

CAL & One in Nine two-day conversation on access to health

19 and 20 September 2018

Objectives:

The objectives of the conversation were as follows:

1. To critically engage with self-care as a form of access to health
2. To reflect and introspect on organizing around access to health from both an individual and organizational point of view.
3. Creation
 - Organizing moving forwards
 - What do we want
 - How do we get there
 - Who should work with us

Discussion of objectives:

Self-Care

A lot of the work that is done around access to health is aimed at partnerships with state institutions to hold them accountable and make sure they provide public health care in quick and efficient ways. But how much of this work can we take into our own hands? How do we begin an access to health that is directed inward?

Looking at self-care as women human rights defenders, what is our relationships with looking after ourselves when our worked is directed at looking after others ie. Other women, the movement itself etc.

How do we determine where on the self-care continuum we are starting? Are we starting with full glasses, empty glasses, or even at a negative balance? What does this mean for the kinds of self-care we [can] engage in?

How do we begin to take care of ourselves where we are? Also thinking of ways that go beyond self-care treatments we need to pay for? How do we think of self-care as a collective exercise?

Self-care as:

- Sleeping
- Saying no
- Drinking less
- Writing
- Taking walks
- Spirituality
- Trusting in others to carry on 'the work' when you need a break
- Does taking breaks have to mean stepping outside of feminism/the movement

Reflection and introspection

Looking into what our individual experiences have been in accessing health care and in organizing around access to health. Being careful to notice where we have made progress and not just as how far we still need to go.

Remembering the notion of looking inward as a form of access to health and being critical of the national discourse of access to health. Maybe noticing when health means drugs (like ARVs) and when we can turn to other, more holistic and traditional definitions of health care.

Reflecting on what we have struggled with and need assistance with.

Thinking solidarity and who we can and can't work with and why?

Creation

How do we create the health system we want to see?

How do we create movements we want to see?

How do we address the (internal movement) problems we have identified?

How do we organize around access to health while taking our own health into consideration?

Programme

Day 1:

Activity	Details
Breakfast tea	
Check-in	A check-in with a deeper focus on how individuals are doing
Introductions	
- Individual	Everyone introduced themselves: name; where are you from; one interesting thing about you
- CAL and One in Nine	
- What are we here to do	
- Expectation	What do we expect to gain from the space
- Creating a safe and conducive space	How do we want to create a safe space in which we can share
15-minute yoga session	
Short film on the holistic benefits of yoga	Begins the conversation of the benefits of connecting to self
Plenary discussion	A guided discussion on looking inward and critically reflecting on self-care as access to health
Lunch	
Making self-care a reality for us as individuals and as WHRDs	How do we do this in the communities and contexts in which we live
Check out	

Day one focused on self-care as a form of access to health. The discussion centered around the relationships we have with our physical and emotional bodies: what kind of relationship do women, black women, black women activists have with looking after ourselves when society dictates that we assume roles as caregivers and how much of this expectation do we carry with us when we become activists and do movement building work.

The participants spoke about a number of factors that they thought contributed to them not being able to carry out or even actively consider self-care in their lives and work:

- Feeling personally responsible for representing their organizations and the work of movement building even when they are physically and emotionally unwell. They feel they are unable to say no to work even when they do not have the capacity to do it.
- Feeling like they need to be there for their friends and family but being unable to ask for support from others

- Difficulty balancing self-care, work and motherhood. Participants reported having difficulty taking a break from their everyday duties to take time for themselves from fear of being labeled as bad mother.
- This was also true for activists who felt unable to say no to work activities because they were afraid their male counterparts would judge and punish them for it, using discourse such as 'women are unable to hold leadership positions because they are too emotional'

The group also discussed some of the barriers women faced in actively engaging in self-care. Many of the barriers were constituted by the roles women are seen as having in society. Even feminist activists who are actively engaging in work to transform society have difficulty in removing the role of carer as the centre of their identity. The same narratives comes through in the way that women relate with and to their family, friends and communities with regards to the feminist principles they may hold. These principles are often times difficult to carry out with people who do not share the same views.

Day 2

Breakfast tea	
Check in	
15-minute yoga	
Reflection and introspection on access to health and it exists in our contexts	Exercises leading us to think of: <ul style="list-style-type: none"> - Our stories - What needs to be improved - Organizing success and failure - Solidarity
Lunch	
Creation	Exercises leading us to think of: <ul style="list-style-type: none"> - What do we want to see moving forward? - Designing or starting to think about process - How and who do we move forward with
Check out	

While day one focused inward, day two focused on our lived realities of access to health and the organising we do around access to health.

In the first session participants split into two groups to speak about:

1. Personal experiences of accessing health
2. Experiences of organizing around access to health

Group 1: accessing health

Negative experiences:

- Nurses take time a long time to attend to patients
- Separation, by colour coding files or having separate rooms for separate ailments causes disclosure
- Nurses don't seem to care for patients
- Terminally ill patients are still expected to queue
- Nurses are often chatting and not attending to patients
- Nurses are often very rude to patients and subject patients to stigma e.g. shaming young women who are seeking abortion and contraceptives and asking patients who have been raped what they did to get raped.

Positives experiences:

- First priority given to elderly, disabled, chronic illness and pregnancy
- There are feeding schemes for poor patients (although some participants noted that most, if not all, people accessing public healthcare facilities are poor)
- Home visits to priority patients

Participant experiences with NGOs doing work on access to health - Red cross

Positive experiences

- They run a Day care centre
- Give medication to those who can't access
- Provide food parcels

Negative experiences

- Food parcels given to patients are often left overs or inedible
- Sometimes staff keep some of the food parcels for themselves

Comments from other participants

- People with disabilities not prioritized
- Stigma against patients with disabilities accessing contraceptives
- Patients with disabilities are often afraid to go to clinic - even when pregnant
- Differences in clinics and areas - difference in clinic processes because patients want different things - how do we stream line?
- HIV positive patients wanted separate care for privacy, but when this happened there was complaints that this was closing disclosure of people's statuses
- We have to look at clinics from policy levels first
- Taking a stand helps - speaking for yourself
- Communities know which clinics work best for particular needs ie.a pregnant patient will know at which clinic she will receive the best care.
- Ekuruleni clinics are failing patients - especially those with chronic illnesses

Group 2 – Organizing around Access to Health

Negative experiences

- Bad attitude from health care workers
- Health care workers do not have time for engagement with activists
- Activists often end up taking over
- Lesbians and people with disabilities have problems accessing health care
- Health workers undermine healthcare systems/institutions - they think they know better
- Organizations end up doing the work that is supposed to be done by healthcare workers
- Being forced to test for HIV first prevents people from accessing health care
- Organisations are not transparent enough in their work
- Organisations often deviate from their assignments - people pushing their own agendas
- Not enough activists who represent people with disabilities
- Organisations end up taking on the mandates of political parties - only look out for members of their political organization
- We don't go back for evaluation
- We have hostile attitudes towards health care workers - because we already have an idea of the bad treatment they will give us

What are activists and organisations doing right?

- Conducting proper research
- Training workshops
- Community engagement
- Reviving support groups to what they used to be
- Changing the health care system

Comments from other participants:

- Nurses don't get debriefing for their own trauma
- Nurses don't get paid overtime

- Difficulty carrying what we talk about in forums into the clinic
- Each side blames the other side

The second session focused on suggestions on ways forward:

1. What can individuals do
2. What can communities do
3. What can the institutions responsible for health do

Individuals

- Know my rights
- Stand up for myself
- Speak my truth
- Ask about the medication I am being given
- Speak up for those who can't speak up for themselves
- Ask more questions about how can I improve about my quality of life
- Complain if not satisfied
- Don't allow myself to be forced to be tested - enquire about why it's important for them to do so
- If you are not treated in time, ask why
- Take into consideration the context of public health care in South Africa
- Honesty is integral

Communities

- Support groups - counselling, education, implementation (we have community members who work in different sectors and we can use these skills in the community)
- Familiarize ourselves with the patient's rights charter
- Keep our health centers clean
- Teach respect - time, rules, clinic policy
- Awareness campaigns
- Take cognizance of the work we do in clinics and willing we are to take on the responsibility/consequences of that work

Comments from other participants

- Sometimes helping someone at a clinic means the liability falls with you and not with the clinic
- Even if government delivers treatment it is often stolen
- Pharmaceuticals also suing government if they try to get medication from elsewhere

Institutions

- Listen to public and adhere to public needs
- On-going consultation - periodically
- Limit contracts with pharmaceuticals
- Communicating with NGOs and communities at large
- Put people in place who will be accountable for a specific illness
- Put self-care programmes in place for health-care workers
- Stop politicizing people's lives
- We should appoint ground-workers to assist healthcare centres
- Put in place health education programmes
- More staff
- Sign language interpreters at hospitals
- Make sure clinic officials are able to deal with mental illness

The final session focused on the kind of support participants imagined they would need to be able to practice selfcare

Support from organizations and individuals in the group

- Resources and strategies for improving the support group model
- Meeting twice a week
- I need less judgement, I need to be heard and understood
- 3day yoga class and social space for engagement
- Help with Funding for the company I want to start\
- Exercise classes
- Encouragement in my work and organizing
- A hotline for when we need help
- Support group where we can debrief as women and activists
- More yoga classes
- Someone I can confide in who will keep my experiences confidential
- Book exchange to share knowledge
- Access to information (feminist theory, numbers for help with depression and anxiety etc.) through articles and pamphlets
- Skills development - photoshop, book clubs, writing
- Venting spaces
- Cultivating of new knowledge and ideas
- Counselling support
- Packaging of the information we share in sessions, so we can share with others who were not in the room
- Starting a book club and writing corner
- WhatsApp support group
- Support and solidarity
- Self-development

Concluding comments

Process

The style of the workshop was informal, in terms of presenting, set up and engagement. This worked well because participants were able to engage at a level in which they felt comfortable. An informal setting also meant that participants did not have to filter what they wanted to share as the style was conversational and not a presentation where the flow of knowledge was only coming from the facilitator. Everyone's input was valid.

Beginning each day with yoga was useful in centering and calming participants. In future workshops it would be more useful to designate a bigger space for the morning stretches as we were limited for space this time. Going forward it would also be useful to consider the abilities of everyone attending the workshop as some participants felt left out because they were unable to do the poses. Specifically, a participant in a wheel chair was unable to fully participate.

Day one was spent in plenary while day two consisted of a lot of group work. This enabled participants to engage in different ways and allowed for more voices to be heard as some people were more comfortable contributing during group work rather than in plenary.

Different activities used different mediums of engagement, including conversation, video and art. This ensured that the conversation remained interesting and lively.

Content

As mentioned in the opening remarks, the conversation had a large focus on self-care. In two days we were able to not only think about self-care activities but also think about our relationship with self-care based on the identities we occupy and the context under which we live and work. This proved essential in forging thought patterns and behaviors that could better foster an intentional and 'selfish' selfcare regimen.

It was also important to look at health care as a multi-puzzle problem consisting of different layers that require different engagements, including individuals, communities, organisations and institutions. This enabled us to view access to health as something we could all partake in at our different levels. This also introduced the idea of access to health going beyond health care institutions and pharmaceuticals. We were able to imagine our health as something we could also begin to hold in our own hands and in our communities.

It became evident that different clinics produced different experiences and brought to the fore that macro-level engagement (ie. The national department of health) would not be sufficient as information and resources took a long time to reach officials on the ground. It also means that focusing on our own individual clinics is not enough because it means change and access for some but not for all.

Participants indicated the need for support group or informal meetings to talk and debrief about all their experiences. It is integral for organisations to create these spaces but it is as important that participants assume ownership of them to sustain and keep them going.