had disempowered and excluded them and

pitted women against each other, seeped back in. Ideas of how society identifies and judges women as good or bad began to surface, specifically, that of stigmatising women who exchanged sex for money and food because they had no other way to survive. Women were re-stigmatising each other. The facilitators realised they needed to dig deeper and to really surface what keeps women divided and silent. They devised ways of unpacking the social norms and judgements that women internalise and use against one another. Remember that one of the ways patriarchy dominates women is to divide them, to use them to judge and control each other.

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### "A movement cannot be built on stereotypes."

– Hope Chigudu

## Good women/bad women exercise

This is an exercise that can be used to explore and challenge stereotypes.

#### Purpose

To help women to explore how society uses them to judge each other and how these judgements divide and weaken them all. To help them to understand how women often have little choice about what to do to survive, to stay alive, to feed their children, and rather than judging each other, to look at why and how women could unite to help each other and work together to change the system. To help them to discuss what to do about this.



#### Resources

- a. Two empty boxes labelled "good women" and "bad women."
- b. A set of eight statements for each group of four-to-six women. If the workshop is only a few women, you can give each woman a set.

#### **The Statements**

Each statement is written on a different strip of paper (these can be changed or adapted to suit the situation and culture of the women):

- This woman does not work outside the family home.
- This woman always has sex when her husband wants her to.
- This woman had never had a sexual partner before she got married.
- This woman works outside the family home.
- This woman sometimes disagrees with men in public.
- This woman has had sex for money.
- This woman might have been infected by a man who was not her husband.
- This woman was raped.

#### Process

- A. Group work: after explaining the exercise, the facilitator divides the workshop into groups. The groups each read out the statements and decide which box the statement goes in, discussing why. (If a group can't agree, they put the statement to one side.) When they are finished, they put the statements into the chosen boxes.
- B. The women then come together in plenary and discuss what the group task was like. How did they feel about dividing women up based on one thing that they do? Were there any that were difficult to agree on/decide?
- C. The facilitator opens the boxes and reads some of the statements, asking the following. How do you think the women in this box feel? Why did you put this woman in this box? What if a woman does one thing from the good box and another from the bad? Are all the women in the good box okay? Which box would you put yourself in? Why? Which of these women do we need to work with? Let the discussion happen.
- D. When enough has been said, summarise the key points of the discussion, including how social norms and judgements divide us by establishing sets of rules about what we should and should not do. We are made to feel bad or different if we do not follow the rules even if this is not our own choice. How do we punish those who do not follow the rules? The rules create stereotypes and these create divisions that make it more difficult for us to work together based on what we have in common. Stress that movements need to make space for everyone and not make judgements about them, this makes us stronger.

For a complete description of this activity go to: https:// werise-toolkit.org/en/system/tdf/pdf/tools/Good-Women-Bad-Women\_0.pdf?file=1&force=

**Credit:** Anna Davies-van Es and Patricia Ardon, with inspiration from Hope Chigudu and Youth Vision Zambia.

## **Understanding Power**

When you are excluded from decisions which affect your life and you feel unable to change your circumstances for the better, power can seem unattainable. It seems as though some people have all the power, some have none. And without power, how can we change anything?

Power is not one thing, but many.

**Power over:** The power to control the lives of others by force or by making rules and enforcing norms that give advantage to one group over another. This can be done visibly

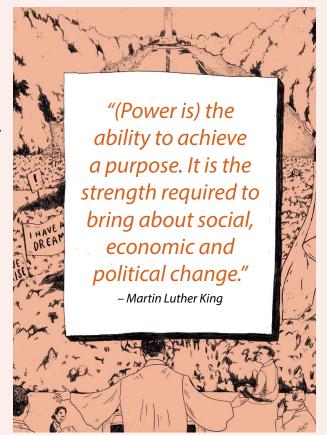
(as part of the political process), in the shadows (through networks of influence), or invisibly (through social norms and ways of working).

Adam Kahane writes that we see power and love as mutually exclusive and challenges us to connect the two. Power without love is abusive and unjust; love without power is sentimental and weak. Power and love together enable us to act to end injustice in a way that does not perpetuate and create injustices.

The first step to taking action to change the way things are is understanding that there are different forms of power and that we can claim power for ourselves. Power can be used constructively as well as destructively.

**Power within:** A person's sense of self-worth and self-knowledge, the realisation that they have power, their capacity to hope, imagine, think critically, question assumptions, say no or yes, respect others, collaborate.

**Power with:** Refers to the power in numbers of people acting together to achieve a common goal. It is about



people unified across differences by shared purpose and multiplying their individual talents, knowledge and resources to make a larger impact. It is about the collective power found in community and common ground.

**Power to:** The unique potential of everyone to shape his or her life and world, the ability to speak up or take action, for instance, to join a protest, write a banner, organise a meeting, scream, remain silent or defy that which is being dictated to someone. This is about the ability to act and comes out of power within and power with.

**Power for:** Refers to the combined vision, values and agenda of change that inspires us and informs the work we do. It builds on the other forms of transformative power and encourages us to create strategies and alternative institutions, relationships and ways of living that reflect our beliefs and hold the seeds of the world we seek to create.

More reflections on power can be found in The Barefoot Guide to Organisations and Social Change, Chapter 3.

[Adapted from JASS, Making Change Happen: Power https://justassociates.org/sites/justassociates.org/files/ mch3\_2011\_final\_0.pdf] After this conversation, the women realised that they could not create a movement if they were only willing to work with those who were "like them." They also saw how, by appreciating differences and seeking to understand others, they were stronger. They could present a united front to those who they were seeking to influence.

JASS worked with women all over Malawi. By this point, there were hundreds of women all over the country who were starting to feel organised, trusting each other because they had shared so much of what had been hidden, and who were preparing themselves to work together to bring about change.

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– Kwangu Tembi Makhuwira, COWLHA, Malawi

## **Building Alliances**

JASS started its work in Malawi talking with other women's organisations and networks, slowly growing a web of women's groups across the country. As the work with the Malawian women grew, they recognised that they needed to broaden their relationships and to forge alliances, including with some unlikely allies. Of particular importance was the relationship with an organisation of progressive religious leaders initiated in 2011 – MANERELA+ (the Malawi Network of Religious Leaders living with or personally affected by HIV/AIDS). The alliance with MANERELA+ was critical, given that many religious groups often perpetuated stigma and blame, especially by blaming "loose women" for the disease's spread. MANERELA+ could bring validation and the political legitimacy of an alternative religious organisation. However, building relationships with mixed-gender organisations in a conservative context to build women's leadership is not always straightforward, and this required skilful negotiation and the building of trust. The effort was important and well worthwhile, bringing visibility and legitimacy to the movement and providing opportunities for changing the attitudes and beliefs of influential people.

## Finding a unifying organising issue

Women living with HIV and AIDS faced so many hardships and injustices – poverty, lack of access to land, abandonment, poor health – that it was difficult to find one issue that the movement could rally around. This was not an intellectual decision, as such, but came out of their direct experience and feelings. They felt it in their bodies.

JASS went back to the women's bodies, to the source of their pain, and the source of their strength and resourcefulness. They now focused on working with women leaders from across the country who had emerged from the initial gatherings.

During a relaxed evening of candlelight, storytelling and song, women talked with honesty about the pain and shame they felt in their bodies. Women began to speak about the changes in their bodies caused by the poor quality anti-retroviral drugs (ARVs) that most of them were receiving from the government. The Malawi government continued to distribute these older ARVs although newer and better ones were available, claiming that they could not afford to immediately roll out the new drugs nationwide. The older drugs caused redistribution of fat in the body and debilitating nerve pain and numbness in many women. This resulted in many women looking physically different, which led to increased discrimination. The chronic pain often meant that women could not do the things they needed to do for themselves and their family in order to survive.

It was the physical changes caused by these drugs and the resulting stigmatisation and mistreatment that became the focus of women's anger. This was not an intellectual decision, as such, but came out of their direct experience and feelings. They felt it in their bodies. As a result, the demand for alternative antiretroviral drugs was a cause that all the women could sign up to.

This single, galvanising issue – that of toxic drugs – brought together many elements of the work: it tapped into women's anger over the government's and pharmaceutical companies' disregard for people, it generated a clear demand – better drug treatment for HIV-positive people – and it activated women's "power to" demand change. This was the spark that focused the organising effort to win governmental responsiveness to and accountability for women's needs through a campaign for access to treatment using the latest antiretroviral drugs.

## Empowering evidence gathering

The women knew in their own bodies the damage the old drugs were doing, but in order to launch a campaign they needed evidence that decision-makers would listen to. Rather than just doing a literature review (something that would have been alien and intimidating to the women), JASS wanted the process of gathering evidence to build people-power and community leadership. They therefore used a participatory research process. Sixty women learnt how to collect data in their own communities. They surveyed 846 women across Malawi in two months, reaching out through their networks and support groups.

The findings were clear: 70% of the women were using a combination drug containing Stavudine, which can cause bodily deformities and other major side effects. When these effects became visible, they suffered shame and exclusion, their husbands often blaming them unjustly for getting the disease. Many women stopped taking the drug because of the changes it caused, risking their health in consequence. Others were not able to access treatment at all.





The data showed that these were not just isolated cases but that huge numbers of women were affected. It showed that the policy of using a low-quality drug was harming women in many ways, physically, emotionally, socially, and economically.

The collection of the data was important in movement building. Because the women had taken on public roles in the community research, their communities began to see them as emerging leaders. This also helped build a network of women across the country who were aware of the issues and ready to get involved. The method of collecting data was therefore as important as the data itself.

With a large group of emerging community leaders, strong evidence, diverse allies and a network of over 1,200 women, the foundations of the movement were in place.

### "Come into the circle and join with us"

The women were ready to go. Now an opportunity was needed for the women leaders to get noticed, to put their demands on the table and to start the process of change.

The alliance with MANERELA+ had proved critical in gaining access to political leaders, but the movement also needed to become visible in its own right and to show its own power. The opportunity they needed came in 2012 in the form of the SAVE Conference,

a high profile national HIV and AIDS advocacy conference where governments and agencies wanted to show their work in a good light. JASS and the women activists organised their own event parallel with SAVE, the National Women's Dialogue. More than 120 women turned up, double that expected. Powerful speakers and dialogue helped women to share their stories and use this space and energy to formulate their demands.

The National Women's Dialogue began with a press briefing that brought together 20 journalists from national and community-based media houses, including the national broadcaster Malawi Broadcasting Corporation (both radio and television), Zodiac, Capital FM, The Nation, and Radio Islam. The women leaders put together a press release about the dialogue and fielded questions from journalists. This resulted in feature articles in two national newspapers, daily news clips on national news, as well as a twenty-minute in-depth news special.



Then, later in the week, at the SAVE Conference, the Head of the Ministry of Health's HIV Unit arrived to deliver his presentation. He was greeted by powerful and well-prepared women with their own agenda.



"We want you to come into the circle and we want you to talk with us," they said.

The women presented their demands calmly and clearly. They wanted immediate access for all women to quality antiretroviral drugs.

"We want you to come into the circle and we want you to talk with us," they said. The women were breaking the expected silence of stigma and making their voices heard in ways hard to ignore. This created political tension and there was concern that there could be reprisals against the women who had previously been so vulnerable and excluded. MANERELA+ proved helpful again, as they had

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inside access to those in power and could reassure them that the women were not a threat.

### Inside/outside strategy

The women had got themselves noticed. Good

tension was generated by their presence and actions at the SAVE conference. They knew they would need to be nimble and politically astute. They worked on the inside by meeting government officials and explaining their demands. These meetings were often brokered by MANERELA+'s network of religious leaders, who were trusted by the government and who could work behind the scenes.

The meetings were complemented by work on the outside. Apart from continuing engagement with the press, they embarked on direct action that brought the issue to the attention of decision-makers and the wider public, putting pressure on the government to act. An interfaith service was held on the second day of the National Dialogue that enabled the women to forge new relationships and demonstrate that women across all faiths were affected by the drugs.

The women planned to take part in a march at the end of the SAVE conference. They developed powerful feminist placards and wrote a communique outlining their demands. They were better organised than others on the march – in fact they were the only ones with placards – so the leaders of the march drew heavily on their communique and read it on the steps of parliament.

#### Success

The women kept up the momentum of the campaign and were able to meet the then President of Malawi, Joyce Banda, as well as the principal secretary of the

Ministry of Health. They had power in directly representing their communities and in being able to place clear evidence for their demands on the table. Their community-based research showed the devastating effects that the drug was having on women's lives and the multiple injustices that women were having to face as a result. The visibility of the campaign in the press and the President's public commitment to women's issues were among the factors that contributed to the campaign's success.

Victory was at hand: the Malawi government changed its policy and agreed to accelerate the rollout of new ARV drugs and to address barriers to access. The rollout began in July 2013.

#### What next?

Though their success was sweet, this was not the time to stop. Changing policy was only the first step in the process. Real success would only be achieved when the new drug policy was implemented in a sustainable way, when women and men were actually receiving the new drugs as they required.

Ongoing monitoring of the implementation is vital for letting the government know that it is being held accountable, as well as for ensuring that the policy is being implemented in the right way. The skills and confidence that the women have developed in the process of building the movement are invaluable in this process. District focal points and campaign committees have been formed to monitor the rollout. Recently, a core group of women asked others to be involved in carrying out a survey to assess how the rollout is progressing, whether women are able to access the services they need and are receiving the new drug. The group surveyed over 2000 women living with HIV and are using this information base to further build the "Our Body, Our Lives Campaign." The solidarity and ability to act is still there.

## Learning for our practice

"If you have come here to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together."

– Lilla Watson, activist, academic and artist

**6** The solidarity and ability to act is still there.

In this story, JASS functions as an external organisation working to help women, who were excluded, to bring themselves into the political processes required to bring about change in their own lives. This raises a number of questions to reflect upon:

How were they able to be so effective? How did they build trust with and among the women they were working with? How did they ensure that the agenda belonged to the women and not to JASS? How did they support marginalised women in becoming powerful actors in their own context?

Before reading on, think about your answers to these questions. Better still, get some colleagues together to study the story and then discuss these questions amongst yourselves.

There are several things we can learn from this story about the practice of organisations like JASS that wish to support marginalised people in creating a movement.

- It is vital to carry out the initial research to gain a thorough understanding of who is excluded and how they are excluded. This is best done by people who are familiar with and preferably belong to the society or community with whom you plan to work. Developing an understanding does not mean, at this stage, deciding what to do – only the group of people affected can do that. Keep an open mind about exactly how people are experiencing exclusion, what the key issue is for them, and what they may want to do about it.
- 2. Start by building trust. Like the women in Malawi, many people have already had experience of people who want to help them. They may have definite expectations of what such processes involve and what they can expect to get out of them. They may be also be suspicious, having found from past experience that outsiders come with their own agendas. Find ways of making people feel comfortable and building their trust in you and in each other. What do people like doing? In what places and circumstances do they feel safe?
- 3. People who have been discriminated against and excluded may not value their own experiences and opinions. This is part of their self-stigma. They have been told that they are not important or have been shown that the society they live in does not value them. By starting with their own experiences and by allowing space and time for them to share these and acknowledge them, people can begin to build their power within again – to feel that what they feel and think is worthwhile and that they deserve to be listened to. Don't hurry them: work in their time, not the donor's time.
- 4. Power analysis is fundamental to the JASS approach. This is not an academic exercise done in an office far away from the action. It is done by the excluded women themselves in their own communities. Developing this understanding of power and how it is working to exclude them is what gives

those who are excluded the power to change things. Respect their own ability to understand exactly what is going on and what to do. This is important to empowerment.

5. Recognise that we are all influenced by the society in which we live and that even when this society excludes us, we often internalise the beliefs and prejudices that have led to our exclusion. This causes us to discriminate against each other. It divides excluded groups and increases powerlessness. It is important to help those so excluded to recognise this when it is happening - as when, during the early stages of movement building, the women started to form allegiances and cliques based around their differences, rather than looking at what bound them together - and then to work with this, rather than just ignoring the processes of exclusion, or to support one group rather than another. It is important that our approach is inclusive, at every level and stage, and works with diversity, actively encouraging people to recognise how excluded people themselves may also be excluding and discriminating against each other.

As women activists, we don't work to say 'I should make the other to say 'Appy', but you work to say person happy', but you work to say and they can see that there is change maybe if they see me, just by seeing maybe if they see that there is change me they can also be changed.'

Tiwonge Gondwe woman activist, Malawi

