focus

"I see myself really as a public health activist": A critical analysis of young people's voices in the National Health Insurance policy submissions

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Abstract

Youth engagement in public policy is a widely trumpeted notion supported by participatory democracy as espoused in various legislative and policy instruments. However, the interventions associated with this commitment do not easily produce the progress sought. This can be seen in the concerns that continue to be raised regarding youth participation in development. Targeted at improving health equity, the National Health Insurance (NHI) policy in South Africa is one such venture in which there are low levels of youth participation – with implications for the social reality of young people of today and into the future. Using feminist theory, particularly the concept of 'systemic silencing', I interrogate and explore the marginalisation of youth in areas of influence, which evidences their low participation in these critical spaces. The outcome of this project is in unfurling the richness of theorising with and not upon young people.

Keywords: youth, participation, National Health Insurance, tokenism

> *The truth is that we were bullied – and of course 2 days before the Public Health Association of South Africa conference, 'to make nice' someone was* [sent] *to try play hero. But we saw right through it ... we had asked if there was a procedure to follow for changing our name and nothing was said and all of a sudden, we were suspended with no explanation whatsoever ... we felt betrayed, hurt and highly disrespected* [as young people] – Danisha, 29 October 2018

Danisha (all names used are pseudonyms) was one of 11 participants in my study[1] which examined the strength of youth participation in public policy, specifically the National Health Insurance (NHI) in South Africa (SA). The NHI is essentially "a financing system that will make sure that all citizens of SA (and legal long-term residents) are provided with essential healthcare, regardless of their employment status and ability to make a direct monetary contribution to the NHI Fund" (National Department of Health website, 2018).

The fiscal thread was commonly used in the media, with headlines such as 'Cabinet may make NHI decision before budget' (Turnquest, 2019). The emphasis on financial aspects as opposed to collaborative commitment in realising the NHI is one way in which we can see how the conversation was far removed from the public, let alone young people. Working through the exclusionary veneer meant that the YPR participants came together to provide a different approach to viewing the NHI – an approach more accessible to everyone. In doing this, they held consultations, workshops and seminars and distributed pamphlets in different languages in order to bridge the gap between the people and policy.

In the excerpt above Danisha, a young medical doctor, recounts when the Junior People's Health Association of South Africa (JUPHASA) – the youth arm of the People's Health Association of South Africa (PHASA) – fought to change their name to the more empowering: Emerging Leaders of the People's Health Association of South Africa (ELPHASA). Significantly, the 11 participants in the study contributed to the only submission made in the interests of young people, by young people to the NHI White paper. Titled 'Young People's Recommendations (YPR) on SA's NHI White Paper', the submission was led by the People's Health Movement and published on 29 July 2016 (Munshi et al., 2016). The YPR is the brainchild of the younger members of the PHASA (specifically ELPHASA), who wanted to voice their views and those of other young people from different organisations. ELPHASA, through their website, identifies itself as "the South African Chapter of the People's Health

Movement (PHM), a global network of grassroots activists, civil society and academics, predominantly from low and middle income countries" which addresses a variety of social aspects of health (PHM SA 2018).

The YPR submission was informed by young people's desire to be part of the process and to voice their concerns about a policy that would affect them. Despite their awareness of the marginalisation of youth in policy, as discussed above, the Young People's Recommendation (YPR) collective (many of whom were members of ELPHASA) embarked on the brave task of compiling a response to the NHI White Paper. Although they were not necessarily feminist-led, their project of carving out their spaces in a constrictive space was conceivably feminist in principle. However, as will be highlighted below, their submission was met with negative responses. As communicated in the excerpt above, as a member of ELPHASA, Danisha's accounts make for a helpful illustration of the experiences the participants had in informing the response to the NHI White Paper. As this paper will illustrate, Danisha forms a crucial part of the many 'youth voices' that challenge the marginalisation of young people in policy making.

Focus of the study

My analysis in this paper is informed by Rebecca Patterson's paper which explores the representation of childhood and youth in South African coming of age narratives (2017). Patterson identifies tropes greatly associated with young people, which include tensions between child/adult. These expose the fissure between paradigms and practice, where young people's representation differ their own nuanced narratives. 'Systemic silencing' is reinforced by the restrictive binaries of child and adult, in which children and young people occupy a low status in society, and are therefore, relegated to positions of powerlessness where they are written and theorised about.

Informed by this perspective, in this paper, as a young person interested in public health issues, in this paper I adopt a feminist lens to reflect on a number of issues in my interaction with participants in the study, and in particular the systemic silencing of young people in policy making. I seek to highlight the different ways in which young people providing commentary for the NHI White Paper were restricted in their efforts to voice their opinions and concerns. I relate this to how the silencing of youth voices contradicts the feminist energy that seeks to recognise and celebrate the voices of the marginalised, including those of the youth.

This paper reports on a study which aimed to understand the role of young people in public policy making and social change, both of which were embodied in the Young People's Recommendations document submitted as commentary on the NHI White Paper. More specifically, the study sought to uncover the context and experiences of the contributors to the Young People's Recommendations document as well as the meanings that the contributors apportioned to the submission.

Methodology

To capture the experiences of the study participants an interpretative phenomenological approach was used. Phenomenology is "concerned with the question of how individuals make sense of the world around them and how [the researcher] should bracket out preconceptions in his or her grasp of that world" (Bryman 2012, p. 30). To generate data I interviewed 11 members of ELPHASA who contributed to the submission made in response to the SA's NHI White Paper in 2016. Data collection comprised phenomenological interviewing entailing semi-structured interviews and note-taking, the use of Voice over Internet protocol,[2] and desktop research in the form of qualitative document reviews and secondary document reviewing as well as semi-archival internet perusal for news headlines with the key word 'NHI'. The 'do not rustle the trees' logic was also applied to the non-participant observation of the ELPHASA National Network 94-people strong WhatsApp group, which was started in October 2015. In other words, observation was carried out without explicit engagement with the other members of the group.

Although the interviews took place two years after the submission was made (in 2018), I relied on the participants' memories of the experience, rather than impartial accounts, in order to understand the phenomenon: their submission to the NHI White Paper. As the researcher I was also called upon to bracket my own preconceptions – however, this was only successful to some degree. Having similar interests as the participants in the field of public health meant that I shared a knowledge base with them, and in one case I had attended the same public health event. My journalism experience from working in three news houses was called into action: listening and withholding judgement in order to elicit rich accounts from the contributors. This was ensured through a hermeneutical approach in which I read back my notes of the participants' responses and asked each whether I had captured their views accurately. The data

was analysed qualitatively to note key themes that arose in the interviews with the different contributors to the YPR. In particular, this paper analyses the interview with Danisha, who turned out to be a key respondent, to illustrate the experiences of the young people involved in the YPR response to the NIH.

Using feminist theory to explore the systemic silencing of the youth

Feminists like Kimberle Crenshaw (1997), Pumla Gqola (2007) and Sirma Bilge and Patricia Hill-Collins (2016) help us understand the influence of ideologies and societal structures in perpetrating and exacerbating epistemic violence against women. Of particular relevance to this study is Nancy Tuana's (2017) piece, 'Feminist Epistemology: The subject of knowledge', which addresses the epistemic injustice that women face in knowledge creation and in their subsequent framing. Tauna argues that the power of knowledge and knowledge production has predominantly remained centred around male and maleness. This falls in line with patriarchy, which derives its power from the dictation of male power over women and younger men. In this case, patriarchy marginalises *young* men and women. For Tauna, the constant relegation of women to objects of theorising robs society of healthy, and indeed much needed, critique regarding society and women. The scholar refers to this as 'systemic silencing', where women are silenced from speaking about their realities and contributing to discourse. Leading with this, "epistemic violence [highlights]… how certain lives, indeed entire populations, [such as the youth] are conceived as less valuable" (Tuana 2017, p. 129).

It is quite common so see young people funnelled into areas of social action, community engagement and art as well as as recipients of education. As Tuana has argued, women tend to be *restricted* to or funnelled into speaking about 'women's issues' only. In the same vein, there is a resistance from the rest of society to young people'sinvolvement in the issues such as finance (tertiary fee increments), decolonisation, development, and policy. This can also be seen through the youth-led movements such as #FeesMustFall and #AfrikaansMustFall which took place between 2015 and 2017. It is not suprising that the YPR received negative responses as it raised questions about development, finance and policy – the very areas which young people are often excluded from.

Findings

As will be illustrated in the findings below, the response to the YPR powerfully illustrates how youth are excluded in powerful discussions – a product of patriarchy's far-reaching oppression.

Different seats at the table

Although the NIH has been touted as an inclusive health care policy, the participants in this study reported experiencing it as partial to the perspectives of more powerful collectives in societies. In her response, Danisha linked the process to the competition for recognition in decision-making bodies within civil society. For her, while this competition, compelled by the restricted nature of who "gets to join the conversation and have a seat at the table", had the positive outcome of motivating collaborations between civil society groups, this did not always mean a seat was reserved for young people. For example, reflecting on a National Presidential event, Danisha lamented the fact that "all the 'private sector heavies' were there" (interview, 2018). Such a situation was evidence of the aforementioned 'differential yielding power' and how people in particular organisations, and in (mostly) senior positions, gain better access to decision making than young people are able to. Although many reasons can be put forward for the void in youth attendance at the National Presidential event, it illustrates some of the ways in which youth participation in decision making and information dissemination is restricted. Despite her acknowledgement of the benefits of associating with senior officials as well as other civil society collectives, Danisha's conviction about the older public health officials was that, by not involving young people, they reproduced problematic power models and structures at the municipal, provincial and national levels. This means that in addition to traditional or standard bureaucratic measures which may exclude young people directly, perceptions around young people further restrict their voices from being sought or considered because of their low value and position in society.

Conversations with Danisha (and other study participants such asEnhle and Anelene) indicated their understandings sensitivity to inequalities related to issues of gender, queer identities and gender non-conformance discourse. For them, these inequalities played a significant role in preventing youth participation in policy. Within the sphere of policy, as the participants in this study suggested, the unflattering perceptions about young people and their value in society translate into a violent experience for those involved.

The marginalisation of young people from policy making is not unique to South Africa. On our continent, the Youth Policy Guide for Kenya (The Youth Congress of Kenya 2015) critiques the exclusion of young people from policy making. It foregrounds the risks of excluding youth from policy making, emphasising how this widens the gap for young people. This leads to the rejection of the policies, challenges and difficulties in implementing them, inefficient and inadequate resource allocation, persistent youth disenfranchisement, and reproduction of ineffective approaches to programming. In the context of the NIH process in South Africa, due to their feelings of disenfranchisement, the ELPHASA committee chose to dissolve. According to the participantsi in this study, they felt bullied into submission, as opposed to being supported. For them, this was illustrated by opposition of those in power to the name they chose for themselves (Emerging Leaders of the People's Health Association of South Africa or ELPHASA) and the transition to the name: Junior Public Health Association of South Africa.

The benefits participating in the YPR

> *"I just would like to reiterate that I did not contribute to the document I merely supported it and its contents …"* (Kyle, 11 November 2018)

While the young people in this study felt that they were ignored and marginalized from the NIH commentary processes, some recognized that participating, directly or indirectly in the development of the YPR and related activities, was beneficial to them. For example, Kyle, another participant in the study, acknowledged that he was not directly involved with the formulation of the Young People's Recommendations document but merely supported its contents by signing it. Although he was not directly involved with the development of the YPR, his perspective on an application for live organ donors and the significance of the information technology sector for SA's healthcare system was informative. According to Kyle, this particular involvement with health and IT involved some red tape with NHI-related information in the company he works at, which he was not at liberty to share.

Further, Kyle reflected on the questions posed within the body of the YPR submission, and how no response to the issues raised was forthcoming. For him, the negative reception of their submission was discouraging for young people who wanted to engage in policy commentary and for their views and submission to be heeded.

Another youth participant, Jared, reported that it was his position in leadership within different professional collegial forms – as well as being closely acquainted with some of the other would-be contributors – that encouraged him to be involved in the submission. A semi-social picnic held for the ELPHASA collective, mentioned by the majority of participants, was one of the efforts which Jared felt were critical in not only facilitating closer relationships among those in attendance, but in creating a wider network for different opportunities to be disseminated among them. The coming together of all these young people meant a sharing of experiences as a learning curve for each of the group members to learn from each other, and from other organisations. As is the case with policy commentary, participating in or supporting the submission played a huge role in bolstering a different form of participation for the young people in this study. For example, Kyle's expertise in ICT, and Jared's leadership position reinforced the idea that specific interests need to be communicated to young people in order for their expertise and capabilities to be activated for analysing and (in this case) endorsing the contents of policy submissions.

Is it apathy from young people?

According to Marsh, O' Toole and Jones (2006), in the late 1990s and well into the early 2000s the question of youth involvement in policy was of major concern. This resulted in the emergence of such terms as 'apolitical' 'apathetic' and 'alienated' to describe the decline in the lack of political involvement among young people in the United Kingdom and beyond. The scholars quote Norris (2003), who elaborated on the idea that

> … many are concerned that the widespread mistrust of government authorities in the mainstream culture may foster a public climate which facilitates the growth of anti-state movements and, at most extreme, the breakdown of the rule of law and sporadic outbreaks of domestic terrorism by radical dissidents (p. 8, quoted in Marsh, O'Toole & Jones, 2006, p. 3).

Similarly, in the South African policy landscape, mistrust has also been identified in recent years. On a macro-level, people's (including young people's) disengagement from political institutions has also been linked to their disengagement from local communities and a general lack of social integration. However, Marsh et al. (2006) propose four arguments as critical

assessments of the idea of youth political apathy. First, they criticise the narrow view of the political (and hence political participation) which “therefore fails to engage with how young people themselves conceive of the political and does not attempt to investigate their political imaginaries” (Marsh et al., 2006, p. 4). This particular argument (as with the three ensuing) highlights the ‘other side to the coin’ – which contextualises young people outside of their own purviews. Second, the authors argue against the “narrow conception of political participation [which], reductively and erroneously, equates … non-participation by young people in a range of activities specified by researchers, with political apathy” (2006, p. 5). To address this, they suggest a more nuanced view of non-participation, where apathy is understood not just as participation’s ‘other’ but in a more wholesome manner that takes into consideration the different ways in which young people define participation. In line with this, the young people in this study recognized that not everyone would contribute using formal written text but would also participate through social media conversation, dialogues and workshops as well – all of which they adopted in compiling the Young People’s Recommendations document.

Third, Marsh, O’Toole and Jones’ (2006) critique uses the feminist slogan ‘the personal is political’ and the politics of identity. For the participants in this study, their emotional responses tied into how they regarded their positionality within the space as young professionals, and for some of the female participants, as women in the health policy space. This was so much so that affect (feelings) in response to the submission was also identified as a common thread in the accounts the participants shared. One way in which this came across was through the intimate sentiments that the participants shared about their involvement in policy commentary (including Danisha’s above passionate language in reference to the ‘private sector heavies’ that attended the exclusive conference).

Fourth, Marsh, O’Toole and Jones (2006) highlight the preferred attention on the behaviourist and intentionalist approach to (youth) participation, as opposed to the institutionalist approach that would unveil the actual inner goings-on of the structures of political participation. The difference being that the behaviorist and intentionalist approaches tend to focus on the lived reality that shapes the actions in political participation whereas the institutionalist approach focuses on repetition and non-critical elements. This results in “insufficient attention [being] paid to the features of the political system itself and how these shape political participation” (p. 5).

Although writing in the British context, the same can be said of the South African and African context, as similar issues are raised in discussions about youth participation. For example, Egypt is one country where the youth used different ways of participation in order to influence a regime change. This "showed the world their strong belief in the cause of a country that was striving for freedom, social justice, and the welfare of its citizens" (Osman & Girgis 2016, p. 1). Despite this youth-led revolution which compelled the regime change in Egypt, Dr Magued Osman and Dr Hanan Girgis of the Egyptian Centre for Public Opinion Research still hold the opinion that there has been a significant decline in social and political participation by young people. They attribute this to various reasons, such as young people being despondent about their particular ways of civic participation not being valued. Osman and Girgis (2016, p. 1) further argue that "[i]t is necessary to influence this attitude and for young people to be convinced of their ability to play a role in decision making and in shaping public policy through different forms of participation". Similarly, the participants in this study reported that they did not feel that their submission had an actual influence on decision making related to the NHI policy.

Writing from a different context, Armstrong Alexis, director of the Commonwealth Youth Programme, Caribbean Centre, shares how his approach to policy has always advocated for "a more enabling environment for youth development and for young people to have a greater say in matters that concerned them and the development of their communities, nations and regions" (Alexis 2005, p. 5). Interestingly, Alexis also advocates for the involvement of young people based on the carving out of their own spaces, almost as if to say 'the table will not be set for you, you need to get up and make space at the table for yourself' (p. 11). Acknowledging the agency of young people, he cushions this suggestion by explaining that the youth activism during the 1960s and 1970s in the Caribbean led to an emergence of youth leaders, "not because they were provided with opportunities, but because they created opportunities to voice the concerns of their peers". He concludes with the caveat that this youth engagement or youth development also requires "development agencies, policy makers and governments [to] recognize the catalytic role they [young people] can play" (Alexis 2005, p. 15).

Young people's issues in the YPR

Many concerns and issues were raised by the contributors to the YPR, both within the document itself and during the interviews. In her interview, Anelene, a public health graduate and participant in the study, argued for the intersectoral influence of the NHI and how it would have an effect on everyone's careers and livelihoods. She shared how different sectors: agriculture, social development, water and sanitation (over and above health) would have value in being considered in the planning for the NHI. Another participant, Francois, a psychology and IT graduate with aspirations towards public health academia also emphasised the notion of the 'far-reaching arm of the NHI'. His mission to bring together IT and mental health issues, as well as highlighting the under-utilisation of Psychology students in the public health care system, were all highlighted as issues young people were concerned about in relation to the NIH. These sentiments, borne of the participants' personal awareness and experiences, have value in contributing to policy aimed at addressing the actual needs of the people it seeks to benefit.

Returning to Danisha's statement in the introduction above, what does it (and the perspectives of others in this study) suggest about the experiences of young people in the NIH policy-making process? For Danisha, writing and contributing from her experience as a medical doctor, she acknowledges her role in public health as an activist: someone who, in their efforts, seeks to realise and advocate for access to (knowledge about) public health, stating -in her own words- that, "*Now that we've done the submission*, *I see myself really as a public health activist*" . Hannah, a pharmacist, also reflected on the complex composition of the group, and the diverse set of opinions generated through the YPR.

Conclusion

This article explores how feminist theory can help us to interrogate the role of the marginalised – in this case, young people, who represent a large majority in most nations but continue to be seen as entities worth only being theorised *upon* and not *with*. Multiple factors that 'systemically silence' young people remain, including how they are treated when they seek to take a seat and join the discussions taking place at the policy table. For example, the moment the youth challenge the status quo and push out of the boxes created for them by society, the noose of silencing is tightened.

As this paper has argued, language is used to portray them in particular ways (for example, as apathetic, unengaged and apolotocal). However, as the participants argued, young people work hard to push back against their marginalisation and to compel their inclusion in varied sectors and areas of society, including poliy-making. This has the dual influence of ensuring that young people feel that they are appreciated as valuable members of society. It also has the effect of initiating the energies and creativity of young people in formulating different approaches and solutions to issues that society faces.

Youth apathy has also been exposed as a failure by the state and bureaucratic structures to actively seek youth engagement for the advantages that it brings. Addressing this requires that scholarship and media reports frame policy in ways that do not further exacerbate the lack of youth engagement in policy making. Of significance, is ensuring that the layered reality of young people is made visible in the various policy making processes and that multiple viewpoints and contributions are taken into account in developming policy and te subsequent programming that follows.

Notes

1. My Master's dissertation (University of Pretoria, 2019) is titled 'Youth participation in public policy making: A critical analysis of young people's involvement in the National Health Insurance policy submissions using Societal Constitutionalism as a theoretical framework'.

2. Voice over Internet Protocol includes such an application that allows the sending of text messages and voice calls, as well as video calls, images and other media, documents, and user location. WhatsApp Messenger is an example of this with freeware and cross-platform messaging and Voice over Internet protocol. See: https://qz.com/africa/1206935/whatsapp-is-the-most-popular-messaging-app-in-africa/

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