# **ARTICLES**

'Making known' or 'counting our children'?

Constructing and caring for children in epidemic South Africa

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#### **Abstract**

The article explores how regimes of documentation, quantification, evidence, and accountability have come to shape encounters between program implementers, researchers, young people, and caregivers in one locality in northeastern KwaZulu-Natal, South Africa. Rather than simply critiquing the overemphasis on counting and accounting in global health, I examine the effects of these processes on the provision of services to young people and families. For those whose lives had been systematically excluded from view, processes of form filling could in fact be construed as services in themselves. Further, encounters structured around form filling could work to facilitate other modes of engagement, centered on the construction of forms of recognition, reciprocity, and obligation, and mediated by complex networks of patronage and dependence. Drawing on these findings, the article describes how local histories and contemporary life experiences can shape the ways in which technologies of global health are taken up, and their effects on everyday life.

#### **Keywords**

Belonging, evidence, HIV/AIDS, South Africa, vulnerable children

#### Introduction

Sithanda Abantu<sup>1</sup> is a small, community-based organization in northeastern KwaZulu-Natal, South Africa. In 2009, when I began to conduct research with them, the organization was receiving support from the US President's Emergency Plan for AIDS Relief (or PEPFAR) through the auspices of a larger national organization to provide services for 'orphans and vulnerable children'. Each day, after school, between fifty and seventy-five young people came to the site to receive a hot cooked meal from the project's feeding program. They arrived in small groups or one by one, entering through a gate between the project's tiny dirt lot and the adjoining schoolyard. They would sit or play quietly in the yard outside while two staff members and a few volunteers, all women, prepared the day's meal indoors. Once the meal was ready, the children were assembled to sing a Zulu gospel song and recite a prayer before forming a line to wash their hands in buckets of soapy water. After prayer and hand washing, the children proceeded to collect their plates from a volunteer, dressed in the pinafore and headscarf typical of domestic servants across South Africa, through the slats of a glassless window in a partially finished wall on the back side of the building. The imposed formality of this moment of service provision was striking - the physical division between volunteer and child created a sense of institutional propriety, despite the fact that the wall was free-standing and incomplete. The volunteer could just as easily have handed the plate to the child directly by stepping two feet to the side, where the wall ended entirely. I wondered what were the motivations behind and effects of this façade of formality.

According to PEPFAR reporting requirements, Sithanda Abantu was expected to take attendance each day of which children were present to receive a meal. During my time there, however, I observed attendance being taken only once, as children sat outside the building waiting to be served their meal. On this occasion, one of the center's volunteers, a young woman whom I call Zinhle, came out with a tattered notebook, opened to a page filled with names. There were no columns for dates or spaces for comments. As she went through the list, shouting out each child's name, she barely looked up to register whether the child was in fact present, and the children in turn did not pay much attention to her roll call. She seemed to be haphazardly placing tick marks next to or on top of each of the dozens of names listed, without waiting for a response. It did not seem possible that she could be accurately translating these pages of disorderly check marks into the structured attendance forms submitted each month at the organization's review meetings, which were carefully counted and re-counted, and summed into

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<sup>&</sup>lt;sup>1</sup> The name of the organization is a pseudonym.

service numbers for PEPFAR reporting. As with the physical façade of formality, the filling of attendance forms seemed to signal a bureaucratic order that was deeply disconnected from both the actual practices of service provision and the experiences of young people being served.

Between 2008 and 2011, I conducted research with service providers and public health researchers at two institutions working within one locality in northeastern KwaZulu-Natal: the small-scale, local service-provision organization described above and a major transnational research program studying the effects of the HIV epidemic in the area. In my work at both organizations, I became aware of a rapid proliferation of various kinds of forms – registration forms, service logs, consent forms, data collection instruments – and observed a variety of encounters mediated through these documents. In this context, the article explores how regimes of documentation, quantification, evidence, and accountability – the 'façades of formality' – have increasingly come to shape encounters and engagements between program implementers, researchers, young people, and caregivers, and interrogates the effects of these processes on the experiences of young people and families in South Africa. What does it mean, I ask, to be counted in these ways, to be accounted for? What effects do these processes have on young people and families, and what do they not do? How are forms of belonging and modes of care affected by these bureaucratic processes?

#### Reconfiguring citizenship and belonging

The research on which this paper is based was initially organized around the implementation of the 2006 PEPFAR guidelines for programs for 'orphans and vulnerable children' (OVC) in South Africa. The 2006 guidelines explicitly restricted PEPFAR-funded services to children 'directly' affected by HIV/AIDS – orphaned or vulnerable due to their own or a parent's HIV status – and excluded from services children made vulnerable by other causes. Through its particular focus on children impacted by one disease, the policy served as a powerful example of the use of biomedically defined categories to decide eligibility for special care and services for particular groups of individuals. The project has taken the entry of the guidelines as a site for examining the construction of categories of eligibility, vulnerability, and risk; the effects of policy and programmatic definitions on young people and families in rural South Africa; and the broader impacts of global health programs and the 'audit cultures' (Strathern 2000) they bring with them in this landscape.

Since 2003, when I first began to conduct research on HIV/AIDS in South Africa, the epidemic and the new programs it has inspired, like PEPFAR, the World Bank's Multi-country AIDS Program, and the Global Fund, have served as test cases for a new style of development and philanthropic aid structured around global public health initiatives (Cohen 2006). This shift has been reflective of a larger trend in global foreign aid and development discourse and practice in which, particularly in the African context, donors have increasingly focused on disease as a central indicator and determinant of 'crisis' and, thus, as the center of their interventions (King 2002). In response to these changes, medical anthropologists and other scholars, many relying on the work of Michel Foucault (1978, 1991, 1994, 2000) and his interpreters (for example, Agamben 1998; Hacking 1990; Rabinow and Rose 2006), have attempted to trace how social and governmental forms have shifted in the context of these emergent epidemics and the technologies they have mobilized. Scholars have described how forms of surveillance and control have shifted from the state's regulation of individual bodies and populations to forms of sovereignty mediated through international donors and private industries, as biomedical technologies have increasingly come to exceed the boundaries of the state (Fassin 2011; Redfield 2012). Through technocratic solutions to globalized forms of suffering that are defined by bounded public health problems or moments of crisis, social relations and modes of citizenship are increasingly mediated, these scholars have argued, by the language of biomedicine and public health (see, for example, Biehl 2004; Lakoff 2005; Petryna 2002; Redfield 2013; Robins 2004; Rose 2005). In this new constellation, disease status can become a basis for claims to citizenship and social recognition in the face of state retrenchment. In her work on post-Chernobyl Ukraine, for example, Adriana Petryna (2002) employs the concept of 'biological citizenship' to understand how individuals negotiate systems of entitlements based on claims of membership in the medical category of Chernobyl 'sufferers'. Similarly, in contemporary South Africa, disease categories have become a new means of determining entitlements to services for some. For example, the South African state grants disability benefits to HIV-positive citizens when their CD4 cell count drops below a certain level. AIDS can thus become a resource for individuals without access to employment or welfare (Leclerc-Madlala 2000). An HIV diagnosis can become a 'transformative event' (Sontag 1991) as people learn to narrate their lives framed around their membership in this category of suffering (Nguyen 2005, 2010).

Drawing on this body of work, my research initially aimed to investigate whether the OVC category created a new form of 'biological citizenship' for children and families in South Africa. I intended to trace how young people's experiences and understandings of themselves would shift

with the entry of the PEPFAR OVC policy and the biomedicalized category it inscribed. For children, whose subjectivity is often imagined and defined in reference to the future, to who or what they will become, the boundaries of the OVC category could serve, I suggested, to delimit their own and others' ideas of what their future holds. Thus, the research aimed to explore the possibilities for action that could come into being for children who fit within the OVC category, how these would change over time, and what kinds of children and actions were excluded from view.

In my work with a small group of young people and families, however, I found that the market-based modes of biological citizenship described in the work of others (for example, Biehl 2007) did not seem to have much salience in this context. Most of the young people I came to know were not in fact accessing services through their membership in the OVC category that were significant enough to radically transform their life possibilities, a problem that has in fact been openly acknowledged by PEPFAR policymakers (Bryant et al. 2012; Nyberg et al. 2012). The primary activities of the PEPFAR-funded programs I studied seemed to be centered on the collection of numerical metrics rather than the provision of care. In the context where I worked, processes associated with the imperatives of counting and accounting – principally the filling of forms – were often the most notable features of many people's engagements with global health programs. More broadly, as Vincanne Adams (2013) has described, the production of evidence has sometimes come to supplant the delivery of quality services in global health programs.

While scholars like Adams have critiqued this overemphasis on quantitative evidence, in the locality where I work, the simple act of being counted – of being recognized – in fact seemed to hold some significance for the people I came to know. In the context of a conflicted history of selective knowledge production and systematic neglect, processes of form filling could be construed in some ways as services in themselves for those whose lives had been excluded from view. Further, they could facilitate other modes of engagement, centered on the construction of forms of recognition, reciprocity, sympathy, solidarity, and obligation. Rather than membership in biomedical categories of suffering allowing individuals to make claims on a modern liberal state, or its more distributed, neoliberal, globalized forms, the dynamics of claims making in the context where I worked called upon older orders of patronage and dependence in ways that were profoundly shaped by the local, historical specificities of this place. In this context, the article describes how technologies of global health, in addition to 'remaking socialities' and creating new

forms of life, can serve to reveal and reinforce existing dynamics of power, structural inequalities, and longstanding tensions in local social relations.

### 'Counting our children'

In 2003, while in South Africa conducting research on 'empowerment-based' HIV-prevention programs, I went to meet with the director of a new research unit at the University of KwaZulu-Natal called the Centre for HIV/AIDS Networking, which had been formed in 2002 to track and coordinate the rapidly expanding numbers of organizations working to address the HIV epidemic in South Africa. On this first visit, I was given a small printed directory of a few hundred organizations across the country that provided HIV-related health and social welfare services. In the late 1990s and early 2000s, a number of South African organizations, many of which were founded during the struggle against apartheid, began to shift their programming to include HIV/AIDS work. Numerous new organizations also sprang up during the period, particularly with the arrival of PEPFAR funds beginning in 2004. By 2012, the directory had grown into a massive online database called HIV-911, which listed more than 12,000 organizations providing HIV services in South Africa. 'It's amazing', Helen Schneider, Director of the Centre for Health Policy at the University of the Witwatersrand, commented in a 2007 conversation, 'how ordinary people have been able to respond so strategically to the availability of funds.'

Orphan Care, as I call the PEPFAR-funded organization with which I worked from 2006 to 2010, was one of the numerous new organizations founded in the early 2000s to address the effects of the rapidly expanding HIV epidemic. Their model of service provision focused on training and equipping local volunteers and community leaders to become 'community social workers', checking on children at home, and identifying problems to be addressed by 'the experts and the rest of the community' (personal communication, Orphan Care manager, July 2006). Rather than attempting to mobilize communities to build new programs from the ground up, they focused on recruiting and supporting existing community-based organizations (CBOs) like Sithanda Abantu that were able to demonstrate that they had already, as one Orphan Care staff member explained, 'recognized the problem themselves, and were doing something about it'.

While Orphan Care staff members spoke of their positive relationships with local partners, and stressed that they were strengthening local organizations through their involvement, the project

director of one small organization I visited in 2006, which had recently been taken under the Orphan Care umbrella, had a different perspective. She had started the organization herself, she explained, as a 'feeding scheme' for children in her community and had worked hard to source funding, initially from local churches and businesses. In 2005, she was approached by Orphan Care through the local chief, and hesitantly agreed to fill out an application to join them. One year later, the woman complained, despite having completed a memorandum of understanding (MOU) to become an official Orphan Care project site, Orphan Care was doing nothing for them except managing their government funding, collecting regular reports, and counting their children. A 2005 article by Helen Epstein recounts a similar tale, in which a South African CBO called Sizanani was approached by staff from several PEPFAR-funded organizations to join their projects. Expressing her unhappiness with the arrangements offered by these large organizations, Epstein (2005, n.p.) relates, the director of the organization explained, 'When the Americans come, we sing, we dance, they take our picture, and they go back and show everyone how they are helping the poor black people. But then all they do is hijack our projects and count our children.'

The account illustrates a common critique of PEPFAR and other foreign aid mechanisms: they function more to serve economic and political agendas and to make Americans feel good about themselves, as Epstein (2007) suggests, than they do to provide meaningful services to young people. Such critiques sit in tension, in a sense, with the work of some medical anthropologists studying the effects of such programs, who have suggested that these programs allow for some to make powerful claims to services based on their disease status in ways that could reshape their sense of themselves and their life experiences (Biehl 2004; Fassin 2007). To interrogate the apparent tensions between such claims and to understand the experiences of local program staff and the young people they serve, in 2008 I moved to northeastern KwaZulu-Natal to study the local dynamics of global health research and intervention at two sites: a small-scale, local service-provision organization I call Sithanda Abantu, and a major transnational research center called the Africa Centre for Health and Population Studies.

The Africa Centre was established in 1997 with the primary mission of quantifying the long-term impacts of HIV/AIDS on a community facing a 'rapid and severe HIV epidemic' and conducting research towards HIV prevention, treatment, and care (Tanser 2008). In order to trace the effects of PEPFAR policies and the bounding of categories of child vulnerability, I also conducted ethnographic research at a small local organization I call Sithanda Abantu ('We help

the children'), the Orphan Care-funded project site closest to the Centre. My aim was to understand the effects of the circumscription of categories of vulnerability and notions of care in the context of the HIV epidemic from the perspectives of the community-based staff and volunteers – the 'middle figures' (Hunt 1999) who were forced to negotiate between bureaucratic imperatives and individual needs – and of young people themselves, whose voices were generally absent from many accounts of the epidemic's impacts (though their images were frequently featured).

## The façade of formality

In early 2009, shortly after I arrived in the area, I went to visit Sithanda Abantu to request their permission to conduct ethnographic research at their program site. I had visited them once before while accompanying Orphan Care's area coordinator for northern KwaZulu-Natal on her monthly rounds to each of the program sites under her supervision. Now that I had come to reside in the area, I wanted to spend some time at the site conducting participant observation, as I had in the Orphan Care head offices, in order to trace the effects of the PEPFAR policy and broader global health imperatives in this locality. Upon entering the center, I was greeted warmly by the project director, MaGumede, a middle-aged Zulu woman. Explained my research, and my desire to spend some time at the center helping out with the program and learning about how they operated. MaGumede agreed eagerly and we made a plan for me to come back the next day. She was glad, she said, that 'Africa Centre' had come to visit them; they had come once before, she said, and given them some food, but they were 'always visiting' iThemba leSizwe, another PEPFAR-funded program in the area, instead of them. I tried to explain that I was not a part of the Africa Centre, but was simply a visitor there, but she seemed unconvinced.

The next day, after explaining the aims of my research to the staff, I offered them copies of the consent forms and other study documents, which had been translated into isiZulu, so that they could have them as a reference if they wanted to learn more about the research. MaGumede took the forms from me, immediately placing them in a drawer of her desk. 'We can take these papers, my child', she said, 'but we don't really need them. We know you already. We know what you are working on and what you want from the children, so we are just taking them to satisfy [Orphan Care] who do not know you like we do.' This comment surprised me, as I had only met

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<sup>&</sup>lt;sup>2</sup> In isiZulu, a woman who is older than you is called by the title 'Ma' (mother) followed by their surname, or clan name, while someone younger is typically called by their first name. In my ethnographic accounts, I follow these naming conventions, as I did in conversation with my interlocutors, though I replace all names with pseudonyms.

MaGumede once before. However, I soon came to realize that the 'you' she claimed to know and to trust was rather a more diffuse figure – the Africa Centre, the foreign benefactor, the American, the white woman, the patron – a point I take up more fully elsewhere (Reynolds 2014a).

When I arrived to visit the center, MaGumede would stop the activities to announce my presence to the staff and young people in attendance, often instructing staff to sit down and speak with me formally, as they would be expected to do for an Africa Centre fieldworker who had come to survey them. When I expressed my interest in helping with daily activities, she suggested that I rather take photographs of the children receiving their meals or sit down and speak with one of the staff members, whom she would instruct to answer my questions. On one occasion, when I brought a few bags of rice and beans to contribute to the afternoon meal served to the young people, MaGumede called all the children inside to announce that I had brought them many gifts, and instructed them to thank me. Eventually, I was allowed to help with the serving of food to young people, passing plates to children through the window in the partially finished wall. Other than the brief exchanges of glances as I passed a plate or offered some other small form of assistance, there was little chance for conversation and engagement with the young people attending Sithanda Abantu, as they would all head for home as soon as the meal was finished.

Though I was initially frustrated by my inability to shift the tone of our interactions and by the ways that MaGumede and others seemed to change their behavior in my presence, I came to realize that these exchanges could offer me important insights into the interpersonal dynamics of local networks of global health and humanitarian aid. As Susan Reynolds-Whyte and her colleagues (2013, 147) have suggested, 'Sometimes the way people react to researchers reveals key features of the situation the researchers are trying to understand.' My engagements with MaGumede and the staff at Sithanda Abantu, and with others in the area, were deeply structured by the same historical inequalities that shaped the provision of services for young people more broadly.

### Visiting homes and filling forms

Zinhle introduced herself to me on our first visit to Sithanda Abantu as 'ivolontiya', using the isiZulu transliteration of the English term 'volunteer'. She was in her early twenties, and had finished her high school degree a few years earlier. Despite her volunteer status, she seemed to

be one of the most dedicated members of the center's team. She was always at the center when I arrived, busy cleaning the facility or attending to children. Though she received no payment for her work, she chose to do it, she told me, 'out of love for the children'. Among her many responsibilities, Zinhle was in charge of conducting monthly home visits to check on the status of each of the forty-seven young people registered as 'non-center children'. These visits generally took her several days to complete each month, walking from home to home across long distances. To observe the provision of services in the home setting and to provide some assistance, my research assistant and I offered to go with her on these visits.

On the first day, as we approached Sithanda Abantu, it was drizzling quietly. Zinhle came running out of the building to greet us. After a brief visit with MaGumede and the two other volunteers working at the center, we set off to begin the visits. For each child she visited, Zinhle was expected to complete a 'Volunteer Checklist' form. The topics covered in the version of the form I had been given by Orphan Care staff earlier that year included the following: the child's physical and mental condition (assessed through a series of seven 'Yes/No' questions), school attendance, and the presence of birth certificates and government welfare grants. The only places on the form where the volunteer was expected to suggest an intervention were under the two questions concerning grants and birth certificates, where the volunteer was asked to report what they planned to do to help the child to get a birth certificate or government grant.

Arriving at the first home, Zinhle introduced us to the mother of the registered child, who seemed less than enthused by our visit. We stood awkwardly as Zinhle pulled a worn notebook from her bag, and began to ask a few questions about the child's well-being. It was clear from her rapid pace that she was accustomed to these visits and the series of questions she was supposed to ask. After about five minutes, she closed her notebook and said we could leave. At the next home we visited, a woman was standing outside washing laundry in a large tub. After introducing us to the woman, Zinhle again pulled out her notebook and jotted a few notes as she asked the woman a series of questions. The questions took a bit longer, as we had to wait while the mother went inside to fetch the child's clinic card, one of the many documents Sithanda Abantu was expected to keep on file for each child in their services so that they would have documentation to 'prove' their service numbers in case of an audit. Zinhle took the clinic card and placed it in the back of her notebook, telling the mother that she would return the document once she had photocopied it.

At a few homes, caregivers interrupted the process to talk about their difficulties, but these conversations were generally short, as the focus quickly shifted back to the structured questions Zinhle was asking. For example, in one particularly poor household, in which fifteen people were residing in two small wooden shacks, the older woman who had been answering Zinhle's questions interrupted her, turning towards me to tell me that her grandchildren had all lost their parents and that she had had to look after all of them on her own. She needed our help, she said, because the girls were getting into trouble, and two had even had babies, whom she was now responsible for as well. Zinhle told her that she would come back to visit the girls another time, and then returned to her questions on the status of the young children in the home.

We visited thirteen homes in all on the first day. Zinhle said that she was happy with the day's work, stating that she never would have been able to visit so many families in one day without my help. I was surprised by how little seemed to have been accomplished in each of the visits besides the perfunctory asking of questions for the Orphan Care form.

A few weeks later, Zinhle informed me that she had been given a series of new forms to fill at each home she visited, part of a new initiative of the Department of Social Development to create a national registry of orphans and other vulnerable children. She had been called to attend a short training on how to complete the forms, and had been given a copy of each. She was told that she would be required to fill out these new forms each month as well as the Orphan Care forms that she was already expected to complete. Department officials had emphasized that they would not be providing any compensation for this work or additional support for the center or for the young people registered by the volunteers. At the end of each month, she would be expected to travel to the department offices in Hlabisa to submit the forms herself. To help Zinhle with this task, I again offered to go with her to visit the homes and fill out the new forms.

Our first visit was to the home of an elderly woman who was caring for her ten grandchildren. Inside the simple concrete home, the house was bare and sparsely furnished. The grandmother was lying in bed in a room lit only by some light shining in from the window. She was covered by a blanket and propped up awkwardly on one arm, and was visibly unwell. At her feet, wrapped in the same worn blanket, was a small infant. It was sleeping, face framed by a beam of light streaming through a large hole in the tattered curtain. The image was striking for its stark depiction of the classic metaphor of the 'AIDS orphan' crisis: an infant being cared for by a destitute and sickly grandmother.

After engaging in brief pleasantries, Zinhle pulled out the stack of forms, apologizing to the old woman for the need to fill out even more forms than usual. She struggled through the new forms, reading slowly and carefully to follow the meaning of the English-language form. She asked the old woman for her ID number, which was retrieved with some effort from a handbag stuffed deep under the mattress on which she was resting. When asked how many people slept here at night, the grandmother listed fifteen people, but was unable to remember the birth dates and other details for all the household residents until she sent one of the children to scour the house for ID books and other documents to show us. Zinhle carefully copied down all the details onto the form, leaving many blanks for missing information. It took more than an hour to complete the forms. The old woman and her granddaughter, who had joined us in the room to assist the grandmother in answering questions, seemed unruffled by the process and answered all the questions patiently. It was apparent that this kind of form filling was not unfamiliar.

The scene was similar at other homes we visited. Though the forms were long, the caregivers were unsurprised and entirely willing to answer the questions. In these initial visits with Zinhle, my strong impression was that filling out the forms was the only 'service' that was being provided, suggesting that perhaps the program was simply 'counting children', as Epstein's critique had claimed. In filling out these new forms, Zinhle's labor began to resemble that of the local community members employed by the Africa Centre to collect data explicitly for research purposes, a point I come back to below.

### Producing service counts

Back at Sithanda Abantu, the various completed forms were sorted and placed in plastic sleeves to be readied for submission to Orphan Care for their PEPFAR reporting. They were not, however, inserted into the children's records kept at the center. Each child had a file, carefully lettered with their full name on the outside, which contained a copy of the OVC Registration Form. Some also contained copies of the child's birth certificate, clinic card, parent's identity documents, and death certificates for parents. There were no records, however, of the services they had received or of their ongoing needs. The service forms completed by Zinhle once a month were submitted to the head offices of Orphan Care, thus making it impossible for staff and volunteers to refer back to them to follow up on concerns or to monitor young people's progress and needs over time. Rather, the focus was on documenting the number of home visits

completed to separate children, and creating the requisite paper-based 'audit trail' to back up service counts reported to PEPFAR each month.

As a PEPFAR-funded OVC care site, Sithanda Abantu was expected to provide services for children according to the guidelines that had been laid out in the 2006 OVC Guidance and other PEPFAR policy documents. In 2009, services that could be counted toward PEPFAR targets were structured around what were referred to as the '6 + 1 needs' of children: food and nutrition, shelter and care, legal protection, health care, psychosocial support, education, and economic strengthening of families and households (2008 Office of US Global AIDS Coordinator). At Orphan Care offices, Zinhle's home visits were counted in PEPFAR reporting under the category of psychosocial support. Psychosocial support (or 'PSS' in the language of program implementers) had become an increasingly popular term in the OVC field, intended to focus on the psychological and social forms of support previously excluded from programming for vulnerable children. The term thus framed the dominant institutionalized form of thinking about what I have approached as questions of kinship, care, and belonging.

Under the PEPFAR guidelines, organizations were not expected to provide all seven categories of services, but rather were required to provide, or support the provision of, between one and three services from the list of basic 'needs'. The OVC Guidance explicitly encouraged PEPFAR-funded organizations to 'leverage' what they referred to as 'wrap-around' services made available through other programs. Through this approach, PEPFAR-funded programs were able to count services for children that they themselves had not provided. Thus, by visiting a home and asking questions regarding the services that children were receiving, and providing advice about how to access government grants on some occasions, Orphan Care programs could report that they had 'directly served' an eligible young person. In this context, form-based home visits and other documentable 'services' were important for the ways they enabled program implementers and policy makers to count 'successes' and thus to continue to expand their programs and funding streams (Reynolds 2014b). Further, as these form-filling exercises proliferated, the possibilities for meaningful service provision were limited by the overemphasis on counting and measuring results. In this context, documentary practices that had initially been intended to improve the provision of services seemed to stand in for the services themselves.

#### Research and representation

In the late 1990s and early 2000s, as many non-profit organizations shifted their programs to focus on HIV/AIDS and new organizations arose to provide services for those infected and affected, another contingent of organizations appeared on the South African scene, focused on measuring the impacts of the epidemic and developing interventions. Over the last decade, families living within the boundaries of the Africa Centre's Demographic Surveillance Area (or DSA) have been regularly surveyed to produce counts designated for research rather than the provision of direct services. Though my research was not initially structured as an ethnography of the Africa Centre itself, as the research progressed, the Centre became an important focus as I came to understand its place as a powerful social figure in this landscape and as I began to see how local life was depicted in the frame of the Centre's database.

The Centre has a massive presence (literal and figurative) in the area. It sits in the middle of the rural area in a prominent and easily recognizable building that is encircled by a series of smaller buildings and parking lots, all walled off from the surrounding area by a security fence. Since beginning research in the sub-district in 1999, Centre staff have conducted twice-yearly surveys with nearly every household in the area and, since 2003, have also conducted active HIV surveillance of all members of the households within the DSA: staff visit each individual aged fifteen and older in the DSA area once a year and request a blood sample for HIV testing. Centre researchers have also taken a particular interest in questions of orphanhood, family structure, and migration, and thus their questionnaires contain a large number of questions on child status and provision of care. Further, in addition to the routine surveillance, the Centre has been the base for several large-scale clinical trials and a host of other biomedical and social scientific research endeavors. At the time I conducted my research, the Centre was the largest employer and one of the primary health service providers, managing the entire PEPFAR-funded antiretroviral rollout for the district, among other services (Reynolds et al. 2013).

In early 2009, while conducting ethnographic research in the area, I also spent time going out with Africa Centre fieldworkers to observe the collection of routine surveillance data. On several occasions, I accompanied teams as they drove to designated areas within the DSA in a fleet of white Land Rovers, emblazoned with the Centre's logo, and then walked with fieldworkers as they traveled over the hills and along paths from one rural homestead to the next. Armed with stacks of numbered forms, GIS maps, and lists of household numbers and member names, the teams of fieldworkers would arrive, often after a few wrong turns, at a designated area and fan

out to visit all of the scattered homes. They would approach a house, introduce themselves, and ask to see the silver Africa Centre tag, on which was written a five-digit code. Matching this to one of the numbered forms in their Africa Centre-branded pack, the fieldworker would ask to sit with the eldest household member present (usually a woman) and read through the questions on the many forms. By early afternoon, stacks of filled forms tucked neatly back into their satchels, the team reunited and piled into the Land Rover for the drive back to the research center. There, the forms were submitted to the Data Centre for entry into the Africa Centre Demographic Information System (ACDIS), the master database. Through these techniques, the Africa Centre had amassed a huge amount of quantitative data on household composition, socioeconomic status, migration, illness, and mortality for all 11,000 households (or 90,000 resident and nonresident individuals) in the subdistrict.

## Research as service, service as research

As young people and families in the area were subject to multiple modes of form filling, many individuals I spoke with found it difficult to distinguish between the form filling of the Africa Centre, aimed at the production of scientific knowledge, and that of organizations like Sithanda Abantu, purportedly intended to directly improve provision of services for young people. On several occasions during our visits to homes with Zinhle, people told us that they had thought we were coming from the Africa Centre – and that they had been intending to hide or to tell us to leave. 'The Africa Centre people ask a lot of irritating questions', one woman reported. At another home, an old woman kept saying that she didn't want to be 'checked', that she was an old woman and didn't have this disease, clearly referring to the Centre's HIV surveillance program, which came to each household in the area once per year to request a blood sample for HIV testing from all adult household members.

While at the Africa Centre conducting my research, I also became involved in an operational study that aimed to understand the dynamics of declining consent rates in the Centre's HIV surveillance program. In a paper drawn from the research (Reynolds et al. 2013), my colleagues and I described how liminal figures such as field workers were forced to mediate tensions between the norms and standards of global health research and local life worlds. We suggested that ambivalent configurations of kinship, obligation, and trust crucially shape the conduct of HIV surveillance and thus the production of knowledge in this locality. These structural tensions contribute to a widespread confusion wherein participants tended to understand research as something akin to intervention. The conflation of research and service was not just a

'misconception' (Appelbaum et al. 1982), we argued, nor did it necessarily suggest 'fundamentally different expectations for health research' (Stewart and Sewankambo 2010). Rather, in the contemporary research environment in Africa, as demographic surveillance sites have increasingly become nodes for a wide variety of health and social research programs (Molyneux and Geissler 2008), individuals living within 'trial communities' like the Africa Centre in fact access significant services through the operations of such research organizations.

While the ends of the Africa Centre's form filling were articulated in quite different ways than the work of form filling among service providers like Sithanda Abantu, in reality, participating in Africa Centre research was one of the central ways in which some people in the area accessed services. In addition to their significant research profile, the Centre employed doctors, counselors, and social workers to staff the area clinics; organized many community events; and offered various forms of assistance to area schools and CBOs, ranging from providing soup once a week to families visiting a feeding center, to constructing and equipping a state-of-the-art computer center for a local school. At the time of the research, the Centre was also receiving PEPFAR funding to support the South African Department of Health in implementing the Hlabisa HIV Treatment and Care Programme within the research area. The program had enrolled over 11,000 individuals, making it the largest rural treatment program in the country. In fact, by most measures, this research organization was offering many more services for community members than 'service' organizations like Sithanda Abantu.

## Making known

In attempting to understand individuals' responses to documentary practices, it is important to contextualize these processes of form filling and service provision within the tangled histories of intervention and exploitation that have powerfully shaped the experiences of those living in northern KwaZulu-Natal. In particular, it is essential to understand the ways that the colonial and apartheid state used modes of selective knowledge production and intervention to both ignore certain people and to control them. Practices of knowledge production were used to exploit and perpetuate inequalities, and to reveal and right injustices. Thus, not only did the process of form filling act as a 'service' in itself, but it also perpetuated older patterns of patronage, dependence, and inequality. Such contradictions are inherent, I suggest, in the dynamics of social life in this locality.

In the preface to the published report of the Second Carnegie Inquiry into Poverty and Development in Southern Africa, the authors highlight how the apartheid state maintained its exploitive and unjust system of rule in part through willful acts of not knowing, a state of mind they describe using the Yiddish phrase, 'Si mach sig nicht wissen dich' (You make yourself not to know) (Wilson and Ramphele 1989b). Similarly, in a 1989 UNICEF report outlining the situation of young people in South Africa, the authors of a chapter entitled 'A Crisis of Caring', highlight the centrality of particular techniques of data collection and knowledge production to the apartheid order: 'The statistical information which a society chooses to collect or to ignore about itself tells one a great deal about the priorities (and the power relations) within that society' (Wilson and Ramphele 1989a, 69). The apartheid state, they explain, developed a strategy of 'making itself not to know' about 'uncomfortable truths' by choosing not to collect information on particular groups, conditions, and regions within the country. In some cases, rather than collecting accurate data, the apartheid state relied on the production of a series of myths to perpetuate its agendas and justify its actions (Packard 1989).

Processes of selective ignorance and the production of particular forms of 'knowledge' in fact began as early as the mid-nineteenth century, when colonial settlers first began to arrive in the region known as Zululand. From these early days, attempts to gain control of land and seize power over the region were often justified as interventions on behalf of the 'natives', particularly innocent women and children. As many Africanist historians of medicine have shown, the history of epidemic patterns in Africa has been intimately tied to the social, economic, and political histories of colonialism and divergent forms of power. Interventions were generally targeted towards the maintenance of laboring bodies, and often neglected the quite significant disease burdens among women and children (Feierman 1985). Many other diseases that affected black South Africans in the reserves and the very high rates of black infant mortality were not addressed, in part because 'African' deaths were unrecorded (Jeeves 1997). Through choosing not to collect data on the mortality of young black South Africans, the colonial state was able to avoid responsibility for the well-being of a large majority of the country's population.

Under apartheid, techniques of selective knowledge production were refined even further. By declaring certain areas of the country to be separate self-governing ethnic states, the government was able to avoid taking any responsibility for addressing the serious problems facing young children in much of the country (Asrat et al. 1989). In Zululand, the most fragmented of the ten Bantustans, policies of 'separate development' and exclusion meant that for much of

contemporary history formal institutional interventions were limited (Packard 1989). Despite mounting evidence, the apartheid state continued to deny problems in the Bantustans, employing partial or fictive data to claim that morbidity and mortality were actually on the decline.

While choosing not to collect data on certain conditions, however, other forms of knowledge production were essential to colonial and apartheid rule. While the apartheid government used particular modes of 'not knowing' to further their racist agendas, the collection of other forms of information was employed as a means of controlling the black population. As Keith Breckenridge (2005) has recounted, from the early 1900s, the colonial and apartheid governments attempted to register and keep track of black South Africans through technologies of documentary regulation, culminating in the imposition of the *dompas*, one of the most visible symbols of apartheid. Under the Pass Laws Act of 1952, the black population was required to carry pass books with them at all times, and could be thrown in jail for failure to produce a valid pass on demand (Bowker and Star 1999).

In response to these faulty forms of knowledge production, during the 1980s, the collection of information about the plight of black South Africans, particularly those living in the Bantustans, became a key component of the anti-apartheid project. Critical scholars worked to 'uncover the truth' and to force the government and others to 'face facts and to understand' the powerful effects of apartheid on black South Africans (Wilson and Ramphele 1989b). Thus, the production of knowledge and collection of statistics took on a powerful political salience for many South Africans.

The ways in which forms of data collection, public health interventions, and local responses were folded into larger social processes and forms of oppression and resistance remained an important element of the history of public health in the region throughout the twentieth century, and continues to structure interventions and responses in the contemporary moment. It is in this light that processes of data collection and form filling could be seen to take on a particular significance in contemporary Zululand. In the post-apartheid moment, for those whose lives had been systematically excluded from view, the simple act of recognition, of registration, of documentation that is embodied in the filling of forms could foster an important sense of belonging and of recognition for individuals whose experiences and difficulties had been systematically ignored throughout much of recent history.

#### Building a sense of belonging

During 2009 and 2010, I accompanied Zinhle on several more occasions on her monthly visits to families enrolled in Sithanda Abantu's services. As I came to know the families she visited and to understand the local dynamics of care provision more fully, I began to notice how individuals engaged with and responded to the seemingly redundant processes of form filling with a great deal of patience and attention, even seeming to appreciate the encounter. Further, though the visits were generally structured around the requirements of form filling, I began to notice that other kinds of conversations occurred around the edges of the structured questionnaire. Here, I briefly describe two examples of these encounters: (1) a group of volunteers pooling funds to support the funeral costs of a young boy who had been enrolled in Sithanda Abantu services, and (2) Zinhle's counseling of young women whom she perceived to be at risk of premarital pregnancy or acting inappropriately. In these accounts, we see how bureaucratically mediated encounters allowed for important forms of engagement, including expressions of empathy, attempts to build solidarity and sociality, and the inculcation of values and morals.

While visiting a home to complete the Orphan Care questionnaire, we were informed that the enrolled child, a young boy, had passed away suddenly some days before. Though Orphan Care did not offer support for families who had lost a child, Zinhle and the other volunteers decided to raise money amongst themselves and to solicit the support of neighbors in order to help the family cover the costs of the funeral. Over the next several days, they went to speak to neighbors and friends and managed to raise a small pot of funds to be given as contribution from Sithanda Abantu to help with the child's burial costs. While funeral support was not included in the itemized lists of services allowed by PEPFAR and other funders, they were in fact a central aspect of life in the area in the context of the HIV epidemic, and families often requested support for funeral expenses from both Sithanda Abantu and the Africa Centre. Though families often incurred heavy costs for burials, they also served important social functions, allowing families to complete the rituals necessary to introduce the deceased individual to the ancestors, thus securing their place in the afterlife, and ensuring the family's well-being by strengthening the relationship between the living and the dead. Further, in the case of the death of a parent or caregiver, funerals were often a site where family and friends planned for the care of surviving children and resolved other issues. These kinds of social processes, so essential in shaping the experiences of young people and families affected by the epidemic, were clearly beyond the scope of the restricted services deemed 'essential' by PEPFAR policy makers. Through the process of form filling, however, modes of solidarity and goodwill were mobilized that allowed

for 'community-based' care to occur despite the restrictions of PEPFAR and the limited nature of formal services offered.

Another key issue that emerged in several of the home visits I made with Zinhle had to do with the situations of young women in unstable homes, and particularly with their irresponsible behavior with boys and their school attendance. In one home, for example, after finishing the formal questionnaire, Zinhle confronted a young woman residing there, challenging her about her decision to leave school and rumors that she was 'visiting' older men. With downcast eyes and one hand covering her face, the young woman responded that she simply did not feel like going to school anymore, and denied the rumors. Zinhle became emotional, trying to explain to her the importance of returning to school and pleading with her to stop sneaking away with men.

At another home, we spoke to a grandmother who complained that her granddaughter, for whom she had been caring over the last several years, had quit school and had become very rude to her grandmother, making her cry frequently. After completing the questions with the grandmother, Zinhle went outside to speak to the young woman, who was seated on the steps of the house. When questioned, the young woman reported that she had decided to leave her grandmother's home to go stay with her father's family, whom she had just met a few months before at her father's funeral. Zinhle expressed disappointment and dismay, stating that it was not right for her to leave her grandmother who had raised her since she was a small child to stay with these people she did not know. She had an obligation to stay with her grandmother, Zinhle insisted. I was struck by this articulation, as it did not align with the child-focused concerns articulated by PEPFAR and by Orphan Care, in which the wellbeing of the child was always the primary concern. In this case, rather, Zinhle was concerned with expectations of and obligations between caregivers and young people, and about broader kin relations.

Through these dynamics, I suggest, the form-filling procedures came to take on richer meanings for some young people and families in the area, though the modes of 'care' provided were not of the type conceived of and counted by PEPFAR program officers. Rather, the process of form filling could serve to facilitate other modes of engagement, centered on the construction of recognition, reciprocity, sympathy, solidarity, and obligation. Encounters mediated through the forms served as a productive 'façade of formality', that allowed for other kinds of conversations to occur, shaped by dynamics of relationship and reciprocity. In the daily work of Sithanda Abantu and organizations like them, however, staff members were forced to focus their

attention on fulfilling documentary processes, shifting more complex, interpersonal dynamics 'behind the curtain', as it were, when visitors (like me) came to call.

### The 'ambiguities of dependence'

The dynamics of service provision were framed by complex notions of patronage and dependence. These historical residues, structured by what Shula Marks (1986) has referred to as the 'ambiguities of dependence', deeply shaped the ways in which both caregivers and families engaged with and responded to external interventions in contemporary KwaZulu-Natal. In her volume by the same name, Marks describes how the contradictions of colonial rule in Natal and Zululand – 'between theory and practice, between exploitation, expropriation, and political suppression of Africans on the one hand, and the ideology of separate development, trusteeship, and paternalism on the other' – continued to shape social life, making ambiguity 'the price of survival in a contradictory world' (Marks 1986, 14). To attempt to provide meaningful services to the young people deemed most 'in need', 'volunteers' and staff at both Sithanda Abantu and the Africa Centre were forced to negotiate a series of equally fraught ambiguities, as I describe elsewhere (Reynolds 2014a, 2014b). However, these ambiguities could also be productive, as they allowed volunteers to move around the boundaries of the formal services, and the forms themselves, to engage with young people in quite different ways.

Even the leadership of the Africa Centre, connected as they were to powerful networks of transnational global health research and governance, was still reliant on historical forms of patronage, tied to the complex history of separate development and indirect rule. In order to successfully complete their activities within the area, the Centre needed the sanction of the local traditional authority and the active engagement of local traditional leaders to encourage area residents to participate in the research. In 2011, for example, to strengthen their ties with the traditional authority and to reinforce their position within the community, the Centre negotiated for the Zulu king, Goodwill Zwelithini, to be installed as official Patron of the Centre. To celebrate the formalization of this relationship, Centre staff organized a large and well-publicized ceremony honoring the king, which included a gift of several large head of cattle. These forms of consent rely on historical forms of patronage that are highly contested in contemporary South African politics and in the experiences and opinions of many individuals with whom I have worked in this locality.<sup>3</sup>

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<sup>&</sup>lt;sup>3</sup> In another piece, I explore the tensions produced through a reliance on such structures in contemporary health research and intervention, and the ways that similar notions of patronage are deployed by a variety

Just as the Africa Centre sought the support of the Zulu royal family and the traditional leadership to support their ongoing research in the area, organizations like Sithanda Abantu and individuals within the surveillance area learned to look to the Africa Centre as a potential patron. Even MaGumede, the director of Sithanda Abantu, expressed an aspiration to be supported by the Centre on many occasions. In one conversation, for example, as she was telling me about the origins of Sithanda Abantu, MaGumede said:

When we were nothing we saw them building an Africa Centre for us. Now we see ourselves as rich because they can give you all the help you need when you get close to them. They come here and go to our homes. They do not go to children only, but go house by house. ... Since AC [the Africa Centre] came with this research there are lots of people who have been helped. ... When we started this center, we started it hoping that AC will help us. We took [Orphan Care] for now because we want food from them, but our main aim is that we want AC to manage us. So we are very happy to see you enter in this door. If AC continues to see us as their people we would be very happy, we can work well, they can help us with everything that they want to help us with in this center. Even if it is theirs and we are under them, that is what we want.

The desire to be supported, cared for, or even possessed by the Africa Centre, perceived as a wealthy patron with riches to bestow on the people of the area, calls to mind much older forms of sovereignty and patronage, characterized by dependence on a chief or traditional leader. Such language is a far cry from modern concepts of 'citizenship' deployed by many medical anthropologists attempting to understand how individuals negotiate systems of entitlement based on claims to membership in medical categories.

In this locality, citizenship is perhaps configured differently than in the liberal democratic ideal of much Western political thought, as James Ferguson (2013) has highlighted in a recent article. In contemporary South Africa, Ferguson argues, relations of social dependence form the foundation many South Africans' interpersonal relations and claims to membership in the postapartheid polity. Writing against the idea that practices of dependence are simply 'lamentable

of individuals in their engagements with the research center and with other service providers in the area (Reynolds 2014a).

manifestations of a reactionary and retrograde yearning for paternalism and inequality', Ferguson (2013, 223) suggests that such claims of dependence serve as practical responses to the 'historically novel emergence of a social world where people, long understood as scarce and valuable, have instead become seen as lacking value and surplus'. In such a context, Ferguson (2013, 231) explains, the worst-off individuals are not those who are being subordinated and subjected, but rather those who 'have become not *worth* subjecting'. 'For those thus abjected', he goes on, 'subjection can only appear as a step up' (Ferguson 2013, 231). Thus, poor South Africans actively seek to construct relations of dependence with, and of recognition from, social actors who are perceived to have the capacity to provide and protect.

Similarly, in my own research, I have found that despite the formalizing practices of form filling and the structures of engagement and authority in the 'new world of global health', the provision of services was shaped by complex interpersonal relationships defined by the complexities of dependence and historical inequalities. Though the circulation of technologies of counting and accounting shifted social relations, the possibilities for such relationships were framed by the heavy weight of history and contemporary conceptions and practices of recognition and belonging in this locality.

### Conclusion

The article has traced the effects of reporting requirements and documentary regimes as they structured the engagements of two organizations in one locality in northern KwaZulu-Natal, one purportedly providing services and the other conducting research. Rather than serving simply as a bureaucratic procedure disconnected from and effectively impeding the provision of meaningful modes of care, form-filling practices shaped the experiences of young people and their families in this area in important ways. First, in the context of a conflicted history of selective knowledge production and systematic neglect, the process of form filling could be construed as a 'service' in itself for those whose lives had been systematically excluded from view. Further, the process of form filling itself could serve to facilitate other forms of engagement, centered on the construction of forms of recognition, reciprocity, sympathy, solidarity, and obligation. Thus, the form served as a productive 'façade of formality' that allowed for other kinds of conversations to occur. Beyond the facade, however, the forms of belonging and modes of care produced through these processes drew upon older social orders and (re)invigorated local notions of support and care tied to notions of dependence. Thus, though the circulation of new biomedical technologies may have shifted forms of citizenship and

belonging, the forms that these relations took and their effects on young people were being restitched out of old materials, colored by the effects of the region's long history of inequality and injustice.

While these conclusions are preliminary, and a much deeper historical and ethnographic exploration is necessary to fully understand the dynamics of research and reciprocity in this locality, it is clear that more is going on in the implementation of global health technologies than simply the creation of entirely new social forms. Rather, existing networks of power, patronage, and dependence are being reinvigorated and reshaped in important ways by the conduct of global health research and the implementation of programs.

Drawing on these findings, my broader aim here is to highlight how particular historical and spatial dynamics can shape the ways in which new technologies are taken up and affect social life. While post-Foucauldian scholarship has offered powerful insights into the ways in which biomedical technologies have created new social forms for some, it is important not to overstate the impacts of these systems in all localities. As Paul Rabinow and Nikolas Rose (2006, 4–5) state in a critique of the overuse of the concept of biopower, 'these concepts are not trans-historical or metaphoric, but are precisely grounded in historical, or genealogical, analysis'. Rather, I suggest that it is necessary to first interrogate if and how these new governmental forms and biomedicalized categories are indeed (re)shaping everyday life in a particular locality. In reimagining and reshaping the concept of 'biosociality' in the context of global health research and intervention, we would do well to pay much greater attention to such processes and to take seriously the powerful ambiguities and contradictions created by the introduction of new technologies in diverse localities.

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