Empathic response and no need for perfection: reflections on harm reduction engagement in South Africa

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Abstract

The importance of community involvement in public health research processes is well established. The literature is, however, less forthcoming about processes of community inclusion in public health project implementation, especially when it comes to projects focusing on key populations. The Step Up Project is the first multi-city harm reduction service provision project for people who inject drugs in South Africa. Since inception, the Project has made concerted efforts to work with and alongside people who actively identify as people who inject drugs. This paper outlines two features in relation to project-beneficiary dynamics that emerged in a qualitative project evaluation conducted by an external researcher and a funder representative. The first was that people accessing the project comfortably expressed criticisms of both themselves and the project, and noted when their behaviour contradicted project ideals. The second was the extent to which engagement with the project was reported to be fostering a renewed sense of personhood and right to exist in the world. These findings are, we suggest, in principle related to two forms of community engagement: consistent empathic response and community advisory groups. This implies that programmes need to focus on their mode of approach as much as on the content of their approach. It further implies that programme impact not be limited to quantitative assessment measures.
Keywords: people who inject drugs, community advisory groups, empathic response, South Africa

Calls for inclusion

At the 2016 International AIDS conference in Durban, South Africa ‘key populations’ were a centre of debate and discussion. Concerns were that the United Nations Joint Programme on HIV and AIDS (UNAIDS) 90-90-90 treatment goals[1] (2014) for the end of the AIDS epidemic will only be reached through successfully responding to high prevalence rates in key populations, where key populations refers to those who face untenably high infection risk due to risk behaviours, stigma and discrimination, criminalising laws and insufficient service provision (UNAIDS, 2015).[2]

Speakers and audience members at the conference called for greater inclusion of key population representatives in programme design and implementation. This was, however, something only partly achieved at the conference itself. While sex workers and men who have sex with men representation was notably present, representation from people who use drugs was markedly lacking (Shelly, 2016) and prisoner representation understandably absent. Inclusion on the global stage, moreover, does not necessarily translate to inclusion on the ground. At the conference men who have sex with men and sex workers spoke of the ways in which inclusion seemed to respond to the requirements of funders, rather than the needs of the target populations. Calls were for inclusion at a country policy and local project level that went beyond tokenism.

A generous amount of literature and process guidelines provide information on how this might be achieved in research processes. (See, for example AIDS Vaccine Advocacy Coalition (AVAC) and UNAIDS international guidelines (2011) and National Health Research Ethics Council (2012) South African Guidelines.) The literature is, however, less forthcoming about inclusion in public health *implementation* projects. In late 2016 the World Health Organization, the United Nations Office on Drugs and Crime and the International Network of People Who Inject Drugs guidance around implementing HIV and hepatitis C programmes with people who inject drugs, with an emphasis on community empowerment and participation.-This paper examines the processes and results of continuous participant inclusion efforts through the Step Up Project, a demonstration harm reduction project in three cities in South Africa. Run by TB HIV Care (THC)[3], in collaboration with OUT Wellbeing[4], the Step Up Project has provided harm reduction services to people

who inject drugs since mid-2015, as one of the first, and certainly the largest, needle and syringe programmes in South Africa.

The project was set up to develop and maintain proximity with people who use drugs. Staff teams included people who use drugs. From initiation stages the Project has made concerted efforts to include ‘service users’ (those accessing the programme services) as active, valuable, guiding voices and to ensure that staff teams include people who used drugs. People who inject drugs were included formative assessment and programmatic mapping stages of the project and continued involvement through on-going Community Advisory Group (CAG) processes, which are described elsewhere (Scheibe et al., 2017). Here we, a group of harm reduction advocates involved either in setting up the project or in evaluating it, look at the successes, limitations and lessons we can draw from this demonstration project related to such inclusion. We draw on a qualitative evaluation process conducted six months after the initiation of needle and syringe services, and a year after the formative assessment.

We started the evaluation doubtful that the service user participants would provide critical feedback. People who use drugs generally have few incentives to reveal their worlds to researchers who are, as we were, passing through. Consequently researchers often end up gathering fabrications (Bourgois, 1995). Indeed, during this research we heard about how people who inject drugs were schooling each other on the narratives that would allow them access to the research process (and related remuneration) being undertaken by another local NGO. Long-term ethnographic immersion is one method used to gain insights into lived experience and the differences between what is said and what is done. As evaluators, however, our engagements were short, and pointed, while the project under discussion was set to stay. Moreover, the fact that one evaluator was from a funder organisation could have

raised fears that admissions of less than perfect implementation would result in future funding cuts.

Harm reduction also relies – at least to some extent – on the presentation of people who use drugs as self-regulating, responsible and responsive subjects, who will, as far as possible, act in rational ways to maximise their own health possibilities. The emphasis on individual people who inject drugs as capable of (and responsible for) care for self and others has been part of a larger neoliberal trend in which responsibility for health and welfare was devolved from the state towards the individual (Moore & Fraser, 2006). While this heralds a notable shift away from the presentation of drugs users as inherently pathological and deviant, what it means is that people who use drugs risk marking themselves as irrational and irresponsible if they acknowledge rejection or only partial adoption of harm reduction discourses and practices (Moore & Fraser, 2006). This encourages the voicing of harm reduction narratives and assertions of adherence to harm reduction principles even when uptake is, in fact, sketchy at best. Ethnographers have noted that people who inject drugs have tended to assert themselves as enacting the ideals of harm reduction projects, while their actions have indicated otherwise. For example, individuals might claim the habitual use of bleach, while openly not doing so (Campbell & Shaw, 2008); or claim never sharing needles, in contradiction to the reports of injecting partners (Maher, 2002), and without mentioning sharing habits within trust relationships that they do not deem risky (Rhodes, Davis, & Judd, 2004). We, however, found that while participants were well aware of the behaviours the project was designed to elicit, they provided us with nuanced responses – neither unremittingly positive nor negative – about their own drug use and the project implementation.

The responses we received could be read, and explained in a number of ways. They could be a happy result of the ways in which the evaluators piggybacked on the trust developed through the long term relations developed by project staff, especially as staff themselves had either historical or present drug use habits and were therefore to some extent insiders. They could also be a result of project staff efforts to implement a "bottom-up" harm reduction approach (Marlatt, 1996) in which service users were actively consulted in project planning and implementation. This approach could have set the expectation that the "ideal" service user (from the perspective of those implementing the project) was a "responsibilised" service user – one who accepted accountability for their own health and health choices (Robins, 2006). Read this way the nuanced responses we describe below are related to complex power dynamics of health care practice (Mol, 2008), the governmentality of harm reduction implementation, and the positionality of the evaluators.

These approaches are valuable, but ours is a different task. Cognisant of how frequently people who use drugs are not regarded as the experts on their own lives we take an ethnographic (and moral) approach of presenting peoples' words and worlds as they were presented to us. We also write as researcher-practitioners committed to developing texts that are legible to (and verifiable by) the people we write about. In this, we suggest that the responses we found were related to the ways in which the consistent empathic responses of the project team combined with the regular CAG meetings regenerated a sense of self and right to influence the world around them in the service users.

Evaluation as method

This paper draws largely on the findings of a qualitative evaluation of project activities that took place in February and March 2016, approximately eight months

after project initiation. The evaluation, as described by the research protocol, sought to assess 'the feasibility and acceptability of providing a package of HIV prevention and harm reduction services for people who inject drugs in Cape Town, Durban and Pretoria'. In this the primary focus was assessment of programme implementation possibilities. Assessment of the uptake and impact of the services was a secondary focus.

We used a standardised process of data collection in each of the three project sites. This included three days' participant observation of outreach and office operations; two feedback sessions with service users; one feedback session with stakeholders; and four interviews with project team members. A total of 55 project service users, 15 stakeholders, and 12 staff were included in the evaluation. Efforts were made to gather a cross-representation of perspectives. This meant including – as far as possible – a representative sample of service users by race, age and gender, something that differed by city (see below). This, to some extent, reflected the limitations of the project. White males were over-represented. Foreign nationals and women were under-represented. The prior because they reportedly avoided the project due to fears they would be asked for their papers; the latter likely a combination of the lesser number of women injecting and (reportedly) limitations placed on their movements by their male partners. A further study limitation lies in the fact that we did not ask individuals to self-identify race. We can therefore only speak in broad brush-strokes about race, and do not link quotes to race.

Participant feedback sessions were divided into two groups per site. One group was comprised of participants who were regularly part of the CAG processes (see below). The other included service users who were not actively involved in CAG processes. This separation was set up to avoid the possible stifling of more critical

voices from the participants who felt increased loyalty to the project through their greater involvement.

Reimbursements of R50 (approximately $3) were provided for participation to cover the costs of time lost to income generating activities. Written consent was obtained from all participants. Ethical clearance for these processes was obtained from the University of the Western Cape Research Ethics Committee. Data was coded and analysed in Nvivo.

Step Up: a process of daily engagement

At the time of the evaluation, the Step Up Project was providing services to almost 1,500 people across the three cities. This is a small percentage of the estimated total 67,000 (Petersen et al., 2013) people who inject drugs in the country. This, in turn is a small percentage of total drug users. In South Africa drugs are more frequently inhaled, even in the case of heroin, the most commonly injected drug (Dada et al., 2016).

In each city, the profile of the population of people who use drugs differed. The Cape Town and Durban sites largely provided services to people who had long histories of injecting drug use, the majority of whom were white.[5] Cape Town had the largest (though still small) representation of methamphetamine injectors. The Pretoria site, in contrast, largely served people who had transitioned from smoking to injecting heroin in recent years, most of whom were black. In all cities, however, white participants were disproportionately represented in CAG groups.[6] The project was adapted to city particularities, such as the (very variable) relationships between the drug using community and law enforcement; the locations where drugs are bought and injected; and organisational infrastructure influences such as team size and

available resources. However, all approaches were underscored with a harm reduction ethos and daily activities were similar across the cities.

Daily activities

In three cities across South Africa, on four mornings a week, small teams of outreach workers, including a nurse, a counsellor, peer educators (outreach workers with social links to the populations served) and a driver, prepared their stocks and supplies for the day. The nurse would work from the mobile clinic or a gazebo providing – amongst other things – HIV counselling and testing, tuberculosis screening, and wound care. Daily stocks included sterile injecting equipment (needles and syringes, alcohol swabs and sterile water); wound care supplies; condoms (male and female); lubricant; a model dildo and vagina (for demonstration purposes) and documents to use in education processes.

Daily routes were influenced by the formative assessment process and reshaped based on input from the CAG processes (Scheibe et al., 2017) in order to reach the maximum possible number of potential service users over a week period. Some – especially those asking for money at traffic intersections – were reached through whistle-stop service delivery at their regular pitches. On seeing a recognised figure, the team would pull the van up on the side of the road, ask how they are doing; check on any injuries or wounds they knew the person to have; and collect used needles and provide sterile injecting equipment. A few minutes later the team would move on. In other places, where more service users congregated, the driver would park the mobile clinic or car in a set location and settle in for half an hour, or more. Some of the project team would stay to serve those who came on seeing, or hearing about, the team's arrival. Other team members fanned out in groups of two or more for safety, seeking people in the surrounding areas. They were to be found in the far

corners of parks and areas of bush, in underpasses and under bridges, and in sprawling buildings that had not seen sanitation or running water in years; the places where they lived and kept themselves – as far as possible – dry and out of sight of often less than obliging law officials. (Harassment, including confiscation of injecting equipment, both sterile and used; extortion; assaults and detention without cause, a continual part of life for many people who use drugs.) They were also to be found in the broad open spaces of public life such as transport hubs and central city streets; places where business, theirs included, was conducted.

For the most part the project teams displayed a carefully balanced combination of haste and patience. Sterile needles were quickly dispatched when queues developed, or when a service user was edgy and impatient in the throes of withdrawal. At other times programme teams settled into languid chats, or detailed, unhurried health discussions and education processes. On a street corner in Durban, a conversation stretched into half an hour as a peer educator explained how female condoms could be used to sex workers' advantage. The peer's offer had been met by refusal, accompanied by laughter and the shake of an armful of bracelets made of the outer rubber ring of unused female condoms from the leader of the group. After the discussion extra condoms had to be fetched from the van.

At another site, two peers walked along an abandoned railway track picking up discarded needles, while another sat in the back of the van providing sterile needle and syringe packs. The nurse sat in the front of the van attending to a seeping wound on the hand of a man, in his mid-thirties, who spoke of his troubles while his wound was attended to. Softly weeping, he spoke of past traumas and his deep depression. 'Who do you talk to [about these things]?' asked the nurse, gently. 'I'm talking to you,' replied her patient. 'We're not here very often…' reflected the nurse. '[Then] I

don't talk to anyone…' Conversations such as this, steeped in sadness, were abundant. But we also witnessed interactions that were jocular – a wide smile and a double thumbs-up as the mobile clinic passed; a wave and a jaunty call of 'I'm coming now!' from someone heading to fetch their stash of used needles before coming to get new sterile injecting equipment.

The team's days passed in these ways: seeking out people who inject drugs in places they were known to live and frequent, supply provision, conversations, health check-ins, education processes, and HIV counselling and testing processes. They would also collect details on human rights abuses; noting them down on site to later feed them into a database for advocacy purposes. At the end of each day they returned to their offices, to fill in their paper work and undertake any immediate office-based duties that had arisen from the day.

Unscripted responses

Summerson Carr (2010) has noted how particular, scripted, ways talking about addiction in treatment centres can become so inculcated that they shape all interactions between those seeking and providing treatment. Others, as we indicated above, have noted that people who use drugs have few incentives to provide researchers with anything but what they are seeking to hear (Bourgois, 1995), or to report critically on their actual uptake of harm reduction practices (Campbell & Shaw, 2008; Maher, 2002; Rhodes et al., 2004).

Our experience was different. For the most part service user participants in the evaluation indicated that their engagement with Step Up resulted in behaviour changes in line with the aims of the implementation staff. They reported, for example, that prior to the project needles were rented, shared and/or used for very extended periods, and that this had changed. 'I remember when [before this service] I

had to use a needle, probably for a month…one needle. You know sometimes you can't buy a needle…' said one man in his late forties. 'I know when there weren't needles around...It was so scary to me. You would see three people on one needle. I don't see that anymore! I don't see anybody sharing a needle anymore. And that is a relief to me' said another participant. But we, the evaluators, were also provided with notably more tempered responses. Across the sites, service users indicate that sharing and reusing of needles was greatly reduced, but that to some extent it continued. 'I think before the CAG meetings we were buying our own needles, so we were using them more than once, now that we are getting our needles for free, *most of us* are using them once then throwing them away,' said one beneficiary. Another explained, 'Before [it was like], "Okay, you want a needle, here's a needle", but now we don't give a [used] needle *just like that*.' And a man in his mid twenties explained that, '*We are supposed to* be one needle one shot…[but] sometimes I use my needle more than once, because I can't carry three or four needles with me if I am going to make four shots in [a particular location] so I take one needle with me, and I swap that at the end of the day'. Service user participants further indicated that they knew that the project advocated for the use of alcohol swabs to clean the patch of skin where they were about to inject to avoid infections at the injecting site, but most indicated that they did not bother with this. They also reported their use of sterile water to be limited.

These departures from the project ideals seemed to be partly due to participants not fully understanding the relevance of the ideal actions. But they were also explained to us in terms of life practicalities. Carrying needles (sterile or used) – especially in numbers that could not be easily concealed – held a risk of arrest because needles could be used by law enforcement as proof of drug use. 'I'm not going to walk around with 21 needles in my bag. If they catch me they will throw

away the key!' Explained one woman, in her fifties. Injecting in a public space has to be done quickly to lower the risk of being caught by law enforcement. Swabbing takes additional time, raising the risk of being caught by law enforcement.

Desperation in times of withdrawal was cited as another reason for not following ideal practice. 'When you're [withdrawing] you don't care!' said one participant. Another, Jason, explained that he knew he should use different injecting sites on his body, but that in the mornings, when he was withdrawing, 'I always use this vein, because…I don't know if this whole vein is blown…I don't even have to aim, I just push the needle in and the blood comes out. Later I change [veins]. Your veins seem to run away when you have [are withdrawing]'.

Laziness and impatience were other reasons provided. 'I'm lazy to look for a vein, and the situation that I'm in, where I'm doing it, you have to be very fast because of being caught, so I always use this vein, it is there at all times. It is quick, I am gone.' Jen, a woman in her twenties spent most of the session semi-asleep on her partner's shoulder, but she pepped up for occasional comments such as 'I don't use swabs at all!' She explained this lack of use saying (with an unapologetic shrug), 'I'm just impatient'.

Service user participants were, then openly critical of the practicalities of the project ideals and of their own willingness to be bothered with following what they knew to be actions that limited the possible risks to their own health. They also admitted that they sometimes manipulated the service provision staff. Moreover, though they were very largely positive about the role the project staff played in their lives at one site a staff member was described as 'miserable, rude, hostile, and stigmatising' and having 'no qualms about [not] hiding her disdain for addicts…'[7]. She explained the alternative course of action she took: She would break the tip of the

needle throw this in a bush and put the rest of the needle and the syringe in a municipal bin. Throwing the needle tip in a bush was her way of reducing the chances that municipal workers would get a needle stick injury when they emptied the bins. By her own reckoning, she was behaving as ethically as possible given the constraints of her life conditions and the risks of law enforcement.

We saw, then, that the service user participants in our evaluation were not, as might be expected from the literature, positioning themselves as ethical beings through presenting themselves as consistently enacting the behaviours the project required of them. Rather, they were positioning themselves as ethical actors through admitting that they, to some degree, were not acting on project ideals.

There are likely multiple reasons for these responses. We suspect that one contributing factor was the attitudes, approach, origin and knowledge base of the evaluators. Both were white women and did not have histories that linked them to the participants, but they did have extensive experience working with people who use drugs and were therefore not shocked or surprised at revelations about some of the grittier details of life. Their presence and engagement was, moreover endorsed by the Step Up Project team members, which – given appreciation of the project – would have provided an immediate level of credibility. They also set up the room to level power dynamics, with the participants and one researcher sitting on chairs in a circle and the other facilitator sitting on the floor in the middle making notes on large sheets of newsprint for all to see. As the participants looked on they were able to correct any errors, and make suggestions about additional important information they felt needed inclusion. Ease was likely enhanced by the fact that the spaces used were familiar to the participants as they were used for other events run by the Step Up Project. Given the extent of stigma and marginalisation faced (and described) by the participants it is,

however, unlikely that it was the research environment alone that fostered the nature of the responses we received. Drawing on the explanations provided by the participants themselves, we suggest that the key contributing factors lay in two aspects of the project implementation: empathic responsiveness and CAG processes.

Empathic response: 'You *are* somebody'

During the evaluation, each feedback session started with the evaluators asking what services the participants had received from the Step Up Project. Most that were described were those we expected: the receipt of needle packs; HIV and tuberculosis testing; information and learning (on, for example, safer injecting and overdose prevention); referral and accompaniment to health care services; and commodities such as condoms, lubrication and hygiene packs, which, at a minimum consisted of a toothbrush, toothpaste and soap. In addition to these expected planned services, less tangible, but equally – if not more – valued services were reported in all feedback sessions. These included presence, listening, counselling and the general feeling of being cared for. 'They're always here for us,' said one young woman in Cape Town. 'Since the project started…we have friends now. If you need someone to go and talk to, you have someone who really cares and understands where you are, where you are coming from,' said a participant from Pretoria. In Durban we were told how the project staff kept a register of service users' closest family members, so that the family would be informed in case of death. That they would not die without the knowledge of their families was provided as an example of the depth of care they received. Also in Durban, but in a different feedback session, the way the staff went looking for service users, seeking them out where they knew they were likely to be was cited as an example of care. 'How does that make you feel?' we asked. 'That

makes you feel like you are *somebody*,' explained an older man, going on to say, tentatively, 'My family rejected me, so…but you *are* somebody.'

The Project's focus on human rights further contributed to a sense of personal value. Recorded violations were compiled into reports to use in advocacy efforts; education processes taught people exactly what the legalities were of their everyday behaviours, from carrying injecting paraphernalia, to living on the street, to begging for money. The teams also engaged with law enforcement and health care professionals, sensitising them to the needs and rights of people who use drugs in a climate where drug use is criminalised, almost all interventions have been abstinence-based, and there is a limited openness to harm reduction. Those on the receiving end of services were not always aware of the intricacies of these activities, but many were, broadly speaking, aware of these interactions (which sometimes verged on battles). As a participant explained, 'They are really trying to get police and the community on board, to see that it is about sickness…they are not encouraging us to use drugs, but trying to prevent us from getting HIV and hep[atitis] C sicknesses and they are trying to get the police and metro police to jump on board with them.' Together, the experience of being looked for, listened to, advocated on behalf of, and provided for gave service users the grounded sense of 'you matter'.

The regeneration of sense of self as a valuable entity was placed in the context of the daily erosion of self-confidence, shaped not only by rejection from families and mainstream society. 'Because we are users, people see us different[ly]. They look down on us…they think we are dogs,' explained one participant in Durban. Jill, a woman in her mid-fifties, added to the discussion, 'As user you lose confidence and self-esteem with the public, especially when you are "hustling" (panhandling) and people are rejecting you all day, you start feeling like shit.'

What the participants were describing as ‘care’ was less about the practical provisions of commodities such as sterile injecting equipment (though this featured) and far more about consistent empathic response. As one team leader said, they had developed relationships through ‘treating everyone like humans’ and through responding to the needs of those accessing services, whether they are within the scope of the work, or not. Another, similarly, explained, ‘If someone is in big trouble, we’ll go.’ He described a situation in which they were notified that a beneficiary was hit by a car, and, though it was late at night, they went to find him and take him to the hospital. ‘That builds a lot of credibility.’ He further said, that developing trust was largely about presenting themselves as fundamentally no different from the people they were working with. ‘We know you, we understand you, we used to be you’, was the message the project implementers sought to give.

Empathic response has been highlighted in the literature as the key element of effective substance use treatment processes. It has been shown to be even more important in improving treatment outcomes that the type of therapeutic response (Ashton & Witton, 2004; P. G. Miller & Miller, 2009; W. Miller & Moyers, 2015). The Step Up teams were not trying to engage people in treatment, but their manner of engagement made people feel like they mattered and their experiences and opinions had value. It seems likely that this affirmation of personhood played into the ways in which service users responded to our questions and probing with responses that did not necessarily cast them, or the project, in the best of light. It is also likely that the norm created by the project of empathic response spilled over onto us, the researchers, and it was therefore assumed that critical engagement would be received without judgement.

Community Advisory Groups

'Community Advisory Boards' (of which CAGS are one form) are a popular way of undertaking community engagement in large-scale health research processes. Their capacity to reduce exploitation in researched communities is not uncontested (see Pratt et al., 2015), but they have been shown to assist through providing a place of negotiation between researchers and participants (Morin et al., 2008). In South Africa, the National Health Research Ethics Committee (NHREC) guidelines (2012) provide a framework for how this should be done. However, as with inclusion processes in general, there has been limited information as to how this approach can be integrated into service delivery, rather than research, activities.[8]

CAGs have been integral to the way in which the Step Up Project has been set up and run. They grew out of stakeholder engagement processes conducted in each city during formative assessment processes during locations frequented by people who use drugs were mapped, health needs were outlined and numbers were estimated (Scheibe et al, 2017). Subsequently they have been run on at least a monthly basis in each city. Fundamentally designed to elicit project input, involvement was minimally reimbursed with R40 ($2.40) per session to encourage participation despite time lost for income generation[9]. As the project progressed the purpose of CAGs started to transmute. Rather than being a place where service users provided input to strengthen project implementation, CAGs started to be a forum for the dissemination of information to service users.

In the feedback sessions we found that participants who were involved in the CAG meetings found these to be so integral to their experience of the project, that they were unable to discuss outreach services without relating them to the CAG processes. Some participants indicated that the reimbursements held diminishing

importance the longer they participated. ‘At first I came for the money, afterwards I came and I met a lot of people, I learned a lot of stuff and the more I came the more I want to be here...’ said one man in Cape Town. Others went so far as to question whether reimbursements should be provided at all given that they saw themselves as receiving, rather than providing, a service. Given the continuous, daily drive to obtain enough money to maintain drug use, and the fact that the CAG meetings took away time that was described as usually used for income generation, this was an exceptional offer, and not one agreed to by all the participants.

As with continuous empathic responses, CAGs were reported to provide a space for the growth of community and the renewal of a sense of self. Amin, a man in his twenties, reflected, ‘If you live a life like ours, you start to see yourself as less than nothing, but here we started to give back some meaning to life and that we also count, we realised that we have rights just because we are also human.’ And Jill explained, ‘They are there as a back-up. It gives me a little bit of empowerment. I am a bit empowered, knowing that there is someone behind me that is not looking down on me. Before I came to the CAG meetings I was quite depressed. Now I know it is okay if someone rejects me, because I know I have my backup and my family.’ The ‘family’ and ‘backup’ Jill was referring to was her fellow CAG members.

The ways in which the CAG meetings have resulted in the strengthening of a sense of community amongst service users, and a renewed individual sense of being care-worthy seems to have been the result of the regularity of the meetings which brought people (service users and providers) together. The development of group solidarity and newly constituted social networks has been documented elsewhere in randomised control trial processes (Morin et al., 2008) and in HIV implementation programmes (see, for example, Nguyen, Ako, & Niamba, 2007). Here we suggest that

a further, inadvertent, result of the CAG processes may have been that the dialogue developed in these processes enabled service users to feel they had a right (and perhaps even a duty) to engage critically with programme provision.

Conclusion

Step Up Project participants asserted themselves as ethical beings through their critical engagement of both their own behaviours and the services provided. We have suggested in this paper that this was largely fostered through a combination of consistent empathic responsiveness of the project staff and the active efforts to generate participant feedback through CAG processes. We want to stress in closing that in saying that the critical responses we received from service user participants was unexpected we do not mean to imply that we expected dishonesty from people who use drugs. Rather, it is to say that we recognised that there were a number of motives for the less than forthright responses to an evaluation processes set up and undertaken by harm reduction advocates, such as ourselves. These include the ways in which harm reduction relies on the presentation of individuals who will do all they can to maximise their health given the opportunities; the short-term nature of the relationship between the evaluators and the service user participants; and the desires service users may have had to provide positive narrative about the people providing them with essential supplies, especially as one of the evaluators was from a funder organisation.

Harm reduction implementation programmes generally seek to impact on health-related behaviours to improve health outcomes. These outcomes tend to be narrowly defined in relation to a measureable reduction in morbidity and mortality. The Step Up Project qualitative evaluation findings, however, indicate that when harm reduction implementation is done in a way that develops engagement – both in

everyday interactions of health care provision and in the more structured environment of CAGs – standardised, easily measureable health outcomes may be accompanied by more subtle, but equally important outcomes for service users: the (re) generation of the sense of a right to exist, comment on and shape the world they live in. Our findings, then, provide a different perspective to the literature that indicates that CAGs disproportionately serve those implementing the project (Pratt et al., 2015). They also suggest that inclusion processes need not be perfect. What is perhaps more important is the consistency of the responsiveness shown to participants and their needs. This should be an aim of intervention projects if they want their effects to be more than skin deep.

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1 These UNAIDS goals are as follows, 'By 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression' (UNAIDS, 2014).

2 The draft of the forthcoming South African National Strategic Plan on HIV, STIS and TB defines key populations for HIV as "sex workers, (MSM) men who have sex with men , transgender people and other vulnerable LGBTI communities, people who inject drugs (PWID) and inmates" (Republic of South Africa, 2016, p. 17)

3 www.tbhivcare.org

4 See www.out.org.za

5 We delineate racial categories with the full awareness that these are constructed and contested.

6 This emerged as a critique of the project during the evaluation. It was likely due to the fact that white people living in poverty and inhabiting the city centre are quickly recognised (or cast) as people who use drugs. The early stages of the project therefore found white people who use drugs and drew on their networks to build CAGs and to find other potential participants.

7 This was dealt with subsequent to the evaluation.

8 The International Network of People Who Use Drugs has, however, recently published a practical guide for implementing HIV and hepatitis C interventions with people who use

drugs, see http://www.inpud.net/en/iduit-implementing-comprehensive-hiv-and-hcv-programmes-people-who-inject-drugs.

9 The role played by reimbursements was not entirely positive. Funding limitations dictated that a limited number of participants (usually between 50 and 60 participants) could be reimbursed per meeting. This resulted in a degree of competition and gatekeeping.

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