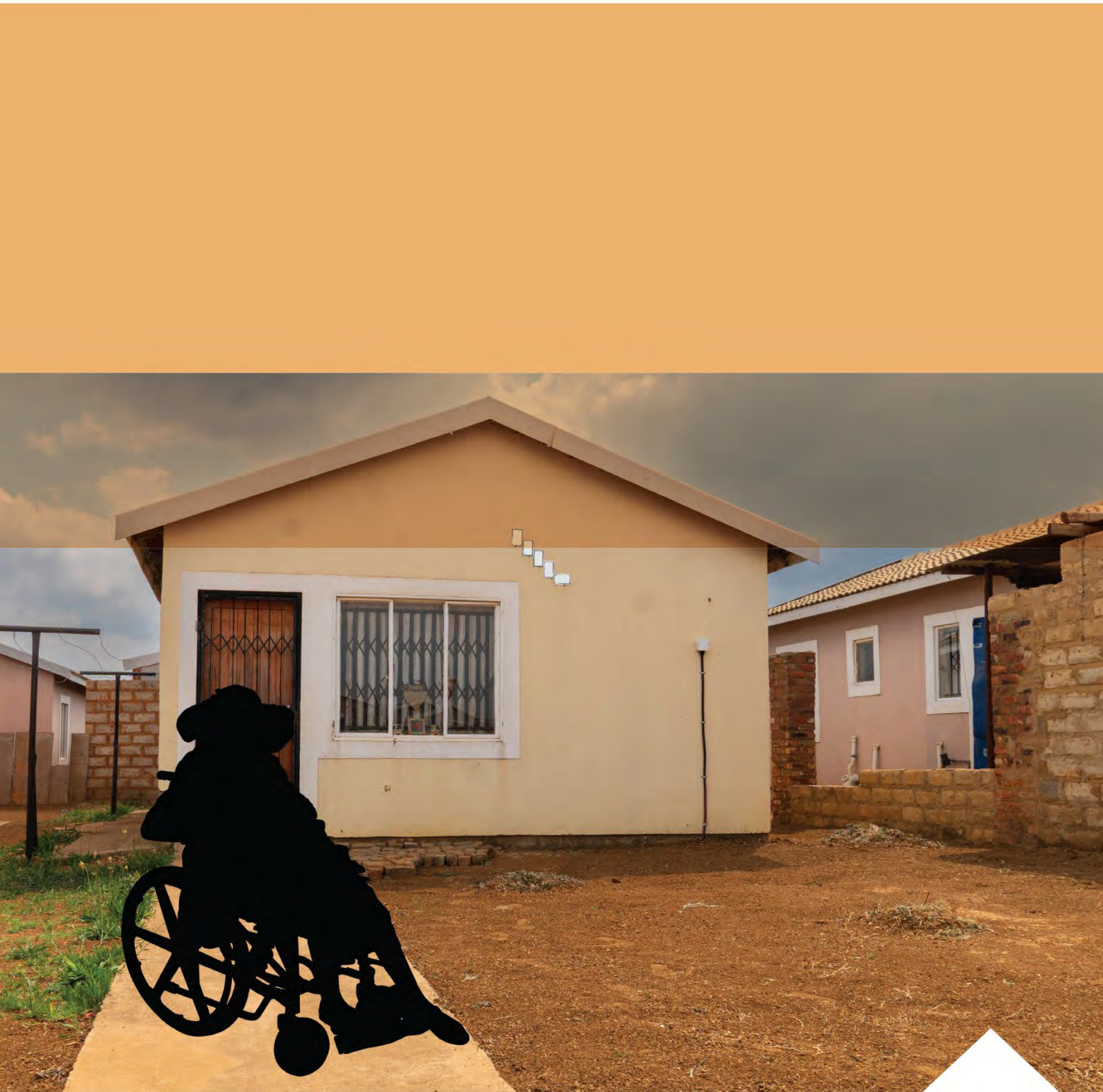


DIKELEDI'S STORY



COMMUNITY-ORIENTED PRIMARY CARE
RESEARCH UNIT
Creating A Service Learning Research Platform



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

OCCUPATIONAL THERAPY

Prologue

It has been an incredible journey that has brought us here to this consolidated story of Dikeledi. Whilst this narrative originally formed a data set for my PhD, it is relevant for additional analysis and may be useful as an example in teaching and learning. My personal narrative may be an important account, describing what researchers and community workers often experience as they navigate the struggles evident in vulnerable communities. I am aware, however, that others may have reacted differently, and had there been better knowledge and understanding of the context, it may have led to different interventions and outcomes. Please remember that both Judith (my co-researcher) and I did what we thought was best at the time, together with what we were capable of doing, considering our own challenges and the various other roles that we were fulfilling.

And whilst this e-book has an ending, it is not the end of our story with Dikeledi's household and extended family. We are continuing to engage with them, and hope that Dikeledi's legacy may live on in her daughters.

Helga E. Lister

Methodological considerations

Please consider the following information when reading this life story:

- This narrative was constructed during five years of engagement with a household in the peri-urban area of Mamelodi, in the East of the City of Tshwane, South Africa, whilst I (Helga, the researcher) was conducting my PhD research – a life history study on the food security of women living with HIV and disability in vulnerable contexts. In the initial phases of the research, myself and my research assistant, Judith, functioned as voluntary community workers. At the beginning of 2019, became employed at the University of Pretoria's Occupational Therapy Department, where I coordinate the community-situated work integrated learning (WIL) module, supervising final-year occupational therapy students in Mamelodi. The Occupational Therapy Department at the University of Pretoria (UP) has long-standing relationships in various communities across Tshwane, including Mamelodi. Occupational therapy students participate in various service-learning activities during their WIL module and are embedded within other interprofessional and interdisciplinary projects.
- The methodology followed in constructing this life history narrative is as follows:
 - Informed consent was obtained from the participant (Dikeledi) at the start of the study.
 - Various interviews were conducted in Dikeledi's home or other sites within the community (as required). Some of these were more formal with a research assistant

(Judith) and translated into Sepedi* in real-time and recorded or translated and transcribed back into English actively during the transcription. Other discussions were more informal and occurred as the relationship continued to develop.

- I reflected on my engagement of these discussions as well as my experiences whilst in Mamelodi through reflexive notes. Photographs, participant observations and hospital records were also obtained. Data collection and interpretation occurred constantly throughout the process, as both Judith (who became a co-researcher in the process) and I tried to make sense of the developing life story being shared.
 - The transcriptions were cleaned by focusing on crucial aspects of the story, joining sentences and words where appropriate, rephrasing questions asked by Judith and me as answered statements (for example, “What is your name?” was changed to, “My name is...”) and reflecting on conversations in the researcher narrative.
 - Where required, Judith and/or my questions have been inserted as explanatory notes to identify the topic under discussion (as opposed to including the direct quotes of the researcher in the interview). Written in the voice of the researcher, these have been highlighted in light blue, similar to the reflexive notes, to separate it from the voice of the participant.
 - Also, if clarification is needed, this has been included in brackets or as footnotes. Even though, at times, the use of the English language may appear incorrect grammatically and technically, it has been written in the way the participant spoke (bearing in mind that English is not the participant’s first language). This has been indicated using brackets [*sic*] where necessary.
- This narrative includes the first layer of interpretation since Judith, and I became embedded within the community of Mamelodi and achieved a greater level of understanding through community-based occupational therapy intervention. This process is referred to by Polkinghorne¹ as narrative configuration. Therefore, the process of data collection, analysis and interpretation did not occur in sequences, but concurrently. Also, the life history is not reflected on in a single interview, but rather as the researcher and co-researcher were embedded within the community of Mamelodi for extended periods of time (and the co-researcher also living in Mamelodi at various times), i.e., we were present whilst life events occurred. This is referred to as the narrative mode of analysis, since analysis occurred continuously whilst collecting data and writing up of this coherent narrative.¹
 - There were periods of lack of contact with the household due to Judith and my changing circumstances, which made it difficult to maintain ongoing connection to the household. There

* Sepedi is one of the 11 official languages in South Africa, and a vernacular language in the community of Mamelodi

were several times when Judith or I tried to call or visit the household, however, no-one answered (due to phones being unavailable or stolen) or no-one was at home.

- The researcher account, as well as the entire narrative has been read through by Judith, the co-researcher, who was present for many of the engagements, and with whom much of the reflection was discussed and interrogated. This serves to enhance the authenticity of the story.

Ethical considerations

- The pseudonym ‘Dikeledi’, meaning “one who is filled with a lot of tears” was requested by the participant herself.
- The names of Dikeledi’s children have been changed.
- Specific names of clinics have been removed to protect the household’s identity.
- There is only one district hospital in Mamelodi, and this hospital’s name has been retained (Mamelodi Regional Hospital). The community refer to the hospital as ‘Dagga’ (pronounced “da-ga”), from its previous name, the Mamelodi Day Hospital.
- The name of the rural community that Dikeledi is from has been changed to Maganeng. This is to protect the participant.
- Specific dates of discussions and reflexive notes have been removed.
- Photos have been taken and published with permission. To protect the identity of the participants, their faces have been blurred.

Acknowledgements

- Thank you to Dikeledi, and your family for allowing me into your lives and for sharing your life stories with me.
- Thank you to Ms Judith Mahlangu (community worker), for being a co-researcher, and for reading through the entire narrative and assisting in member-checking the information provided.
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- Thank you to the South African Medical Research Council (SAMRC) for your generous funding of the National Health Scholars Programme through the Public Health Enhancement Fund.

Other

- Most of the photos were taken spontaneously by the researcher (with permission).

Acronyms

- CHW: Community health worker
- NPO: Non-profit Organisation
- NGO: Non-government Organisation
- OT: Occupational Therapy

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Reference

1. Polkinghorne DE. Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*. 1995; 8(1):5-23. doi:10.1080/0951839950080103



Image above: Dikeledi in front of her home

LIFE STORY – DIKELEDI

Discussion: December 2017

My name is Dikeledi. I live in Mamelodi. I am sick, I am HIV positive, and I am disabled. I have spinal TB [tuberculosis]. I have been in a wheelchair for about, since [sic] 2012.

I grew up in Maganeng^a in Mpumalanga, near the mountains. I have been married before. I have lived in this house since 2012. That is when I got sick. They took me back home from here to a hospital back home, Glen Cowie^b. I live here with my partner. I met him in Mamelodi. I went to school until standard eight^c. I haven't really worked. I was just self-employed. I was selling products like Angel, Avon^d and so on.

I have two kids. My first child's name, her name is Lerato^e, and she is sixteen years old. The second, her name is Naledi, she is eight years old. Naledi was born in 2009 and Lerato in 2001.

I get a disability grant and childcare grants for the children. I can't walk, I am always on [sic] a wheelchair. There is a problem that affects me in the house. When I want to move around or leave the house, I can't move around on this wheelchair. I need someone to help me. I have to be bathed, my children have to cook for me before they go to school and dish up the food for me and leave it on the table, so that when they are at school, I am able to get the food and water. Sometimes the children don't cook food in the mornings on school days, but they leave leftovers from the previous night. Supper, they give me while I lay in the bed. I usually eat pap^f during the day. I eat cabbage, spinach, potatoes, and meat. I buy the food with the grant money. The children push me, and we go together to the complex [at Spar^g]. We store our food in the cupboards. We have a fridge. Now, when I don't have food, there is a woman in Mamelodi that assists. My kids will go and ask for food that side, and she will give pap and sishebo^h for my kids to come and eat. The food will be enough for everyone. She is just someone I know. I once sent my child to the clinic, she met Lerato who explained to her that, "I'm here for my mother, she can't walk and she's in a wheelchair". After hearing that, she came here with Lerato and that's how we became closer.

There are times when there is not enough food in the house, and we only have a little to eat as a family. I don't really count how often it has happened. It has happened, but I don't count. There has been a time

^a Name of area changed

^b Name of hospital changed

^c Grade 10

^d Cosmetic products that are sold by representatives who receive a paid commission from each product that is sold.

^e Pseudonym used

^f A South African dish of white maize meal

^g A retailer in South Africa, selling mostly food items

^h A relish of African descent, here meaning additions to the meal like chicken feet, cabbage, and potatoes

when I did not eat, not because there was no food, but because I struggled to eat due to illness. It happens often that I would like to eat something different or a variety of foods, but circumstances do not allow me to afford them or access them. For example, pap, meat, and vegetables, but because of financial constraints I can't afford them.

The home-based care workers often bring us food, but it is the expired foodⁱ. One is called Lydia, the other one is Thandiwe and Shelton^j. Their car has a bird [logo]. I don't know where they are from. It's a blue bird. They found me, because some ladies came here once, going around taking details and found that I was sick, and they called them for me.

Before I had this disability, I managed to bring food in the house. In order for me to be able to use the stove they have to bring it down on a lower table and I have to get close to it and cook.

Things changed when I was bound to the wheelchair, I would get a bit messed up. My body would be itchy, I couldn't eat, losing weight, diarrhoea, throwing up and not knowing what was going on. I take ARVs^k. To collect the pills at the clinic, sometimes there is someone that goes for me, and, on other occasions, I collect them myself. I would get someone to take me to the clinic and back. At the clinic, they explained to me what food I must eat with the ARVs. They said when I drink cool-drink, I should drink Fanta Orange. When it comes to food, they said that I should eat leafy vegetables, bananas, and apples. Eish^l, I get bananas and apples sometimes after a while.

And then, because I can't go to the toilet by myself, I have to wear a diaper. If it is hot in the house, I can't go outside. Wait, I can go outside, but the problem comes when I have to go back into the house. You may find that because it is hot, the weather could change, and it might rain and there is nobody to help me back into the house. I am able to transfer myself onto the bed, but when I am weak I can't.

I would like to ask, I can't go to the toilet and sometimes I can't control my bladder. I would like to find out what causes this and where will I end up with this condition? The diapers are very expensive. I sometimes spend my money on nappies^m and then there is no money to buy food.

I cannot understand that Dikeledi did not get proper rehabilitation in terms of her bowel and bladder. She was asking why she cannot control her bladder? I explain to her, that “the TB, it affected your spinal cord, which is in your back and the spinal cord has all the nerves that go to the muscles. And nerves also go to the bladder, but if now your TB affected that nerve, then the message can't go to the bladder to control it.” Judith translates, “Your spinal cord has nerves that send messages to the rest of your body. So, there is a nerve in your spinal cord that sends messages to your bladder, the thing that holds your urine. So, the

ⁱ Previously, home-base care services were mostly provided by NGOs and NPOs (non-profit organisations)

^j Pseudonyms used

^k Antiretroviral medication

^l A colloquial term used as an exclamation

^m A South African colloquial term for diapers

nerve cannot send the message to the bladder that you need to go to the toilet now. Do you understand? That's why you don't have control of your bladder.”

At the hospital they give me a catheter. I used it for a long time, but it was hurting me. It was pulling blood [sic] and I have to drink water very often. I went to ask the doctor and they said that I should drink a lot of water. There is a tap outside here, but, you know, drinking water all the time is a problem. But there is no point in not using the diapers, because I still need to use the toilet, which a catheter won't help with. We do not have a toilet; we use a bucket.

I try and explain to her that she should ask the rehab[ilitation] team at the community health centre to make her a commode from a chair with a hole in it and place a bucket underneath. She says she knows the occupational therapist at the community health centre.

We went to the community health centre on Thursday and Tuesday. There is a session with a mat, and we train on the floor. We turn and kneel on our knees on Tuesday. On Thursday we sit on the wheelchairs and train on the wheelchairs. It's after every two weeks. There are people that take me. Sometimes I go with Lerato when they go to school because they go past there. I will then get people, get people I know that I can ask to bring me back home. If I have something to say thank you, then I do. If I don't have money, I tell them that I don't have anything to give them.

Discussion: March 2018

After we visited Dikeledi last year, we were supposed to go back on the day that my phone was stolenⁿ. Unfortunately, we could not get to her. We received mixed messages from Martha^o that Dikeledi had moved to her family's home and, because that was inaccessible, she had moved again. In this time, her phone was also constantly off and we could not reach her. Finally, after persevering, Martha arranged a meeting and we could go and visit her. I had listened to the first interview with Dikeledi again and decided to query specific things that I had questions about and where I was confused about the story she had told me.

On the way, I asked Martha whether we could speak with her first. She had said the previous time that we should interview her, because Dikeledi had told her a different story to what she had told us. However, Martha said that she had spoken to Dikeledi and asked her why she had not told us the truth the last time. She had said that because it was the first time that she was meeting us, she did not feel comfortable to tell us the whole story. But now she feels she will tell us everything.

ⁿ At the beginning of 2018, whilst Judith and I were driving on our way to a clinic, we were following the GPS, which took us on the road going past the dump site. On the way, we were stopped by some people, who then proceeded to steal my cellphone.

^o The community health worker who first introduced us to Dikeledi

We got quite lost along the way and Dikeledi told us to come to the Chinese church, which was a big brick building, and then ask anyone around for where the woman in the wheelchair lives. We finally found the shack^P. It is situated quite high against the mountain, with gravel terrain all around. The shack had a gate that we had to go through and then sheeting under which Dikeledi was sitting, with her wide-brimmed hat on and in her wheelchair. She was in a very happy mood, and it was great to see how approachable she was to us coming.



Image above: Visiting Dikeledi outside her second home with the CHWs

The community health workers (CHWs)^Q got chairs from inside and we sat down and started chatting. I thanked her for seeing us again and asked her to tell us what had happened in the meantime since we last saw her. She had quite a story to tell and it was interesting to hear in what a bad place she had been when we last saw her, compared to how much happier she was now.

^P This is a colloquial term in South Africa for an informal dwelling built mostly from corrugated iron sheets, and often attached to a basic wooden frame

^Q CHWs are employed by Gauteng province to visit households in allocated ward to do screening, health promotion and referral.

Since I last saw you, I had a thought about changing my things. I went home^r since it was December. As I was sitting at home, I thought about the life I had lived there [the place where she previously stayed in Mamelodi] and the way I was when you found me. I thought about how that was not a good life, so I decided not to go back. Then after that, I came here without fighting or doing anything with that person [her ex-boyfrined] and he was shocked and wondering what was going on. I never went back. I only sent people to go fetch my stuff. I took all of my things and left his place.

While we were together, he was also having another girlfriend. He is staying with another woman now. He found me with my children, but he is not the father of them. When I met him, I was still walking with my own feet.

Where I am staying now belongs to someone I met at home in December. He told me he is working, so we can stay here in the meantime, but I am also looking for my own place while I'm here. I heard that my



Image above: The CHWs entering Dikeledi's house

^r Many individuals and households that live in urban and peri-urban areas have rural homesteads, where their family members live. Some of them were also born there. These homesteads and communities are still often referred to as their 'home'. In Dikeledi's case, this is in Maganeng.

house^s is available in Denneboom^t. I heard some people from Denneboom saying they heard my name being called out, so I could come and fetch the key, but I couldn't go. I don't have money. I want to go and get the keys from the office in Denneboom. My house is going to be at [sic] the other side of Mamelodi.

My children are still at their old schools. They have transport that I pay for. It's R350 for the older one and R250 for the younger one^u. They liked my previous boyfriend; the young one says she misses him. But it was such a difficult life. We were always fighting. He was always swearing at me, calling me a bitch that's sitting on a wheelchair, while he knew what he was up to. He stopped buying groceries in the house and I had to use my grant to take care of myself and the kids. He would come, but he would not sleep at home. He would come to check on us and say he's going to watch TV somewhere and not come back. He would sleep at the other woman's house; she stays in Phase 3. He once brought her while I was on the wheelchair. He showed her to me and said that whenever he is not around, I should know that he's with that other woman so I should stop looking for him. I was always stressed while I was staying with him. I think it was more than five years. He sometimes calls me and tells me that I am his woman, and nothing will change that. He says I shouldn't have left, that we could've tried to fix our relationship. I said no and told him about the woman he once brought to my house and how he said I should stop looking for him whenever he's not at home. So, I left him with his woman. The woman is a foreigner and they're dangerous, so I don't want to die and leave my kids to suffer, while I'm already sick.

The home-based care workers still visit me. They were here just the other day. They brought food the other day. I get a disability grant and childcare grants for my two children. I also have to buy nappies and pay for my own transportation, but I don't pay rent here. When I get paid, I go shopping with the kids and buy everything – food and the nappies. Then I use the rest for transport to move around and to go to the doctors. If I ask someone to help me, I pay for their transport and give them some money to thank them. I've got different trips, for physio [physiotherapy]; it's twice each month. And then for medication, it's once a month. And with the doctor, it's sometimes after two months. I spend my money on my children, like transport and food, nappies.

I wouldn't say we lived completely without food. If we had run out of money and there was no maize meal, that was when the children would go and ask Mrs Moroke^v if I had no money to buy it. I wouldn't even eat at all. I didn't like food. I didn't have an appetite [be]cause of how I lived at that place. The reason why we ran out of food was because my boyfriend would not buy any, but he would come and eat the food. I couldn't tell him no or hide the food because it was his house. He's working as a plumber halfway

^s Here she is referring to her RDP house that had apparently been allocated to her at that stage. Later, we were made aware that this was not the case, and that she was still on the waiting list.

^t Denneboom municipal offices manage various services for Mamelodi

^u These are the monthly costs for transport

^v Pseudonym used

[to] Joburg^w. He would also prepare food for his lunch box. He went shopping with me and we would buy everything we needed together. But he was not contributing his own money. What happened with the money, we would buy some certain food that will last at least half or towards month-end then he'll come and use the food and it will finish before... earlier.

Now this place [where she is currently living], my expenses are more because of transport, but the owner of this place stays here with us and he is working so he helps us sometimes. He helps us get food. He is my boyfriend. But I'm looking for my own place to stay. I'm relaxed, but I don't know him well. What if he changes on me like the last guy, where will I go? I want my children to be okay. I don't want to continue exposing them to these lifestyles. Whenever I get a boyfriend, we move in together and start living together as a family. My children get along with this man, they even gained weight. But, it's still early days, so I wouldn't know if things will change. Just like my last boyfriend, we were fine, but things changed. He changed when I had to go into the wheelchair. This man is accepting the wheelchair just fine. He even wants to take me to church where they can heal me. It's a church we saw on Tshwane TV in Hammans kraal^x.



Image above: A view of the washing machine and water containers [since there is no running water]

^w A colloquial term for Johannesburg

^x A semi-rural community in the greater City of Tshwane metropole

My kids are enjoying school. They get food from the feeding scheme at school. For Naledi, I pay a once-off fee. Naledi goes to primary school. In her class there are about 40 [learners].

Lerato was transferred to a school for kids with special needs and she takes classes in cooking, welding, and hospitality. They also bake and do a lot of handwork. It's called prevocational. She has been going there for two years.



Image above: The inside of the one-roomed shack – this image showing the bed where they are sleeping

In Maganeng, my one boyfriend is the father of Lerato. Then I came to Mamelodi with one child. Then I met Naledi's father. My previous boyfriend got me from Naledi's father. He knew that he [I] was with Naledi's father, but he still took him from me [from him]. Naledi's father was ill-treating me, so I left him for the other guy. Naledi was only a year and a few months old. I don't know which partner gave me HIV. But the one I was staying with previously was drinking [ARVs], so we were both drinking the ARVs medication. I think he's the one who gave me [HIV].

In 2012, I started getting sick. My ex-boyfriend called my family to come and fetch me. They took me home from Pretoria; when I got home, I went to the hospital in Sekhutlong^y. I was told at the hospital that

^y Pseudonym used



Image above: The bedroom area, seen in the previous picture, is separated from the rest of the house by a curtain



Image above: A view of the other side of the one-bedroomed shack, showing the living area

I had TB spinal [sic]. I can't remember how long I was in the hospital. I stayed there for a long time. I stayed very long. There they just helped me with exercises. They would sometimes take me into a room with a bed and they would exercise me on the bed. They discharged me without a wheelchair. I couldn't walk. They discharged me with a catheter. Then I went back to Maganeng. Then, the man I was staying with came to fetch me from Maganeng. They carried me. Here in Mamelodi, I met Martha. I can't remember how long it was.

Martha applied for me to get a wheelchair at the clinic in 2014 when she started working with me. It took just a month to get the wheelchair. I learned how to use a wheelchair when I started with physiotherapy here at the community health centre. In 2014 I was taking TB treatment; after that it became TB plus HIV and that's when I found out. They realised that there were no changes after I had completed the treatment for TB spinal. So that's when they tested me and told me I had HIV.

I have a wheelchair cushion. I can feel but I can't move. When I came to Mamelodi I was still using a catheter, but then I started getting pain with the catheter. I was using nappies for number two and the catheter for the urine. They didn't teach me a bowel routine at the hospital.

I applied for the disability grant in 2014 when I came back from Maganeng. My boyfriend at the time used my disability grant money because he wasn't working. We did not struggle to get food because my boyfriend was selling fruit and vegetables until he got a job. At some point he started working. I don't know when he got the other girlfriend. He hid her, so I didn't know. Then I later found out. I found out last year that he once told me he was going to work while he was going to the other girlfriend, and I didn't know. Then I bumped into him coming from her while I was going to a meeting at Lerato's school while I thought he was at work.

The nappies are too expensive for me. Martha used to bring me nappies when we first met. She was then with an organisation that offered nappies before she moved to the clinic². But they've stopped now. That's how it is. I also buy food, pay for the children's transportation and their hair. I buy food when I get paid and as time goes, we will run out of food. With the little money that I sometimes have left, I then buy nappies instead of food and that's when I'd send the kids to go and ask for food. I get enough food during some months and not always. I buy in bulk or buy large portions. The neighbours, they always give, but we don't ask on a monthly basis. They give just a little bit. If you ask for cooking oil, they'll give you a little bit.

² As part of a restructuring plan, the CHWs from NGOs and NPOs were absorbed into the public health system by Gauteng Province

It is very difficult to get to the bottom of her food insecurity. When Dikeledi answers the questions to the General Household Survey (GHS)^{aa}, she gives different answers. It seems as if she feels that there is enough food for them, but when you probe deeper, it does not sound that way.

Martha tried to assist by explaining, “There was this time when she couldn’t afford to buy food, like the time when she was not getting the grant money, so I referred her to social workers so she could get food parcels. After getting her grant money they stopped giving her food parcels, so they could help others who had no income.” I think perhaps I am trying to force her to say that she doesn’t have enough food – but the reason she is not saying that is because of the pride that she has in being able to care for her children. It is more important to say that she does have food and that her children are not going hungry, than for her to say she needs food. Also, were it not for the food parcels that she was receiving from social services, she would have been food insecure. Were it not for the neighbour, she would not have had enough food. And then again, there is the reduced quality of food, variety, and nutrition security. So when Martha first met her through the organisation she previously worked for, she provided her with food parcels, nappies and organised the wheelchair from the clinic. The reason why Martha had said she was food insecure, is because she was depending on the support from the centres.

Judith came in here and tried to explain an important concept to me, “The understanding of communities, the amount that we’re talking about and the little that they’re having, the mentality they’re thinking it’s okay to live with that because they’ve never been outside this world^{bb}. They’re thinking that whatever we’re getting, this little bit that we’re getting it’s okay for me. It’s something that’s enough for themselves. They haven’t understood that you’re entitled to eat various food. They’re eating pap with that or having a certain amount that you’re having. The mentality in this certain type of environment [is] it’s okay to have that. So, she’s saying it’s fine, she cannot complain, it’s better than not having at all, according to my understanding, because she’s receiving money, there is Judith who’s not working, doesn’t get anything so I’m better than Judith. It’s better than nothing. That’s the mentality in the community.”

Martha also explained that when she was working for the non-profit organisation [NPO]^{cc}, it was easier to assist the clients, because everything was there. They could refer quicker, and the response was quicker. As Judith elaborates, “because they were working under an NPO before they can be placed at a government institution at the clinic, it was easier to pick up problems in the households because the NPOs, they are easy to access the clients than there. There they’ve got their own procedure of allocating clients and all that. For her it was easier. They would come and bathe her and give her toiletries, food if there’s no food in the house. They’ll note today that there’s no food, tomorrow she’ll get food so they would help instantly instead of the clinic. [With] [t]he clinic you have to go through the procedure. If you need

^{aa} The GHS is used in South Africa to identify progress of development and where service delivery gaps exist. It includes questions on household food insecurity and hunger. These questions have changed over the years.

^{bb} Meaning they have never been exposed to a different worldview or a different environment

^{cc} As previously noted, CHWs worked for NGOs and NPOs, before being absorbed into DOH

nappies, you have to apply for them whereas [with] the NPO, they're always there. They just get nappies, then tomorrow they take nappies for them. So, they would rather save the little bit [of] money that they have because the nappies they'll ask [for] today and tomorrow they'll get [them]. Now, before they get nappies they have to apply, take time until they use the last cent that they have. So they'll provide everything even toiletries, Savlons^{dd} [sic], everything and even the services to come and help bathe them. What she's trying to say is NPOs versus the clinics, there's a huge difference in terms of reaching out to the clients." It seems that there has been a significant change in the way that the community is serviced by moving from the NPO to government^{ee}. Martha states that "Now we use gadgets, according to the household registrations each health worker must reach 250 houses, so you don't give special attention to one person." Judith also explains, "While they were at the NPO, they would also encourage them to stand up on their feet, like when they get to their house and find that she's still in bed, feeling maybe depressed or whatsoever, they would just encourage her, help her bathe, give her medication, eat and motivate her so those are the services that used to because they were direct observation treatment. They were observing directly going straight to the houses and seeing them and do this and that for them. So in the clinic, it's different, the services are different because they have to go according to the policy of the clinic, which takes time for their reach."

In the beginning, when Martha was still working for the NPO, sometimes she came here, and I was lying in bed and I didn't want to get up. I was sad and down. It was at the time when I was still weak and had no strength, so they would come in the morning and help me get up. They would make my bed, clean the house, hang my blankets to dry and open the windows. This is when I was on TB treatment, not ARVs. These days I can push myself and go out on my own. I've accepted my disability. Because even nowadays I can be able to walk^{ff} alone and independent. Not around here, because of the concrete the wheelchair gets stuck, but in places where I can, I do move around on my own. I get to the other areas by taxi. The guy who lives next door is a taxi driver, so if I want to go somewhere like the community health centre for physio or the clinic, I ask him to take me there and he drops me off at the robots and I'm able to push myself from there. Sometimes I pay him, but at other times he tells me not to.

What seems to have deepened Dikeledi's depression was the change in Martha's responsibilities when she moved from the NPO to DOH. Martha says, "I once felt, somehow, because I had worked with Dikeledi for a long time, so when I was moved to the clinic, she stopped confiding in me, and she would cry whenever she saw me. She felt like I had abandoned her. She didn't want to confide in me anymore. When I explained to her that I was no longer at the NPO, she was sad and felt like I had just dumped her."

^{dd} An antiseptic soap

^{ee} Home-based care workers absorbed into the DOH system as CHWs, no longer provide home-based care services.

^{ff} Even though Dikeledi uses a wheelchair, she would frequently describe her movements as "walking"

I would cry whenever I saw [Martha] and didn't even wanna [sic] talk to her. I was angry at her. Because I would see that she was still working, but she had stopped coming to my house. I used to go to her house still, to confide in her and share my problems with her. She'd tell me that she no longer worked for the NPO.

I continued trying to ask when exactly the periods of transient food insecurity were. Because Dikeledi agreed there were times when she had food, and other times she didn't. But she was unable to clarify when this was. Then Martha explained, "When I met Dikeledi, the boyfriend had [a] food market, so they would depend on that food market money. Sometimes they would get enough, sometimes they don't [sic] get enough. And because of that I could realise that sometimes they have, sometimes they don't have looking at what they are getting from the vegetable garden. I then intervened as someone who shares with her and works with her; I got the food parcels for her to close that gap when there's not enough from that market. She doesn't understand you. She got [sic] food, but it was not enough, sometimes it would go off. That is the reason why we brought food parcels. But, when I left the NPO, Dikeledi was doing okay. She had applied for both [the] child support grant and her disability grant. Her boyfriend had found some odd jobs.

Let me tell you why I struggle to remember some things. That's because when I got sick, I suffered a minor mental illness, so that's why I sometimes can't remember details about when things happened.

On the way back, I question Judith about our interview. She feels that there is something going on, because she asks, "Why would Dikeledi be jumping from one man to the next within very short periods of time?" She was together with her husband, and then her boyfriend took her away from the husband. And when she left her previous boyfriend in December, then she had a new boyfriend either in December or January when she was in Maganeng. She says that she wants to move out from this man's house again and live on her own – and when I probed whether she would feel that she will be able to survive on her own, she says yes. But I am not so sure she really believes this.

Discussion: March 2018

It is flooding in Mamelodi. We went to see Dikeledi for another follow-up interview, and she had moved again. I could not believe it and wondered what had happened. She told us where to drive and then someone would meet us and direct us the rest of the way. A girl eventually came to the car, and she joined us and directed us. We soon find out that she is Dikeledi's daughter. We get onto a dirt road; the road becomes more and more bumpy and inaccessible. Eventually I say I cannot drive further. Judith goes inside one of the houses there and asks whether we can park our car in their yard. They agree, and we proceed on foot, armed with our umbrellas.



Image above: The road to Dikeledi's house



Image above: Arriving at Dikeledi's house

We get to a small little shack and the daughter struggles to open the corrugated iron door to let us in. What we see inside completely throws me off. Her belongings are all packed on the one side covered by a piece of cloth. She and her other daughter are sitting on a blanket on the ground (there is no floor). There is a wheelchair on the one end, and some grass that doesn't completely cover the ground, which is slowly turning to mud.



Image above: Inside the house

I moved from that house because that man is not treating us well, so we had to come here. And I gave the ladies the money to put cement for me on the floor, but they didn't put cement. From Monday, I gave the money on Monday. I told them that I am well settled where I was staying, and they knew that I was not living well. I moved yesterday. This is all my stuff. They said they will organise a toilet for me, but I should find someone to dig a hole for me. The lady who I bought the shack from said that. I bought it for R3500, but I gave her R1500. She asked for monthly instalments of R500 each time I get paid. I am still searching for one who will dig the hole [for the pit latrine] for me.

[On] Monday, the man [her previous boyfriend] didn't go to work. I left with the kids in the morning, because I thought he chose not to go to work just for me. I asked myself what he wanted to do to me, because I know that he is troublesome. So, I left with the kids. "Let's go Lerato." My daughter pushed me before she left for school. I waited at the preschool, waited for a while, they even dished up for me. After school, when they came back from school, the kids fetched me where they left [me] at the crèche, just on the road. I went back with them and found him there, and I didn't say a word. The following day, as he left for work, on Tuesday, he kindly said his goodbyes and he left for work. When he came back from work, he greeted us and after greeting us he sat still without saying anything. When we went to sleep, he made it difficult for us to sleep. He spread himself onto the bed and gave me little space to sleep on. You could tell that something was wrong. He then placed his elbow and placed it on top of my head. And when I

spoke out, he swore at me, “Voetsek^{gg}”. When he woke up the following morning. He didn’t talk to us, no salutations whatsoever, he just left. He left without saying goodbye. I then said to my children, “Can you see the kind of life we are living, we don’t know what this person thinks. As you can see, he is sober, and he normally acts like this when he is drunk, but this time he is not drunk.” So, because I realised that we are struggling, I decide [sic] that since the shack is already installed, let me go with my kids and stay in that shack even though it’s not complete, let us go. I left with this child as she pushed me on the wheelchair as I was searching for a bakkie owner to help me out. So, I found Ntuthwana^{hh}. He got a van to come take my things while the man was away. When I enquired more about Ntuthwana, I was fortunate to know that he is from the same place where I grew up. That’s when he agreed to come help us around 2pm because he was still washing his car. He never came through [at] the stated time and so I sent the children to collect him, and they found him bathing. Soonest he was done, they came back with him. Then he came to collect these things; he did two trips. I had promised him R100, but when he left, he never made mention of it, he just left.

I would take note or record everything he [the previous boyfriend] did when he was drunk. Everything, even when he would call me by names, saying that he picked [me] up from the dirt in my wheelchair and I will die in his place. The neighbours would come and reprimand him. He once pulled me from the chair when he was drunk. Then I screamed my child’s name., “Lerato!” Lerato, my daughter, she came and picked me up, and she asked him “Why do you hurt my mother?” Then he said, “No your mother fell on her own.” Then my daughter said, “No way, my mother has since been sitting here without falling, but when you come back from drinking, she falls?” Then it was all fights.

I ask whether he ever hurt the children, and Dikeledi says we can ask them.

Naledi says, “He wanted to hit my mother with a chair and as I was trying to help my mother, and I was wearing a neck piece. He pulled it very hard and used it to hit my ear. He was trying to smack me with the neck piece, then he hit my ear and I got a swollen ear. I got swollen for days and he called me names like, “Voetsek wena!” When he was playing with me, he touched me on my private parts and so my sister Lerato asked him “What are you doing to my sister?” Then he strangled my sister and said to her, “You are disrespecting me, nehⁱⁱ, are you telling me all that nonsense?” Then he strangled my sister.

When we asked Lerato what he had done to her, she said that he once slapped her.

I insist that Dikeledi goes to the police.

He doesn’t know this place. I have also called him to order and even asked him why does he play with my child by touching her vaginal area. So, he went and called his sister[s]; bear in mind that we once had a

^{gg} A rude Afrikaans word used as an exclamation of dismissal or rejection.

^{hh} Pseudonym used

ⁱⁱ A slang word meaning “isn’t that so?” It is often used in a dismissive sense.

fight, and with our endless fights, they called his sisters. They came on the 4th, on a Sunday – the eldest and the youngest one. One is Tsholanang and the other one is Itumeleng^{jj}. When he called them, they found me bathing in preparation to go to church. As soon as I was done bathing, my kids had given them chairs to sit outside. I found them sitting there and they told me that “We are this guy’s sisters, we came to sort out your feud, because apparently you guys are fighting.” As well as the fact that he had told the neighbours that he doesn’t want me anymore and he wanted to kick me out of the house.

Then I explained to them what the man was doing and so they asked, “What kind of a man takes a woman who is on a wheelchair?” Then they said, come Good Friday, he must pack all my belongings and take me home. So, when I asked about my kids since they schooled here, what will happen? They responded by saying its none of their business. What should they do?

When I tried to explain that he touches this child’s private parts when he plays with her when he is drunk, and so when we reprimand him, they say, “Not our brother, we have kids the same age as this one and he never touched their private parts; no ways, not our brother. You all just want to get him jailed so that you can get his stand [as] soon as he’s jailed.” And then they said there is no such a thing. And so, I responded by saying, “Okay, because that’s what he does, and you disagree with what am saying. Soonest he starts doing that I will tell my child to videotape him so that you have proof of what we say”. So, they told him [the brother], “You have heard that they want to take you a video and take it to the police to get arrested”.

That’s when my people from church called me, because I am a church goer, but I didn’t know where the church was located and Church starts at 10[am], so they called and asked me to [sic] where I was, and I kept saying, “I am on my way, I am on my way”. Then I left them there and their brother gave them each ten rands to leave, but before he had bought cold drink for them. They drank and left, but before they left they came into the house to check out my things, my machine, a fridge, and all that. And they asked my daughter, “Does this belong to your mother?” Lerato was annoyed and started telling them that, “It’s my mother’s, this one we found it here, this table was found here”. Then they all left because I had already went [sic] to church. So now the sister called me to check if I had left or not and I didn’t answer, I just looked at it written, I didn’t answer. I just look [sic] at it and think to myself, “What do they want, they said he must take me home”.

Now, I don’t have money. The money I had was for Lerato’s taxi fare, just for her to go to school, after school she walks back and its far. She used to travel by special transport [arranged transport] but then I cancelled it, because it brought her home very late, around 6pm, and also took her at 6am. I used to pay R350. The one using transport is this one [Naledi]; its R250. If it was not raining, she would be dressed by now so she can wait by the road for them to see her and pick her up. I do have the number of the taxi

^{jj} Pseudonyms used

driver. When I call it, the line does not go through. I don't know his name, because I saved it as 'Driver'. When they take them to school, they use that one that's like a half truck, right? And when they come back, they use [a] Quantum^{kk}. They used to collect her at around 7[am] but now, because there is this other little girl that goes to school with as well, so past 7 it would pass here. Lerato walks back. She leaves school at 3pm and sometimes comes back around 4, 5pm.

I see that there is schoolwork that Naledi is working on, so I ask whether she can share it with me.

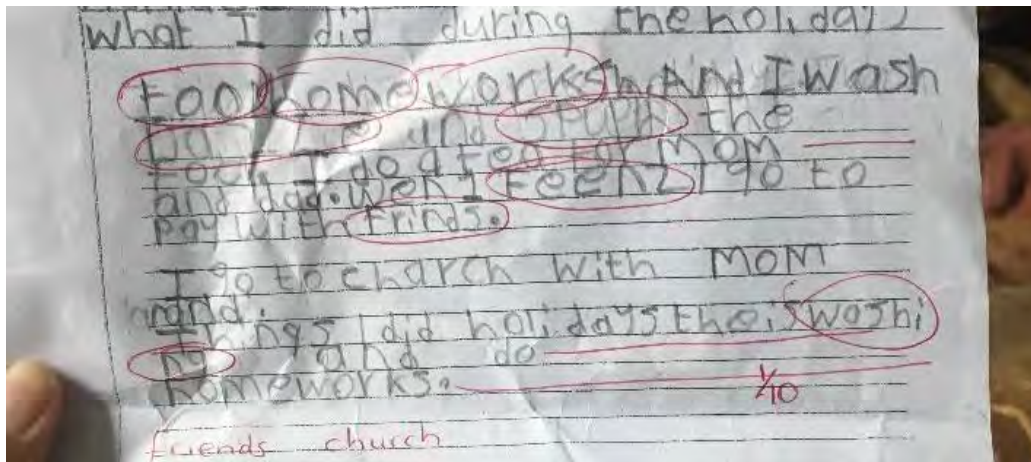


Image above: The first demonstration of Naledi's schoolwork

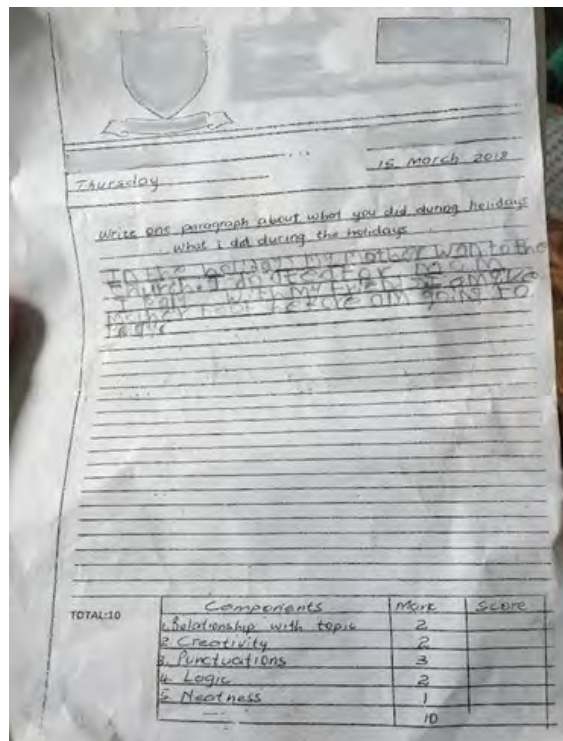


Image above: The second corrected version of her story

^{kk} This refers to a Toyota Quantum, which is normally used as a minibus van as a taxi in South Africa.

The teacher has asked Naledi¹¹ to write about her December holidays whilst she was in Maganeng. There seem to be two versions of the same homework. The second version is the corrected version. She says she loves her teacher, and there are about 40 children in her class. I am concerned about the effect of her circumstances on her development and her schoolwork. I wonder whether the teachers know about their situation. There must be more children like Naledi. Where does one even start? We engage a little about the things that she is learning – she is excited to share them with me. Then Lerato and I discuss her school. Lerato says she has been at her new [prevocational] school for two years already.

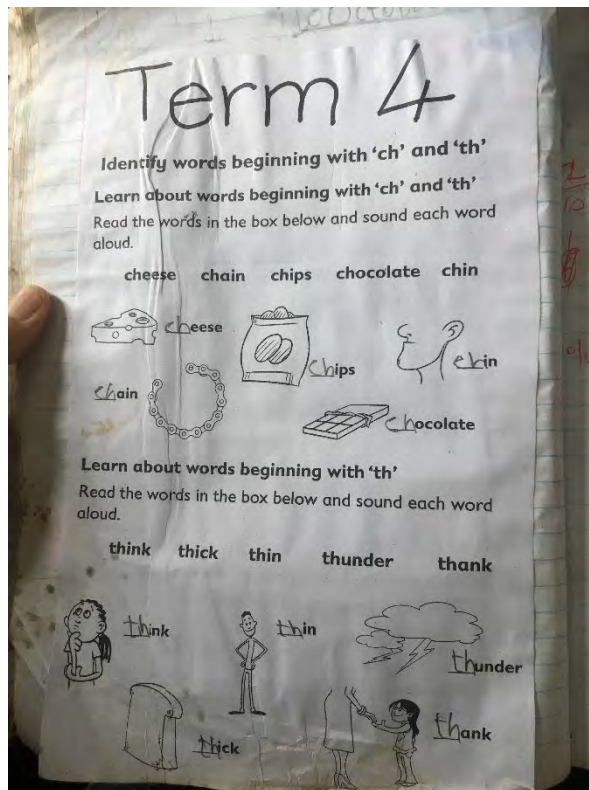


Image above: Another page from Naledi's schoolwork

Dikeledi explains to Judith that she would like me to listen to a recording that she took of her ex-boyfriend talking to her. It is in Sepedi, so I don't understand. Judith explains what it said, "that he doesn't want her anymore, she must go back, she must go. And I found her in Mamelodi and not in a village. Then the daughter says, but you found my mommy in Maganeng; you brought her here and she went back home, and you brought her back. Now the neighbours are intervening asking him why you are chasing her and all that. But the tone of his voice is abusive."

He [her ex-boyfriend] lied saying he found me with men and not at home. The people who brought me here are worried about me. They say that this place is dangerous for me because it's close to the river and

¹¹ Naledi is in primary school

it's not at all good for me at all [sic]. It is next to the dam and floods are a common thing here. They say it is not okay for me. My wheelchair mobility is also a concern for most of them.

My aunt's daughter, this other child that we used to stay with, is coming to see our new place. I want her to come clean the yard for us; not sure if she will be able to. I am still waiting for the RDP^{mm} house. I last went on the 1st [of the month] and they said I'm on the waiting list. They also said they don't know to [sic] when they will be issued. They said they will call me. So, I decided to buy the shack. Even this stand was sold to me. Because they say its R1500, but I paid R500. The shack is R3500, and the stand is R1500. The person that helped me to search for these stands is the lady that works at the crèche. She helped me find someone by the name Raymond. He is the guy that sells these stands. He came and took me to where they sell shacks. He told me to pay R1000 as deposit for them to start building the shack and that I should give him R500. So, I am going to slowly pay it, I am just waiting to get paid and buy a bed or even a sponge [mattress]. Because the cements guys [sic] are wasting my time, because I gave them money and the cements [sic] are available. I don't know why they are taking their time. They bought two bags of cement, I gave them R200 to buy cements [sic]. I think I will just buy [a] plastic flooring product. I am only going to use it for now so that I don't stay in a place full of grass. I am still waiting to get paid [receive her grant money].

At the moment we ate bread and tinned fish and atcharⁿⁿ. I have one of the stoves that uses paraffin [primus stove], but I am not sure if there is paraffin. I have rice, I don't have maize. We will cook it, get soup, and then eat. We don't have a lot of food; things like maize meal we don't have. We are going to eat rice with soya mince soup until my grant money comes. We also have oats and bread; these kids eat it, I don't. I prefer it with milk, unlike when it's just plain. We [are] not sure how we will charge our phones, we just came here yesterday. This person calls and then hangs up. Things will be better soon.

I still have nappies, but the complex is closed; they are on strike. So, if I need them, where will I get them, because these other places are not cheap. There are no bucket toilets on the road. We brought some water with yesterday. The children wash their clothes every day when they come back [from school]. They only have one shirt; they wash it and it dries up quickly. At school they want money to finish paying for the uniform. They wrote us a receipt and it says R560. They took uniform on credit, and now they wrote a letter that she must bring the money. There is this other lady that understood that I am poor and said why wasn't my daughter adopted by other teachers at school?^{oo} I don't know why they didn't, I am surprised that they didn't do this with my daughter.

^{mm} This refers to a Reconstruction and Development Programme (RDP) house. RDP houses are provided free of charge by the government to beneficiaries.

ⁿⁿ This is a cold, spicy sauce, commonly made from fruit or vegetables

^{oo} There are several teachers at the school that will take care of children that require additional financial assistance, and provide them with basic items [for example food and clothing]

Naledi says that there is a principal who is always telling the children that they need the money to buy uniform for the children. I try and encourage Dikeledi to meet her neighbours, so that they can support her. Her aunt's daughter who was on her way has apparently gotten lost and they do not know where she is.

I am just stunned and unable to think about what to do... I tell Dikeledi that the important thing is for her to settle down and figure out who her neighbours are, so that they can support her. We also advise that



Image above: A section of the road to Dikeledi's house has been washed away

she goes to the police. Judith queries whether Lerato is fetching Dikeledi's aunt's daughter, but, apparently, she got lost and they do not know where she is.



Images above: The roads are chaos as I leave Mamelodi, with bridges washed away and everyone driving to get where the need to be



Images above: Since there is no proper drainage system, when it floods in Mamelodi, there are large gullies formed by the eroding water

Reflexive note: March 2018

I go home, traumatised and immobilised. I message my supervisor, who responds with “F***!!! What a life”. Yes, exactly – that is how I feel too. My husband is very much action focused – what am I going to do. He motions to a piece of plastic and says that even this would help her, because she could put it on the floor and at least have something to protect her from the cold.

I contact people in the evening to try and get some advice. The one lady says she will put it on their community forum WhatsApp group. The other one debates with me the complexity of personal versus community intervention. Where are the limits of what I’m supposed to be doing here? I cannot move her into a house and pay rent for a month if that’s not sustainable. She will probably lose her deposit and the money she has already invested into the shack. But why spend more money on something like that, putting in a floor and building a toilet, when it is completely inappropriate for her. She said yesterday, “it’s going to be okay.” Really? Where do you get the optimism from? How can you keep that in the face of the challenges?

I think about the lessons that Naledi is learning from term four – identify words starting with ‘ch’ and ‘th’ and the words include “cheese, chips, chocolate”. What does it mean for a child who is unable to have these treats to have them as the words that she needs to learn from; what would this say for those who cannot afford these luxuries to have to see what they are missing out on?

Eventually I go to bed with no real answers. My supervisor says, yes, I must intervene. Judith is brainstorming. It will have to wait until morning. Judith says we will pray about it and hopefully have more clarity then.

Reflexive Note: March 2018

It's the next morning. It's still raining. I'm on the internet, calling people, asking around and not really getting anywhere. And all this time Dikeledi is sitting probably on the ever-increasing muddy ground, just sitting. I'm not sure if her children will be with her again, because I can't imagine that their school clothes got dry in this wet weather.

The people I'm speaking to seem to think that this is just another case. One that they have heard so often, and that will just go in the line of more people that need intervention when there really isn't anything sustainable to do. I need to phone back. They're not in their office. No, they're not going into Mamelodi today. The occupational therapist from the local clinic tells me that there are going to be many people in Dikeledi's situation today. They will probably gather in community halls. I am frustrated, because Dikeledi is not just another person. She has just fled her boyfriend, she is a wheelchair user, and how is she supposed to get to a community hall when the terrain is inaccessible?

I chat to Judith who is completely distraught. She didn't even leave Mamelodi last night. She stayed with her uncle. She called Dikeledi at night to see how they were doing, because it continued to rain. Dikeledi told Judith that the water was coming through the shack. So throughout the night Judith tried to get help. She phoned the local police, and they responded that they cannot help if no one is in danger of drowning. If the water is just coming in, they should stay in a safe place, considering the police cars cannot get there. Judith then called the fire station, but they said that the whole area was flooding and they were rescuing people and were understaffed. She tried anyone she could think of to try and do something for Dikeledi. I admire Judith so much. She doesn't have anything herself, and yet she is so concerned with the plight of others. She said last night that she was thinking of giving her bed to Dikeledi, just so Dikeledi and her girls don't have to sleep on the floor. How would she even get her bed there? And then what would she do? But such is the heart of Judith. Dikeledi's phone is off, so we are going to go through and see her so that we can use our phone to call social services for her again. I hope they will be able to do something. I'm not sure what. But at least we must try.

Discussion: March 2018

When we arrive at Dikeledi's shack, we are grateful that they are still okay, and say to her that we need to discuss her long-term plan. It will be difficult for her to move around in this area, even when the flooding has stopped, because of her wheelchair. We need to try and think of other long-term solutions. I ask her, "Did you think you could make this a permanent home for you or was it just a temporary home?"



Image above: Dikeledi's house on the left, with Judith at the entrance; the area in front of her house is flooded. There are no pit latrines or electricity



Image above: They left their shoes at the entrance, to not bring dirt into the house – however the existing grass mats do not cover all the ground, hence the visible mud.

The reason why I am staying here in the temporary [shack], [is] because I'm still waiting for my house to be allocated. That is the only thing that is holding me. I have been waiting since 2006/2007. But those who applied in 2008 have got their houses. I do not know why I haven't gotten my house yet. They just told me that I'm on the waiting list for Mamelodi.



Image above: Most of their belongings are covered in a curtain

I want to stay in Mamelodi, because I've been staying here for long, and I've been working here for long, [since] the time I was able to walk. I do have friends here, the likes of Reneliwe and others. [Reneliwe is at her house right now.] I have family here, but you know how the families are, they won't agree if I stay with them. My uncle is somewhere in Section 16, others are in Phase 4, others are in Tembisa^{PP}, but they don't care.

I'm not going to go back to Maganeng. It doesn't mean that I don't like Maganeng. The problem is I've got my older brother who is also abusive, especially when he is drunk. He really can be abusive. He even kicked the door and said, "This is my house – you're locking the door on me." [He] break [sic] the door. When I report him to the police, they say they don't discuss with someone who is drunk. The following day when the police come, they can't find him. Both my parents passed on. So, it's my brother and his wife.

^{PP} An area approximately 60km from Mamelodi [a similar name has been used]

This is all my stuff. There is none of it that belongs to my ex-boyfriend that he might come and get it. Everything belongs to me.



Image above: Dikeledi, Naledi and Lerato, keeping themselves warm inside the house.

I try and urge her on, that we need to find a temporary place for her. I say that even if she stays here, she will be spending a lot of money on building a cement floor and a toilet. There is no electricity or running water, and it is very close to the river. I explain that since she has been abused, and since her children have been abused, there are various government facilities available in the meantime that will be available to assist her. An idea is that she and her children are able to live in a temporary place of shelter until we can assist her in sorting out her accommodation. Dikeledi has numerous questions.

Are you saying I must separate with my kids? Where is it? What about the children, where are they going to attend school?

I explain further that she will not be separating from her children. The shelter is in the inner city, and we will be able to find out from the shelter what their recommendations are regarding schooling. Lerato interjects, saying, "My previous school referred me to my school, and they told me I mustn't leave this school until I finish there." I try and explain that we need to find a temporary place where they can stay,

until they find better accommodation in Mamelodi. Judith agrees that there may be an alternative school for Lerato that operates the same way. She continues that their situation is terrible at the moment, and if they stay another day or two, it may not be possible to rescue them from here. Since it is going to continue raining, they will be washed away if they stay here. I ask whether they know anyone that can look after their things. Lerato indicates that someone who works at Naledi's school can assist them, "She is a nice teacher". Judith is wary that those who are hungry will come and steal their things.



Image above: Some of their food was being stored in the washing machine

The number I have is for Mrs Moroke and Lerato says she can keep them for us. [The] problem [is] I'm not sure if she has space. There is someone that she knows that can keep her stuff in the house, but the daughter says she has space, but she doesn't know how big the space is. But she is worried because sometimes the nyaope boys⁹⁹ jump over to steal the stuff. But in that area there is someone I know who has a double garage, but they also kept their stuff in and it is full.

Judith further states, "But if you don't leave today, you won't be able to leave this place tomorrow. There is no car that can pass, roads are terrible. Just you don't have TV, the whole of section 4 [where Dikeledi previously lived] is down. Roads and houses are damaged. Just in front, the road is damaged and divided into two parts. Here we don't know when will the damage be [sic], but it can crack and break while you

⁹⁹ This is a colloquial term for adolescent men or young adult men who are identifiable by their poor personal hygiene, and who use substances. They are often known to resort to stealing in order to purchase substances so sustain their habit.

are sleeping.” Dikeledi and her daughters discuss the situation. Lerato says that it is terrible that the road fell.

It is terrible that it fell. It’s terrible. What must we do?

Dikeledi asks Lerato whether they should call Mrs Moroke to keep their things. Judith elaborates that they could get someone to dismantle the shack and pack the zinc^{rr}, or could they ask someone to stay in the shack temporarily? Dikeledi and Lerato discuss asking Marco^{ss}.

I thought of this guy called Marco, but these kids are not sure if he can come. Our phones are also off, no electricity.

Lerato insists that they try Mrs Moroke first.



Images above: The water containers inside their house

Even now we are getting wet where we are sleeping. It is soaking wet.

^{rr} Corrugated iron

^{ss} Pseudonym used

I explain that it is not good for her to be wet, especially since she is using nappies, and if she cannot change the nappies, then this will be dangerous for her skin. Lerato agrees that it is not safe to stay, because her mother “can’t even run”. Judith says she will call the CHW manager at the community health centre to see whether there is a locally available place of safety. After Judith spoke with her, she says that she is going to be calling around to see what can be done. We try to call Martha, however, she is not answering. Judith decides to call her friend to get the number of the ward councillor of this area. Judith asks what the year was that Dikeledi received help from councillor Thapelo.

I didn’t ask help, is like when they enter house to house when we in these situation [sic] at my ex-boyfriend house. They were checking if we were not affected by floods. They entered and found that we were affected [by the situation], but they didn’t do anything.

Judith tries to convince her to give the councillor a final chance. I agree and say that this time it is not just her, but we are all working together to try and help her. There are more of us; this time it is the CHW manager, Martha, the OT from the clinic, Judith and me. We can lobby together, and if they do not do anything, then we can go to the newspapers. Judith explains that we will work as a team, since the councillor has said he will push the process.

If that’s the case, it is ok. But Lerato wants to stay here.

Judith explains that, at her age of 17, she cannot stay there alone, it is not safe.

Let us try Mrs Moroke. We cannot ask the neighbours; we don’t know them; they don’t know us.

Judith asks again, “Maybe we ask neighbours to keep the stuff for them. Nice thing the shack is movable. If we get someone with the yard to erect the shack it will help. You don’t know any male that can sleep over for two days? Because according to the councillor it is a process for today and tomorrow. Probably up to Sunday. Monday we will have [a] way forward.”

Dikeledi is cautious, she does not think that the young man will agree. I ask her what is in the containers, and she explains they are clothes, buckets and basins, electric extensions, and the radio set. We ask whether they know anyone else that will stay there. Besides Marco, Lerato considers Letsha^{tt}. Dikeledi agrees that they should try Letsha. He stays in Phase 2, but they do not have his number.

We don’t know people of Phase 2. Let us try Marco.... Even though, hey, he has stories. He can say this and that.

After numerous telephone calls, we have a way forward. David, Dikeledi’s cousin, has agreed to stay in their shack to look after their belongings. The driver who previously assisted Dikeledi with moving to the current shack will take them to the community hall, which has been set up for those whose houses have

^{tt} Pseudonym used

flooded. The hall is far away and Dikeledi would not be able to get there with her wheelchair and the current conditions of the roads. I give Judith some money for the transport and in case she needs to purchase anything else.



Image above: Some of their available food; the rice was being cooked on the paraffin burner



Image above: Naledi eating rice and tomato sauce



Image above: Leaving Mamelodi again, observing flooding in the various areas

Reflexive note: March 2018

In the afternoon, Judith said she had to go and buy a lock for the door that she would have to get to David, so that he could keep the shack safe. She was going to go through to the community hall to meet the councillor there. The councillor had told her that he would send a local leader to Dikeledi's house, and that she was probably there already.

Moments later, Judith sent me a voice note saying, "This lady called Mamello^{uu} phoned and Martha directed her first to the previous house and she went to the house only to find the boyfriend. And when she got to the boyfriend's house, she said, "We heard you got flooding in the house and we came to rescue you and Dikeledi and all that". Then the boyfriend said, "No we had the flood, but Dikeledi went to the shops. She is coming back". He lied that Dikeledi is staying around, and the lady says the guy started calling Dikeledi's number, but Dikeledi was not picking up. But Martha, by accident, told the local leader, because Martha doesn't know the whole story about her [Dikeledi] running away, she thinks she is still at the

^{uu} Pseudonym used

house. I tried to get hold of Martha the whole morning, [but] she was not picking up. They [the other CHWs] said she [Martha] got a disaster at her house also... But I'm meeting them at half past five, she will tell me the whole story. But she assured me that Dikeledi will be safe taken to the place [community hall] for now, but she will find a [RDP] house. I will update you later on."

That evening, Judith told me she had spoken with the social worker regarding the RDP house and it may be allocated before the end of April. She left them sleeping safe at the community hall and they had received four blankets. There was not any hot water. She would purchase Dikeledi's nappies tomorrow or on Sunday. Judith messaged, "Nappies [are necessary] because the toilets are not wheelchair friendly, so she is going to use nappies for number two also. She [Dikeledi] told me she has more nappies till month end. I tried to ask if they can't help her go toilets, [but] I could not get volunteers. So, I thought they will finish before time as she will have to change regularly."

Judith used the money I gave her, to paid for Dikeledi and her daughters to be transported to the community hall, where many other community members affected by the floods are also staying.

Reflexive note: March 2018

Over the next few days we continue to engage with Dikeledi to ensure that she is taken care of. At the community hall they are provided with food. Judith continues to discuss with the councillor the urgency of allocating the RDP house to Dikeledi and her daughters. After a week, when the rain and flooding had finally subsided, Dikeledi and her daughters had to return to their home. They had asked the councillor to arrange for them to be brought back to their house, and were the only ones left at the community hall for a night. However, the community hall serves as a library, and they wanted to open it again to the community. Eventually Judith arranged for the driver to pick them up again and went to the hall to pay him from her own funds, since Dikeledi said she did not have any money to get back home.

Reflexive Note: April 2018

We are concerned about the children. Judith has gone to the Itsoseng clinic^{vv}, which we heard about from the CHWs. They provide free counselling services. She explained to them about Dikeledi's situation and enquires how they can receive counselling. They inform her that Dikeledi needs to come herself with the daughters, but that there is an extended waiting time. Judith also went to visit Naledi's teacher to try and understand what was going on. Judith told me, "The teacher told me that Naledi seems like a sweet child,

^{vv} The University of Pretoria's Psychology Department was offering psychology services (free of charge) through the Itsoseng clinic to the greater community of Mamelodi [this service has since closed down]

and she is so clever in class, just she is always talking about how her mother is sick and going to die. She says she wishes her mother could get well and work and buy them a big house in Letsatsi^{ww}.”

Discussion: April 2018

I tried my best to make my house look better, but they are going to move me. They showed me another shack around here. They said it's not safe here. Some people placed shacks, but don't stay here and those of us who stay here get affected by the floods, so they are going to move us. It's the same people that placed me here. They said they're going to take that shack because it's not occupied by anyone, and it doesn't have a roof. They're going to bring it here, take mine and put it there. They said they're going to move me with my stuff. They said there's a meeting on the 5th [of the month] and that it'll happen after the 5th. These are cements [sic] I bought, and they said they would put them in the floor for me. I sent the kids to get them. Mzansi^{xx}, he even put in a door for me as you saw the door was falling out. They said I shouldn't do the floor in here but rather go do it at the new place. And then take the one that side and bring it here because we stay here and it's flooding. The owners of those shacks don't stay there.



Image above: Dikeledi and her daughter reorganised the house and separated the area where they sleep with a curtain

Lerato's friend from school came and helped us put everything in here. I used my grant money to buy food and I also bought a bed. I bought nappies too, but I couldn't get enough because they didn't have my size. They were smaller. I bought two packs. One has nine nappies and the other has 10. I didn't write down

^{ww} This is an area in Mamelodi where there are large brick houses where people in a middle- to upper socio-economic status live (by comparison). Colloquially, they are referred to as "fancy people".

^{xx} Pseudonym used

things in the book that I bought. I wrote down the things that are short because we are still short of a lot of things. Even now when schools reopen, I'll be stressing about the kids' lunchboxes.

They'll need some food and pocket money. Like Lerato, she's using a taxi to school these days. I cancelled her transport. I felt it was too expensive for me. I cancel now because of the holidays. I realised that if takes a taxi, it's going to be R150 per month to school for Lerato and then she walks back home with her friends in the afternoon. One way is R10. She walks back home with her friends.

I am concerned. Judith had been in constant communication with the housing department management and the councillor to try and finalise Dikeledi's RDP application. The councillor finally said that they had approved her RDP house, but they could not allocate it. Dikeledi had to send a text message confirming that she would build a ramp to the house, since the house that they had available for her was not wheelchair accessible. Apparently, the government did not have funds to build the ramp, and even though there were going to be houses built that would be wheelchair accessible, they had not yet been built. Dikeledi said, however, that she did not send the message, but she told Judith that she agreed. I tried to explain to her she had to send the message, because that is what they were waiting for to allocate the house to her. She then said that she didn't have airtime, and her daughter didn't have airtime. Finally, she said that she will get some money and buy it. I tried to emphasise that this was all they were waiting for, and that the sooner she did this, the sooner she would be allocated the house.



Image above: Judith sending messages from her cellphone, trying to plan for Dikeledi and her daughters

It wasn't nice for me staying at the community hall. If I get a [RDP] house soon, I will be glad that the hall helped. I'll be happy to get another house. Since I've moved in here, I went to the physio, then I went to Vista^{yy} to get Lerato's results from Itsoseng clinic. I then went to my daughter's school on the same day. Then from the school I went to my uncles in Extension 16. From there I came back home. People would push and help me along the way. I took a taxi from here to Vista, but people pushed me on the way. Lerato had to get tested. It was for her mental wellbeing; it was to check her psychological wellbeing. She was transferred to the special school when she was taken out from her previous school.

They share the report with me and allow me to take photos of it. We had not known that when Judith went to Itsoseng clinic, they had already been there previously for an evaluation. When I looked through the pages, it dawns on me the incredible mismatch between the assessments that occur in a clinic and the lived realities of the households that the children who are referred come from.

Her report gives a different first name than what her mother has been calling her. She was tested on two separate days, and her background information included that she was 17 years old and spoke Northern Sotho. She was referred by the school because of her poor academic performance. The school letter explained that she had problems reading and writing sentences in both English and in her home language, and that she was experiencing problems in Mathematics. I wonder whether the school knows anything about Lerato's circumstances at home and whether they have ever referred her for additional support.

It says in the report that Lerato lives with her mother, stepfather, and sibling. But Dikeledi wasn't married to the previous boyfriend, so I question them about this. Lerato appears concerned. She says, "They asked who I live with at home. They said they wanted the truth. They said I shouldn't lie." And Dikeledi clarifies, that she said 'stepfather' meaning he's not her biological father.

The report continues to explain that she lives in a one-bedroom shack. They explain that her mother is "seriously disabled and immobilised because of illness". I am not sure whether the assessor knew what disability Dikeledi has or the history of her disability. It continues to say, "the family is still awaiting the RDP house that the mother applied for years ago. The mother is reportedly under a lot of pain and frequently hospitalised".

The summary of Lerato's behaviour during the assessment indicates that "she presented herself obediently. She was very cooperative and pleasant to work with. She required the assessments instructions translation from English to Northern Sotho. During the Standard Progressive Matrices assessment (SPM), she remained calm, obedient, and focused. During the Draw a Person [DAP], she seemed to get excited because she has a passion for art and drawing. During the Bender Gestalt II assessments, she was very relaxed. Lerato was obedient during all assessments. She approached the test

^{yy} Mamelodi campus was previously Vista University. When this merged with the University of Pretoria, it became the Mamelodi campus. Many in the community still refer to the campus as "Vista".

in a positive manner and understood instructions. She carried SPM instructions out correctly. She appeared to have no problems with most items, while she struggled with others.”

The report continues to explain the results of the assessments. She scored “extremely low average” on range in the Ravens SPM, which, according to the assessor, contradicted the qualitative observations made during the Draw a Person assessment. The Bender Gestalt II test indicated that she was able to follow instructions in her home language, and she scored high in the perception and motor tests.

The conclusion read: “What was most apparent throughout the testing process was Lerato’s ability to set her personal problems aside and focus at the task by following the assessment instructions. She performed well [high average] on DAP assessments; this may be an indication of how she approaches the challenging tasks at school. The fact that attention, concentration, motivation and short-term memory also play a role in the performance of this test is consistent in what she achieved in Bender. Lerato’s SPM results of low average suggests that she may struggle with a certain degree of insecurity about her academic performance and may even have a low self-esteem when it comes to her own intelligence.”

The recommendations read: “It is recommended that Lerato receive assistance in how she approaches various academic tasks, particularly in relation to following instructions and assessing what must be done before attempting the task. The services of an Educational Psychologist would be a good consideration with regard to this. With regard to her difficulty with associative learning as observed with the SPM results, it is recommended that she see an occupational therapist. A social worker will be referred to assess the family living conditions.”

I feel defeated when reading this report. It seemed so out of context. There are not enough resources to provide individual therapy. There should be family intervention, where everyone’s needs will be considered, as well as the home environment. Dikeledi said this report was about Lerato’s psychological wellbeing. But it does not really say anything about her psychological wellbeing, nor anything about why her self-esteem might have been affected. The report did not express her reality.

When Judith engaged with Lerato, she appeared to not want to go to school, since she wanted to remain at home and care for her mother. However, Dikeledi wanted her children to attend school and to become “better citizens”.

That clinic has lots of professionals. I took this letter to the school. They made copies and gave me this one. She did this last year, but then I got sick and couldn’t take her. So, I had to start again and take her this year. Lerato does Maths, English and skills at her school.

She has a large amount of vegetable oil and we ask her what her she wants to use it for.

With all this oil, she [Lerato] is going to bake. She is going to make vetkoeks^{zz} and pancakes. I had joined a stokvel^{aaa}. I didn't buy the oil. I joined a grocery stokvel and they robbed me and only gave me the two oils. I got them last year.

I also went to see my uncle from my father's side who stays at Sixteen^{bbb}. While I still was staying in Block 2^{ccc}, he used to come and visit me when I was sick. He's a pastor so he would also come and pray for me. But, I didn't contact him when it was raining, because his wife would never agree. Even when I was sick while my mother was still alive, my mother said I should go and stay with them, but his wife didn't want that. The last time when I was there, I was passing by and decided to go in and see him. I found him napping on a chair. He was so happy to see me, he even prayed for me. As soon as his wife arrived, I left. He's an old man. He's a priest of *the pigeon*^{ddd}. It's next to the community health centre. His wife is not a good person. I would like to go to my uncle, and he loves me too — he also wishes to know where I am, and he likes to come to me. He's taking very good care of me. Okay, and then my uncle sent me to the church a while back, because of these papers for the stand. He said, "Dikeledi, my child". And I said, "Uncle?" He said, "I've been telling you to take these house papers and take them to church. So that they can bestow grace upon them. So that your matters can be resolved. Maybe they are under the clutches of something, for it has truly been long."

He was worried, because I was really struggling and he could see something was off. I never found someone to take me, so I never went. So, I said "Uncle, can you not take them there?" And he said, "No, it is necessary that you take them yourself."

The person who was pushing me was a man from Block 12. He was the one who was helping me. I gave him money to buy cool drink. He's not working. He found me on my way from the community health centre. The route from the community health centre is slightly downhill, so I'm able to push myself. At the physio, we exercised with the arms and legs. They said they're taking us on a trip on the 11th. I heard them say FNB stadium. I know a lot of people there already.

It was raining the other day. The water got in and it's wet where Lerato is standing. I suspect it comes from the bottom. My ex-boyfriend hasn't been here. He was calling constantly, asking where I was. I asked him why he wanted to know. He said he wanted to give me money, but I told him I didn't want his money.

^{zz} A fat cake in Afrikaans

^{aaa} This is a investment of savings society, where members who are a part of it, contribute regularly to an agreement amount. At the ed of a certain time (normally at Christmas), they then receive a lump sum payment or a large amount of groceries (depending on what was agreed upon at the beginning).

^{bbb} Referring to the extension / phase / block that he stays in

^{ccc} Mamelodi is divided into sections called extensions, phases or blocks [the real numbers of these have been replaced with others]

^{ddd} The way in which community members refer to the Zionist church, because of the pigeon on the church's badge

I'm not sure, but I think he knows I'm here. I heard he once came while we were still staying at the hall. He was directed here.

I feel okay, but I just want to see myself in my own house. My family has not called for a while. It has been raining and it was shown on TV that a lot of homes in Pretoria were damaged by the floods, but they never bothered to call and ask how I'm doing. The only person who checks on me is my friend called Matshepo^{eee}. We come from the same area back home. She stays in Mamelodi. She's looking for a job.

My friend is Reneliwe^{fff}. Reneliwe was telling me about you. I asked her how she knows you and she said she's trying to find clients for you. I'm stressing, because I don't have enough nappies, there isn't enough food and money for the kids at school. Because I bought so many things like pots, food, candles and the bed. I saw it was important to buy the bed instead of sleeping on the floor, because sometimes when it rains the water gets in from the bottom. There's no floor, so I bought a plastic floor carpet for R100. I bought pots and I didn't have a knife and spoons.

I try and gain clarity into understanding who she has made certain decisions regarding her purchases. We first ask her why she bought a whole bag of spoons.

They are sold in packs at Nizams^{ggg} [in bulk].

I also ask her how she decides on what food she wants to buy. Amongst others, she has purchased cornflakes and yoghurt in small six-pack containers.

Every time when I buy food, I buy cornflakes, oats and Weet-bix^{hhh}. I buy bigger packs so they can last for longer. For lunch we cook rice. We eat twice a day. We eat breakfast and supper, but if they get hungry during the day, I tell them they can have sampⁱⁱⁱ with mayonnaise and tomato sauce.

We ask her whether she purchases fruits and vegetables.

I sent them to go and buy a bag of potatoes yesterday. They came back with a small bag.

The grocery stokvel from last year gave me oils, two bags of flour and two bags of sugar. It wasn't a lot of things. And small tins of fish. Six bottles of tomato sauce. And six jars of mayonnaise. And soup. They are all finished. We ate it all during December. I was paying R250 every month for that. We start paying from February till November. They eat the mayonnaise and tomato sauce all the time. I had put them at some woman's house, and she took one mayonnaise and gave me R15 to buy it. I think they're finished. We took some home. Some they were broken, but they paid me money for them. We shared them while I

^{eee} Pseudonym used

^{fff} Pseudonym used

^{ggg} Nizams is a franchised retail supermarket

^{hhh} Cornflakes, oats and Weet-bix are all traditional South African food eaten at breakfast time

ⁱⁱⁱ A South African dish consisting of dried corn kernels, that have been chopped or pounded until broken

was still staying in Block 2 with the previous boyfriend. So, I kept them at a relative's house. I do talk to them, but they had a fight about shoes the other day and they involved me in their fight. The woman called and apologised while I was staying at the hall. They were fighting about shoes. There's a lady that was renting a room in that house and she knows Lerato as she used to be her teacher. The family has a child that's Lerato's age. She used to give them her old shoes, clothes, and stuff so Lerato chose those shoes that the child also wanted. That girl tried fitting the shoes and then took them and put them in her room. Lerato went to get them, and that girl only realised after we left that Lerato had taken the shoes. Then they called me and swore at me asking why Lerato went into their house and took the shoes without their permission. That's when they told me to come and take the stuff I had kept at their house, so I went to get them. Whilst I was in Maganeng, I kept them in that house. I only took a few home. They gave me two of each, so I took a 10kg bag of rice, some tomato sauce and some tinned fish and left the rest. Now I have two oils, 10kg of brown sugar and flour left, and rice.

They robbed me. That wasn't all of it. You know the December groceries normally come in bulks and not two of each. They didn't even show me the till slips. And when they went to get the groceries, they said they would go with Lerato. The woman who lived next door said she would go with Lerato, but she never did. I woke Lerato early in the morning to go to her house so they could go together, but she found that she had already left, probably around four or five. Then she called to say I should send a child to come to Silverton to get the groceries. I asked how, when she had promised to go with Lerato. Then she called when she was in Kit Kat^{jii} and said "Send your child to Kit Kat. We're here sharing the stuff". Then I said, "How must she come there because you said you were gonna [sic] go with her". Then she brought them herself, since she was the one who collected the money from me, the R250. When she brought them, it was only those few things. I asked where hers was, and she told me her sister took them home. I asked her for the till slip so I could see if we all got the same stuff. I could tell it was too little. I went to the police station and brought the cops who did the calculations in front of that woman and found that I had contributed a total of R2500. Then they went through a list of the things I received and compared it with the money I contributed. They told her it was a serious case and asked her what she was going to do. She said "I agree. I'm not disputing that. I made a mistake. We bought everything in a hurry." The police asked why she left my daughter behind, [be]cause we had agreed she would go with her. They explained to her that I couldn't even see if we all got the same things. They told her she could also see that the stuff I got wasn't worth the money I paid. They told her that was a serious crime and asked her what she was going to [do to] fix it. She said she was unemployed so she didn't have any money, but she would pay the money; that for now I should take the food and that she would pay me back in the following year. She gave me R400 back last month. We went to her house this month, but she wasn't there. They said she went home. When I call her, she doesn't answer. She didn't give me anything in January and February. She told me

^{jii} This is a general cash and carry retail store

she didn't have any money. She sells vetkoeks, bananas and stuff at BP^{kkk}. She had promised to pay me R700 or R500 per month. I was surprised when she only gave me R400. She must pay me back R2500. She's now left with R2100 cause she only gave me R400. That's what she said to the police. She said I could keep the food, it doesn't matter. She said she would pay me back in instalments. That was not my decision. That's what she told the police. I didn't want the food. I told her that I was very heartbroken. I told her to take her stuff and give me back my money. She refused and said she didn't have any money. I could see that I had been robbed. She didn't even have a till slip. This was last year on the 16th of December.

I went to Maganeng on the 17th of December. There was a ceremony at my brother's house in Maganeng on the 16th. There was a huge party for his children, and I couldn't go because of the grocery issue. It was December time, so we were planning to go home either way. My boyfriend had been abusing me all along. When I got home, I decided not to go back to his house. My boyfriend wasn't there for December, and he left without saying goodbye. I just heard that he was on his way to Bushbuckridge^{lll}. I had to take the fridge and the machines to other people's houses to keep them safe. People could easily break in knowing there was no one in the house and steal. When I got back, we went to fetch everything where we left them. The only thing we collected were the clothes that were left at that house. It was Lerato and myself, but I stayed



Image above: One of the shacks next to Dikeledi's house showing a satellite dish for television coverage; a fence around the house and a window

^{kkk} Referring to a petrol / fuel station

^{lll} A large rural informal settlement, close to the Kruger National Park

in the car while she went in. He had changed the locks. We had called him, so he called his girlfriend and the other lady. They have a hair salon, so he called them to let them know we were coming to collect our stuff.

Discussion: April 2018

When we visit Dikeledi again, it is a bright beautiful day. Dikeledi's shack had been moved and she is staying in a new place. This shack was in a better position than the other one and, at least, it now had a floor in it. Dikeledi is doing so much better, and we are so grateful that she has moved to a slightly safer environment.



Image above: Various shacks in the area

I went to the housing department last Thursday and they told me I'm on the waiting list. I was sent by councillor Thapelo^{mmm}. Truth is, I didn't hear what he said. He told me the name, but they said they don't know anyone called Kele and that they know Nkele. Thapelo said Kele. I tried calling councillor Thapelo, but he hung up on me. I think he was busy. Councillor Thapelo said I should send a message, that SMS, to confirm that I will do the ramp. I confirmed that, so I was doing the follow-up wanting to hear the progress from councillor. Thapelo then he said I must go and see them, and then he said I must go on Wednesday. I told him I couldn't go because there was no one to take me. He said I should go on Thursday when I get someone. My problem is that I don't have anyone to take me there. The man who used to take me is in school these days.

We asked Dikeledi about her past relationships.

The other men were not abusive, but they did not treat me well. They were working, but would not take care of me and the kids. They would tell me that the kids are receiving child-support grants and I could make my own money by selling stuff on the street. So, every time I asked for help with the kids they would

^{mmm} Pseudonym used

just tell me that the kids get a grant and I'm also selling things. The last boyfriend I was with came here around eleven at night. He knocked and knocked at night, called my name. "Dikeledi open!" and then I didn't open, I was quiet. My child was trying to, one of my daughters tried to stand up and then I just kept her quiet and then he left. In the morning he came back and then I shouted and screamed at him, and he left. I called the neighbours to help me.

I tried to get to the answer of why she decided to be in a relationship with this past boyfriend. Dikeledi continued.

To be honest I didn't want to be in relationship with him. I wanted him to take care of me and my kids so my kids can go to school. I didn't want to go back to that other guy, because he was abusive. No, to tell the truth, I didn't love him. I just wanted a place to stay while I was at his place. He said we can come and live with him because he loved me, but he could see that I didn't love him and he even told me that he could see that I didn't love him. There were no signs that he would be abusive. I just felt that he wasn't the right man for me. When I was at home in Maganeng I started sleeping with him.

It was not the same with the previous man. We were in love. We had been together for six years. The man before that was Naledi's father. I loved him. Naledi's father was working and getting paid on a fortnight, but he was no longer buying food or taking care of us. I was using the grant money to take care of myself and my children. He was saying my kids are earning grants and I'm getting disability. You have to take care of yourself and all that. Even his sisters supported him and said I should buy food and that he was preparing to marry me. When Naledi was two months old, I went home with her. They said they would come to meet my family, but they never did until I came back [be]cause Lerato was in school. I was staying in Phase 2 with Naledi's father and this one [the next boyfriend] was having a tuck shop that side. I started having a sexual relationship with him while I were [sic] still with Naledi's father.

Before I was disabled, we used to go out together and have fun. It was nice, and he was supportive. After I became disabled, he changed. At first, I didn't see it, but he knew what he was up to. He started taking calls outside or in the toilet and I would hear him talking to a woman. He would ask about their child. They were speaking in Xitsonga and even though I don't know it that well, I could understand what he was saying. Then one Saturday he lied that he was working. I went to a meeting at Lerato's school and bumped into him coming from Phase 3. He started having relationships with other women a long time ago and I only realised it too late when there was even a baby involved.

Our sexual relationship didn't change much from before I was disabled until after I was disabled. We still continued to have a sexual relationship, but his other girlfriends were using mutiⁿⁿⁿ and that affected me badly. I would get sick, and my body would be very sore, and I'd also vomit. I don't understand what the muti was for because he used to bring some to drink, and he would boil it. He told me that he wasn't

ⁿⁿⁿ Traditional medicine, often plant-, mineral-, or animal-based.

feeling well that he was breathing heavily and when he was sleeping, he could feel something choking him. He didn't tell me a lot of things, I just saw puncture marks, like needle marks, like he was coming from a traditional healer, and he had threads^{ooo} that I didn't know. We go to ZCC^{ppp} church, but he was wearing different threads. He didn't go to the doctor to find out what was wrong, he went to the traditional healer.

My previous boyfriend told me that he believes in those things with traditional healers and medicines, but I never saw him taking it. We did not use protection when we were having sex. I don't know if he is HIV positive. I never saw him drinking ARVs. He saw me drinking my ARVs, but we never talked about it. We didn't use protection, because he said he doesn't like it. Just like the one from that other place. He also doesn't like using condoms.

So, I had four relationships. It was Lerato's father, Naledi's father, the one from that place, and this one.

I can feel during sex. But I'm unable to do all the positions. I'm only laying and then the man comes on top. That's because my legs are not working anymore. The boyfriends were satisfied with that. I realised that my boyfriend he was cheating while I was able to walk, but I realised about the cheating after I was in a wheelchair, because he's got a baby that came in before the disability. I don't know why he cheated, but I think it was because of the lady who works at the salon, her name is Jeanette. She calls him uncle. She's the one who finds him girlfriends.

I want to have a relationship now with someone who is going to take care of me. Someone who is going to love me and take care of me with everything. I'm gonna [sic] give back the love that he needs. I won't look for him. They see me when I go out, so he'll find me.

At that community hall, there [were] other men that I was talking with that I'm still in contact with now. They still call me. They have visited me. It's just one. I'm still checking him out to see the kind of person he is. I never had sex with him. Where would I even do it with the kids in here? He says he stays in Donkerhoek^{qqq} and I don't know where that is. He's working, he's a security guard. He came twice and it was in the day. He came with a friend.

When asked what she is looking for in a man, she said the following:

Firstly, if a man drinks alcohol, I think he's a problem. Secondly, I can quickly tell if a man is a liar. That's all. It doesn't matter if he has a job or not, as long as he takes care of me. Even if he's not working, he can still get odd jobs and be able to provide. I mean take care of me with everything like love and everything.

^{ooo} The threads are used by traditional healers

^{ppp} The Zion Christian Church

^{qqq} A farm area close to Mamelodi; name has been changed

In terms of his relationship with my children, just to take care of them and show them that he loves them like he loves me.

Naledi misses the guy from Block 2. I don't. He says he still loves me, but I don't love him. I asked him how, [be]cause he has a girlfriend. Then he says "No, I want you back." He hasn't been here. He doesn't know where we live. I told him not to call anymore. When he calls, he wants to speak to Naledi, because I told him I have nothing to say to him. I told him this is not Naledi's phone, so he should stop calling. He said he'll buy her a phone after Good Friday. He was just lying.



Images above: The new shack has a concrete floor

Sometimes, when I meet men, sometimes they help me out of pity when I'm alone. Like when I go to church, I meet people, and some would give me money. Like when I walk on the street, they'll just help me, push me with the wheelchair or the other one will just take out R20 and give me on the road. Others tell me I'm gonna [sic] get better and that the wheelchair is not suited for me. Some men stop and talk to me. One said to me that if he told me to stand up, I will. He said the wheelchair is not for me. I just laugh, because it's only men who tell me these things. I feel happy and wish I could really stand up if they tell me to stand up.

Now the previous boyfriend, you said that his sisters phoned you and said to you that you're in a wheelchair, you can't do anything and said some really bad things about you being in a wheelchair. How did that make you feel?

It really hurt me, that's why I left his place and moved here before Good Friday. But now he's still after me. He didn't feel like his sisters. He didn't have a problem. He agreed when they told him to take me home for the Easter holidays, but as soon as they left, he said they were crazy and just wanted to break us up.

I wondered why it appeared that Dikeledi's experience was a 'positive' one when it came to being disabled? What made her different from the negative stigma that people with disability often experience?

I don't know. They say that they don't think I'm disabled, that I just sit on the wheelchair. Some say I look like I'm sitting on a chair from a distance. One said he'll marry me and ask his brother to push the wheelchair. I'm not worried that a man might want to be in a relationship because of my disability grant. Most of them don't know that. They think I still need to register to get it. Like the previous boyfriend, he thought I was still in the process of registering for a grant. I did not tell him, because my heart just said I shouldn't. He knew that I was getting grants for my children. He mostly bought mielie meal and sishebo. He didn't buy a lot of things.

Child [support] grant is now R400. It was increased by R20, before it was R380. So Lerato's grant paid for her transport, Naledi's grant paid for her transport, and I was left with R100. Then my grant is R1400 so I was left with R1500 and he bought food and I bought nappies. I also had to pay who helped me. The kids also get their hair done at the salon, even now they did their hair. When I started looking for a place, I moved around a lot. Then I found Raymond and paid a deposit and then went to look for a shack.

I might have taken them to the salon at the beginning of the month, when I had money, then I ran out of money towards the end of the month, and I couldn't buy food. They eat like now [sic] [because] we don't have sishebo because I bought the bed, the pots and stuff. I bought the carpet and the cements. I don't have any money left at the moment. We are eating pap and soup and we're left with four tomatoes. We still have corn flakes and oats, but we don't have milk. I still have plenty of flour. Lerato is lazy to bake. I bought two yeasts, but she's lazy. Because at school they're teaching them how to make some pancakes and all that, but she's lazy to do it. I can do it, but I'm lazy.

What ensued was a confusing conversation about why Dikeledi would not make food when there was food available and she could make vetkoek. Even after much probing, we did not really get to the answer. I asked her, "So you'd rather go hungry than do it?"

As you're talking like that, Naledi was crying yesterday that she ate but she wasn't full because we didn't have enough sishebo.

Judith asked again, “We want to understand that you’re saying you’re lazy, Lerato is lazy to do it but there’s flour, oil, sugar, salt, a stove, and paraffin. Why are you making your other child go hungry?”

I will do it today. I didn’t do it, because I saw that the sun was not out. How was the dough going to rise?

Judith continued probing, “Dikeledi, you don’t need the sun. The purpose of the yeast is to make the dough rise. It sounds like you’re making excuses here. Don’t be embarrassed if you’re lazy. It’s okay.”

But Naledi was crying yesterday. She ate, but it wasn’t enough. Yesterday I felt very bad. I’m just lazy. I don’t even feel hungry. I don’t like eating. If you give me a large portion, I won’t finish it. I’ll leave some. I get full quickly.

I want to ask you Judith. You promised me some nappies and I want them. I’m left with just three. I’m naked right now. But there are some that are like panties. I don’t know where I put them. I think there are two or three left. If I get money, I’ll buy nappies and food. If someone gave me money right now, I would buy nappies.



Image above: The inside of the new shack, with a bucket that is used for washing clothes

Discussion: May 2018



Image above: Dikeledi in her new home

Today Dikeledi got her RDP house. According to her, she has been on the waiting list since 2007. After 14 years, she finally has a new home. After seeing where she lived, and after seeing the destitute situation



Image above: Dikeledi and Judith

she was in, she now has a new home! I can't help but feel slightly disappointed that she didn't inform us. But when we saw her, she had a massive smile on her face, and that was worth a thousand words.

It concerned us that the first thing she said to Judith when we arrived is that she doesn't have money to move in it, because she spent all her money buying a solar system. This was really important to her, to enable her to charge her phone. As a result, she doesn't have money left for transport.

We don't understand the decisions that she is making. I asked her "Do you have enough money for food?" She replies that she has enough food for the rest of the month. She bought enough.

I have another brother who's got taxi's and everything. He's the one with whom I get along quite well. He's already quite elderly. I'd say he's already getting old. He's someone who's always thinking too much, and then he's also got diabetes. But he used to help me often times with many things. And then he also wears spectacles; his eyes bother him. He helps me, not with money, but he might buy me groceries. Not with money itself. You see that time when I used to stay over there in Section 4? He would bring me food, meat. And then, if I was ill, he would take me with his car to the hospital. Then there's my mother's family. I only started to know them here in Pretoria, and then we met up and went home together. When we arrived home, before my mother died, that's when they got to know my mother. They didn't help me the



Image above: Dikeledi at the entrance of her home [note the ramp has not yet been built]

time I came to stay here, because I hadn't even thought about them because I was so stressed. I forgot them.



Image above: The solar system that Dikeledi bought

One of Dikeledi's friends, Siphon, pushed her from Extension 22 to her new home. This is approximately 12 kilometres! He was busy covering the windows with newspaper. I asked him, why. To this he replied, "No, they have to do it, because otherwise people come and steal stuff inside. And they steal the basin, they steal the piping, they steal the tabletop, the sink and everything." I said, "How do you know that they steal it?" "No, no, because he's got people that live here. The newspaper, it's helping because then they can't see inside. But someone must stay there at night from today, [be]cause the most vulnerable time is today and tomorrow if no-one's staying there yet. Because then they can easily vandalise the place." Dikeledi contacted Marco, her friend that previously stayed at the shack, to ask him to come and stay in the house. Judith assisted by explaining the directions. Siphon said that Dikeledi has to move in by Saturday; she cannot wait any longer. He explains that if you're living in the house, then the community won't vandalise. I struggle to understand that the municipality only inserts the taps once the new owners have moved in. Dikeledi still has to build herself a ramp, so she will require money. We were talking about the money that she paid for the shack and the piece of land. She paid R3900 already. I do not know how she accumulated these funds. Unfortunately, she says she will not be able to get it back from them. I ask "What about renting that place, then you can get a steady income from it. How much could you get?" "R250 a month"

I say, “That’s a lot of money, maybe you can get that.” She replies that this is a good idea, she thinks she can do that.

We suggest that Dikeledi writes a letter to thank the municipality for the house. There are some final things that need to get sorted out, for example, she can use the cement that she got previously to build the ramp to the house. Also, she has several wheelchairs that are on the roof at the shack, that she should return to the clinic so that other people can use them. Dikeledi agrees to this.

We discuss God.

Right now I am attending this other charismatic church right here. I go each and every Sunday. Sometimes when I don’t go, they call me and they ask me if I want to go. They come and fetch me with the car and then they bring me back again. It’s now that I begin to see that God is truly there. Beforehand, I just thought that God exists, but why doesn’t He answer me when I cry to Him? I had been crying and praying to Him for a long time — opening the Psalms, and some of them made me cry, the ones that spoke about me in the Bible. But, I didn’t see myself being answered. But, now I can see my matters being [answered]. I go to church with Naledi. The person who avoids church is Lerato. She really doesn’t want to go to church.



Image above: Dikeledi’s street [a number of new houses were built recently in this area]

I don't know why. She just says that she will come, she'll come, but she keeps avoiding it. She may even walk me to the church and turn around at the gate. She often speaks about the apostolic church^{rrr}. That she wants to go to the apostolic church. And the church that she's speaking about is so far away. There in Section 4. And she doesn't go. She just speaks.

Discussion: May 2018

The people who are cleaning outside, I hired them. This one man, I think he's from here, he's one of the people who work around here. And then the other one stays in Block 10. On Friday, he came to drop them here. This is a bit better. My daughters are well. They are happy. They go to school okay, but the only thing that remains is for me to find Lerato's transport. And that place is far, for her to get to school. Sometimes she sleeps there in the shack because she struggles to get to school. I left them with these one [sic] here, Betty and them [the neighbours] to take care of her [sic]. But her teachers said they would help me find transport. And we've already found transport for Naledi.



Image above: Dikeledi selling items in her spaza shop

^{rrr} A Christian denomination

I've met my neighbours. These people here have been here, and the ones who live over there. But these ones don't stay, they just come and go. The people, they are fine. I've missed you.

Sipho helped me with packing. Already when they moved me from down there where I was staying by the water, when I went to live a little more north, he came to help me pack up. I got to know him a long time ago from physio.

I'm selling cigarettes. There they are in the black plastic bag. I started selling them when I was staying up there. When I had just moved north from the place where I was flooded, and then I started selling cigarettes. Here and there are people that know I'm selling, not many. Because I put the chair outside and then put the stuff outside so that people can see. I bought the cigarettes a while back in Marabastad^{sss}. Okay, they vary. The originals, it's three Rands. And then the fake ones, it's one Rands.

I'm still in bed, because it just felt like there was wind outside. I will go out, though. You see when I'm sleeping here, I feel a wind blowing. I think it's windy.

I am amazed at how entrepreneurial Dikeledi is. She has started a shop here at the new house and is selling items. She has also started networking; there is always something new. She is paying someone to do something. But then, on the other hand, she is still in bed late in the morning. It is like there are these two different sides. She wrote a poem, which she shared with us, after we suggested that she write a

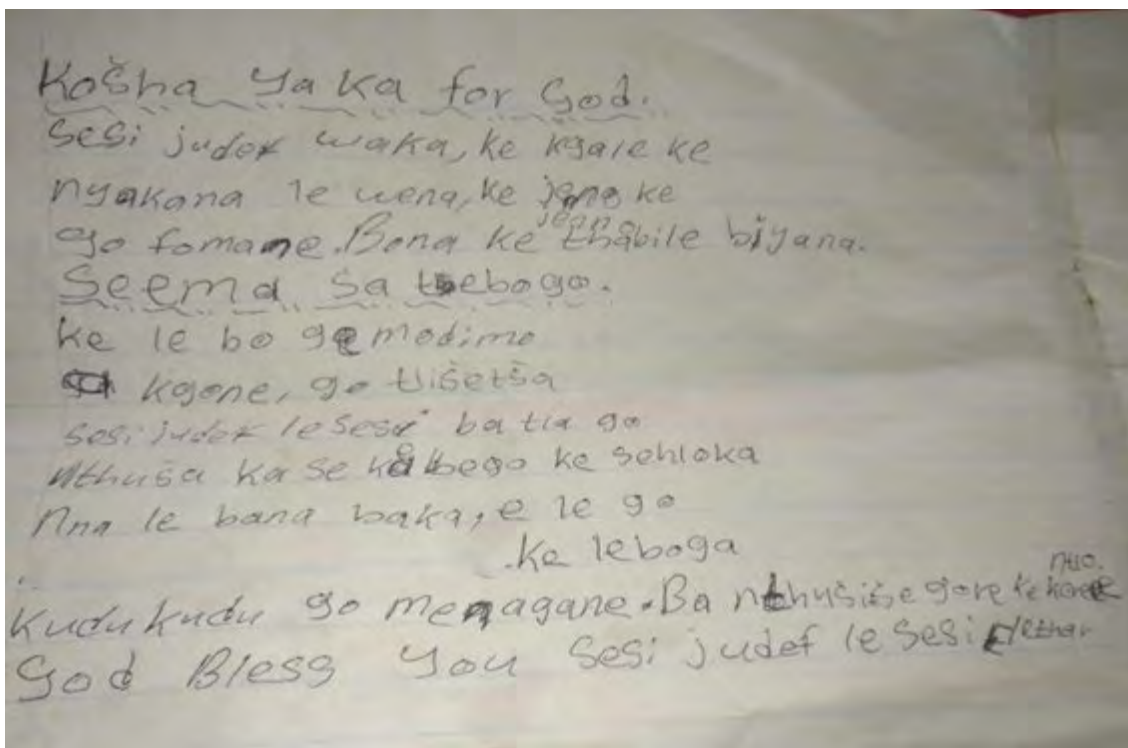


Image above: The poem of thanksgiving that Dikeledi wrote

^{sss} A historic business area in Pretoria, that consist of a variety of retail stores, spaza shops and 'muti' shops.

letter to the municipality to thank them. Instead of thanking the municipality, however, she thanks God, and she thanks us. She always used to call me Nethar. I don't know why.

My song for God

My sister Judif [Judith], it's been long I have looking for you, today I found you. Look how happy am I today.

Song of thanksgiving

I thank God who brought sister Judef [Judith] and other sister by coming to help me with what I was in need of. Me and my kids, Lerato and Naledi. I so much thankful [sic]. They helped me to get a house. God bless you sister Judef [Judith] and sister Nethar [Helga].

Discussion: June 2018

I do not know what to do. We are trying to help Dikeledi, her friends are trying to help her, and it seems that she is burning bridges everywhere. She says she does not want help and it appears that she is being harmful to herself. Judith tried to get hold of her today, but Dikeledi is in the hospital again. Reneliwe was visiting Dikeledi in the hospital. Judith told me, "Reneliwe said Dikeledi was causing very big chaos [sic] in the hospital, wants to leave the hospital, pushing the trolley, the hospital beds and breaking things in the hospital; very angry, wants to leave the hospital with immediate effect. The doctor told me they need to observe her and they will release her tomorrow. But Dikeledi was crying and screaming, saying she wants to be released from hospital. And she insulted Reneliwe in such a way that Reneliwe wants to chase the kids away because I [Judith] called Reneliwe to ask if she cannot keep Dikeledi's kids by her house. Now she says I must come get Dikeledi's kids from her house and she doesn't want to have anything to do with Dikeledi. Dikeledi doesn't appreciate her, and she insults her and she speaks as she wishes to her. It's like she insulted in a way that Reneliwe didn't like it [sic]. She end[ed] up [that] she doesn't want to help Dikeledi anymore. She is so much upset [sic] and also the boyfriend [is upset]. The kids are still in the house. There is no social worker to be tracked. It's like we, by asking Reneliwe a favour to look after the children, it's like we have given Reneliwe a burden, according to how she expresses it. It's like we [have] given her our burden, because from the onset she was not planning on keeping the kids in the house, but now this escalated in a way that she is very much upset after [how] Dikeledi has responded, and everything she is doing. Saying she is doing this and buying things for the child, but now I think Dikeledi is also upset that Reneliwe was using money for the kids and she didn't allow it. Dikeledi is very upset. She didn't even want to speak to me over the phone, she refused to speak to me."

So, Reneliwe and her boyfriend are upset with Dikeledi that the kids are still in their house. It appeared as if Judith was feeling very helpless, because she was at home and there was not much that she could do. The doctors were also really frustrated with Dikeledi. They said that she had been having unprotected sex,

and that she was not looking after herself. She should not be sleeping on the floor. They moved her from one ward to another ward because of her behaviour.

I do not know what to do. How can she get discharged when she is still sick? What is she trying to do and why is she reacting this way? This whole thing with the children, and Reneliwe and the boyfriend, and her thinking she was doing us a favour is also a big problem. This has become a big mess.

I spoke to Judith who also doesn't know what to do. I asked if she could please go and visit Reneliwe to try and sort out this problem. She said she would.

What have we done? By intervening, suddenly we are the supporters who are being called upon to sort out the problems in the community. We were concerned, but we do not have the skills to address these burdens. Where is the line? How, when you are doing research of this kind, do you put up boundaries from the start?

Discussion: June 2018 (a week later)

Over the weekend I ran the Comrades Marathon^{ttt} and injured myself. I am not sure what happened, but I am unable to walk without pain. However, I had to go and visit Reneliwe to try figure out what had happened, and how we could repair the damage that had been caused. Judith came to fetch me, and she drove me to Mamelodi to visit Reneliwe. Judith had already been to visit Reneliwe last week because of all the stressors, and I realised that it would be important for me to go as well and also explain it from my side to ensure that the relationship is restored. Reneliwe was the one who had referred us originally, Boitumelo [one of my other research participants], and who Dikeledi had said was a friend of hers. She had indicated last week how upset she was with us for giving her a burden.

I wasn't exactly sure what to say, but I explained to Reneliwe that it was made really clear to the research participants at the outset of the study that the research would not directly benefit them. The point was to understand their story, so that we could take the information that they provide us with and take it to the people that are in positions of power, to make a difference. The stories would be collated so that they can understand their situations are complex, that they need to address it in its complexity, and then try and come up with solutions.

We also understood that, although participants had agreed to participate in the study and with this clearly outlined, they probably still hoped that they would get something out of it. For example, when Kelebogile^{uuu} had told us about Boitumelo, the first thing that Boitumelo said to us was that Kelebogile had said to her that we can help her to get food. So, there was this expectation and confusion, even

^{ttt} The Comrades Marathon is an ultramarathon, run annually between Pietermaritzburg and Durban. It is approximately 89km, and is the world's oldest and largest ultramarathon race.

^{uuu} A person with a disability in the community that referred me to other participant in the PhD study, Boitumelo

though we tried to be as clear as possible. And I can understand that people still think that maybe something will be done – after all, we are coming from a university. I, as a white person, am entering a predominantly black township and I am seen to come with resources.

I continued explaining to Reneliwe (probably as much to myself) that we had spent a lot of time with the different participants, and there were visits where we realised that there were situations that really worried us. And even though it's not something that we are supposed to do, we thought that perhaps we can link this person up with structures in the community that can help that person. This was an example of what had happened with Dikeledi, where she left her abusive boyfriend, and she moved into the shack where it was raining and she was lying on the floor, and we were concerned about her safety, and we realised we had to find out about emergency services and what we could do to intervene.

Reneliwe indicated that she was grateful that we helped Dikeledi to get her house and that now she has a house. And I agree; I am glad that we could facilitate this process. It seemed that Dikeledi had gotten cross with the Housing Department, and, even though she was on the housing list, something had happened, but who knows what. And, perhaps, if we had not been here, she would still be in the shack.

Reneliwe said that since Dikeledi has returned from the hospital, she is demonstrating a negative attitude towards her.

I cannot understand Dikeledi. We've known her since last year, but every time we go it's as if there is something different; her story is continuously changing. She is vulnerable, but, to us, it seems as if she also makes bad decisions.

According to Reneliwe, she has picked up that she is drinking a lot of alcohol. She does not eat and doesn't take her medication well. The reason she is always complaining about money is because she is drinking alcohol.

I wonder how ignorant we had been. Is this not something that we should have known?

Reneliwe told us that a week before Dikeledi was admitted, the social workers or the CHWs came to Reneliwe's house [we are unsure if this was Ontiretse^{vv}] because they didn't know where Dikeledi was living. Then Reneliwe took them to Dikeledi's house, and there was tension and an argument ensued, because the house was dirty and Dikeledi was lying on the floor^{www}. Dikeledi did not speak well with the CHWs, because they were asking her why she was sleeping on the floor when she has a bed, and then she apparently spoke with them disrespectfully. I wonder whether Dikeledi didn't tell them that she had to sleep on the floor because the bed was getting wet?

^{vv} The CHW manager at one of the clinics.

^{www} Referring here to Dikeledi's new RDP house

Apparently, according to Reneliwe, Dikeledi's boyfriend^{xxx} brought alcohol. They were drinking and then they had unprotected sex. Then they started arguing, and as a result the boyfriend left her again. The day after, Dikeledi said to Reneliwe she wants to take her to the mall to spoil her and buy her slippers; she was insisting that they go and have fun. Then Reneliwe said that they came to her house and Dikeledi bent her head over, and Reneliwe could see that she wasn't feeling well at all. Apparently, she was also vomiting. Judith and Reneliwe think that perhaps Dikeledi realised that Reneliwe saw her drinking alcohol and she was trying to bribe her so that she wouldn't tell other people she had been drinking. Then they started arguing, because Reneliwe said they should go to the hospital, but Dikeledi wanted to go to the shopping centre.

At the hospital, the doctor apparently had also mentioned alcohol and that Dikeledi was not eating well and not drinking her ARVs. Judith said that the doctor had tested her blood and realised that she hadn't been taking her ARVs and that she hadn't taken them for about three to four days. They also knew she was having unprotected sex, since they were concerned that Dikeledi's boyfriend had been "too big for her". As Judith said, "The guy was not comfortable on her; he infected her so much. And also, having unprotected sex, also infected her. He has another STD,^{yyy} and also the size, it has hurt her. Because the doctor said she cannot bend properly. They made her exercise to see if the guy was too big on her."

The medication for STDs is five days. She goes home after five days, the doctor wanted to keep her for seven days, but then they released her [not willingly] because she was irritating people and shouting at everyone.

Reneliwe agrees that she is "not doing well mentally", because at the hospital she was insulting people. According to Reneliwe, she was also seeing dead people.

When Reneliwe went to the hospital, Dikeledi's boyfriend, asked whether Dikeledi has a funeral cover. The following day when Reneliwe went to Dikeledi's house, she took the clothes and money that Dikeledi had taken to her when she was looking after the children to return it. Dikeledi's boyfriend apparently asked her again whether Dikeledi has funeral cover. He also said that she had lost Dikeledi's ID book and that she had lost her family in Maganeng's contact details.

I'm worried about the children. It is clear that Dikeledi loves her children and cares for them. She is, however, also having sex while the children are there and is allegedly drinking too much alcohol.

Reneliwe indicates that she thinks Dikeledi is not doing what she should, because she [Reneliwe] had to buy socks for the children's feet because they were cold. I don't know how we are going to solve this

^{xxx} This was the first indication that Dikeledi had a new boyfriend

^{yyy} Sexually transmitted disease

problem. There is something bigger going on. As Judith says, Dikeledi makes bad choices in her life, she is buying alcohol as opposed to getting socks for her children, or getting a funeral cover.

Reneliwe says that she has been speaking with Dikeledi for a long time about taking care of herself, about ensuring that she manages her finances. Reneliwe says that she normally discusses the financial issues with Dikeledi, and Dikeledi says she has a lot of debt.

I explained to Reneliwe that what was happening here is beyond the scope of why we met her. We are unable to get Dikeledi to change; we cannot take control of her money. It's a very tricky situation for us, because we got involved and what we did made a difference, but it is outside of our scope to continue with intervention. We cannot continue intervening indefinitely.

Reneliwe explained that from the behaviour Dikeledi portrayed in the hospital and afterwards, Reneliwe has put in her boundaries and said that Dikeledi should not come to her again when she is unwell.

She also thinks that Dikeledi is insecure, because she thinks that Reneliwe is trying to take away her boyfriend. In the hospital apparently she was accusing Reneliwe, because she asked why they come together and leave together. This is the reason that Reneliwe has set this boundary with her, because she said that Dikeledi's boyfriend must not contact her, because she has her own boyfriend, and she doesn't want to be accused of making moves on Dikeledi's boyfriend.

Judith feels that Dikeledi does not appreciate what everyone is doing for her. She has spent a lot of money trying to assist her, taking transport to Mamelodi, airtime. Judith went to visit Dikeledi in hospital, spoke to the doctors and convinced Dikeledi to stay in hospital. She told her that all will be well, her children are safe, and Dikeledi agreed to stay.

Judith also tried to tell Dikeledi that she must appreciate the doctor, the nurses, and Reneliwe. If those people were not around her, no-one would look after her. She was shouting, "Go home!". Judith said she could hear heightened emotions in the background. The following day the doctor called Judith to say that Dikeledi was throwing tantrums and refusing to eat. He said that Dikeledi had the right to go home if she did not want to receive treatment. Allegedly because Dikeledi threatened to sue the hospital, they released her.

Reneliwe was saying that Lerato urinated on the bed twice whilst she was staying with her. This creates huge anxiety in me. As Judith says, Lerato may have had someone that raped her, because why would she urinate. The ex-boyfriend abused Naledi, perhaps he also abused Lerato. Judith and Reneliwe agree that Lerato should go and see the psychologist.

Reneliwe thinks that the first boyfriend in the first house where we met Dikeledi started abusing both the children. Because every time Dikeledi did not come to physiotherapy, Reneliwe would go to the house to

find out where Dikeledi was. When she got there, she would find Dikeledi very upset, and the children would have tears in their eyes.

Again, according to Reneliwe, Lerato was trying “to make a move” on Reneliwe’s boyfriend whilst she and Naledi were staying with Reneliwe. She would wear “suggestive” clothing and go into the bathroom whilst Reneliwe’s boyfriend was in the bathroom, and use sexual innuendoes whilst she was speaking with him. The boyfriend then said to Reneliwe that he is worried about the child, because “she’s doing this and this and this?”

Reneliwe thinks that when Dikeledi isn’t there, that Lerato sleeps with Dikeledi’s boyfriend or when Dikeledi is sick and lying in the other room, that Lerato will sleep with the boyfriend in the other room.

She also says that they stole Reneliwe’s daughter’s clothes when they were there at her house. When they arrived at the house, they found that Dikeledi was wearing these clothes. Reneliwe, however, said to the daughter that they should just let it go.

We have tried to get a social worker to handle this situation. Reneliwe said she will introduce Judith to the social worker that they normally work with.

Reneliwe is talking about the lack of initiative in the community and among the people who have disabilities. The social workers came to Dikeledi and said to her that she doesn’t clean herself, she doesn’t keep the house clean, it is so dirty – Reneliwe has one arm and she cleans her house herself. They said that she must take a walk and go around the block, but she is sitting and doing nothing.

We didn’t want to place Reneliwe in a difficult situation, but we are feeling very out of our depth. We have to get the social worker that works with Dikeledi – everything that happens, it should go through the social worker. The contact details have to be shared, because if Dikeledi is going to the hospital, the family must come and look after the children so that Dikeledi can be helped.

Reneliwe once asked Dikeledi and said, “You are staying in a severe situation.” Apparently, Dikeledi said her family doesn’t like her. But Reneliwe believes that Dikeledi is “full of lies”. Reneliwe said that Dikeledi once shared with her that she was someone with pride, she didn’t like family members, and she will do things by herself, and not care about other people, so God put her in the wheelchair just to humble her.

I am not sure how my health will be and how often I will be able to go to Mamelodi^{zzz}. I am hoping that my leg will heal soon; for now, I can’t drive yet.

^{zzz} At this time I was using a wheelchair and unable to drive. I did not know that I would continue to wait for my leg to heal, whilst using a wheelchair for another three months. After this, I had an operation and then had to use crutches.



Image above: The ramp going to her house that Dikeledi had built

Discussion: July 2018

Judith is upset. She feels that Dikeledi has been taking advantage of her. Judith had been using her own money to assist Dikeledi [e.g., with calling to help, transport, etc.].

When I came back from the hospital, I started having a speech problem. I can't speak properly.

Lerato explained that she felt her mum was stuttering, she would say "piece piece piece" instead of just piece.

But now I feel better. When I speak, I can't say some of the words properly. I lost my ID book at the hospital. At the hospital I don't [sic] know what I was doing. They were inside a plastic bag then they moved me to another bed in another ward. I lost food and some cool drink, the wheelchair sponge, even my shoes. I left everything there, even the wheelchair. Luckily, I got the wheelchair back.

I was so cross at the hospital, because they gave me too many injections. They were hurting me. As soon as they did that to me I started screaming. There's a drip and then there's an injection that they put inside and then it hurts. And they injected my bum.

This woman with a security top [shirt], she's a friend, staying around, helping around here as a security officer, and her mother once came here and found me very sick. They helped me go to the hospital. Reneliwe didn't want me to leave. She wanted me to stay for too long at the hospital. She said she'll look after my kids, and I should stay in hospital. She was trying to help me to get better, but I didn't want to stay, so I left. I spoke to the doctor, but Reneliwe stopped me and said she wanted to help me and stuff like that. I made peace with her now and we were fine again. She saw that I was okay [be]cause she could see that I wasn't okay, my head wasn't okay. I wanted to come home from the hospital. I didn't want to stay there.

Naledi also interjects and says, "She said she won't go to hospital, she had been in hospital for too long and had not seen us in a long time while we were at home. Then they brought her back and took her to the clinic and there she was told to go to hospital, and she refused to go. Then she went to church in Extension 5. When she came back from the church, she was okay. She wasn't vomiting anymore, and she wasn't crying about the pain in her back and legs." It seems that Dikeledi doesn't remember exactly what happened, which is why Naledi is telling us and not Dikeledi. The only thing she remembers is being by the hospital door and they told her at the clinic that they should bring her there and she refused. We aren't sure what is going on.

The hospital isn't nice. Yes, and when we want help they just shout and don't come to help us.

Judith asked her, "You're very sick. You must go to hospital. But you must stay alive for your kids. Do you want to die?"

I won't go to hospital. I'll go to church.

As much as I try and explain that God gave us medicine to be able to help us get better, and that God enabled humans to be clever to study things and find them out, she doesn't change her mind.

They don't help us move and turn on our beds. We just sit there and when we ask for help they just ignore us.

Judith again tries, "We understand, but you need to look after yourself for your kids' sake." Dikeledi seems confused about what happened in the ward that they put her in. She is asking what happened there.

I ended up crying cause I didn't want to stay in that ward, so they held me down and gave me an injection. My family hasn't come to check on me. We only spoke on the phone. My brother called, but I can't remember what he said. The line was also bad. My brother's wife called. She asked if I was okay, and I said yes.

We decide to shift the conversation to other things and ask about rent from the shack she has.

Yes, the other room, the tenant has moved in. But the tenant did not pay. He bought a bed and said he'll pay me later. The cigarettes are finished now.

Judith wants to find out more about whether she is changing now to look after her children. It's not good to stay in the house all the time and she should socialise with other women. She is encouraging her to spend time with other women, to be able to go out. In Mamelodi they have societies, which is like a stokvel, where they contribute money. Women meet every month.

I don't have a society or stokvel. I had one from the church, but I left it. It was a burial society. I paid R45 a month. It covered me and the children.

Judith is trying to explain to Dikeledi that she should have a burial society, because "Let's say something happens to you or one of your kids, how are you going to bury them? You see that could be a problem? You should think about that too." She continued, "We're not saying you're going to die, but you know we can't predict the future, that's why I have a funeral cover. Even if you're not sick, you understand you must have a funeral cover in case something happens, but that doesn't mean you're waiting for something bad to happen." What made her stop her funeral cover? I know she hardly earns anything, but the tricky thing is what would happen to her children if she were to die – who would pay for her?

I stopped since I got sick. I just stopped. But I'll do it. I'll pay.

I try and follow up what happened with the psychologist at Vista and whether Dikeledi has taken Lerato there. We had spoken to her about taking both her children to see a psychologist, because of the abuse that they had witnessed and experienced. We try and understand from Dikeledi whether Lerato was abused.

Only Lerato has seen a psychologist. No, it never happened. She was never sexually abused. But it nearly happened. There was a time when I was sick and sleeping. He went into their room naked, while the kids were sleeping. Lerato is a light sleeper, so she heard him come in and asked what he was doing, then he just kept quiet, but he was already in her bed, so Lerato pretended to be sleeping and after a while she realised that he was gone.

This doesn't make sense to us, because the shack didn't have different rooms. We try and clarify, and Dikeledi insists this was when she was staying at Block C. Which one was block C? The shack we saw with

the man that according to Reneliwe abused the children, was a one-roomed shack. There were not separate rooms in this one. We proceed to ask her about Lerato.

Lerato is being sexually active. She is using protection. She has a boyfriend, but he's still a young boy. He comes here to the house sometimes; he sometimes sleeps over. When this happens, Naledi sleeps with me. She told me, from what she has said, when I was sick, before I got better, "I have a boyfriend." So she told me what he was doing to her. She said he was kissing her and told her about sex and stuff. She told me that he's trying to seduce her. She got angry and said she didn't want any man in the house anymore; that they should leave

As we are talking, someone comes into the house.

This is Molefi^{aaaa}. Sometimes he gives me R20 or bring sishebo on some days, just enough for us.



Image above: Lerato cooking maize on the paraffin stove

^{aaaa} We then learnt that his was Dikeledi's boyfriend at the time



Image above: Dikeledi and myself [I am still using a wheelchair]

I have enough food at the moment. I bought two 12,5kg bags of maize meal, tin fish, corn beef and a few other things.

Judith leaves with a last plea, “Please try to stay healthy. You must be there for your children. You must eat well and take care of yourself and go for all your check-ups because you have to be healthy.” And I add, “have to use protection when you have sex.” Dikeledi insists that she uses contraception.

Didn’t you see them under the bed?

I explain that I’m worried about Lerato and that she should be using contraception. I explain, “You have to be careful. I mean, she can’t fall pregnant now. She needs to go to school, she has to look after herself.”

I took Lerato to the clinic for contraceptives, but she stopped going. She refuses to go to the clinic. I don’t know why. The injection makes her menstruate the whole time and it doesn’t stop.

The problem is that the injection doesn’t protect her from HIV. And what about Naledi’s exposure to sex.

When Molefi comes, then Naledi sleeps with Lerato.

I ask her what happened at the previous house where she was staying, that was only one room – where did the children sleep then when Molefi came over?

They were staying in the other shack, Lerato and Naledi. They were watching someone's shack cause the owner was staying at another place.

I am concerned that she hasn't told us this before.

Social workers came and said that the kids can't stay alone at another place while I stay in another house.

I understand. She didn't want the social workers taking the children. She was worried what we would do if she told us. I insist and ask her to please take the children to Vista to be able to see the psychologist. But, I know that the service at Vista probably won't be adequate. Perhaps I should have rather insisted that they both go to Mamelodi Hospital or the Stanza Community Health Centre psychologists – although unfortunately these services have also, at times, proven to be woefully inadequate.

Discussion: September 2019

It has been almost two months since we visited Dikeledi. It hasn't been an easy two months; I was still using a wheelchair and the stress fractures hadn't healed yet. I have been to various specialists to find out what would be the best way forward. Judith had come to fetch me so that we could see how my research participants were and check up on them. Things in the house with Dikeledi were looking a lot better. Lerato was at home, she said she didn't go to school because it was Friday and they are writing exams. She was busy cooking chicken feet. The house was looking much cleaner than the last time we had been there. Naledi said she had to still clean her room, but Dikeledi was proud of hers. They were going to still swop rooms, so that Dikeledi could have the bigger one.

I've got a store that I'm selling. I'm selling sweets, chips and cigarettes. The cigarettes they make money more [sic]; they sell more. And the chips and sweets the kiddies do buy. When times goes, I will also have bread. Most of the people here they want the match boxes and the candles. I get the stock from Kit-Kat. I go with Lerato. We take the taxi from the main road.

A man has arrived. He tells us that he's doing a visitation with her, telling people about Jesus, and just checking up on Dikeledi. Dikeledi asks how my leg is, but wants to make sure that I'll be fine. We laugh as we compare our wheelchairs – I jokingly say mine is cleaner.

You must leave me, because mine drives all over. I drive every day. I went to Extension 22 at the old place, and it was muddy, I've just been through. The place is fine; they installed illegal electricity. It cost me R450. They just installed those very thin cables, and they used a sort of pole to connect it. You buy a pole that

connects it – the risk is high. Badiri^{bbbb} is now staying there. He’s like a brother to me. He doesn’t pay. But a family came and said they want to buy the stand. But, I’m not selling. From way back, I don’t want to sell it. I struggled a lot with that place. I love that place.

According to Judith, it seems that Dikeledi has an incredible sense of pride regarding her shack, which includes that she took ownership, moved away from the alleged abusive boyfriend and went to live on her own. We ask whether she would rather have stayed there than move here, and she laughs.

I will come and visit here. I want to go and stay that side, and then I’ll come because the kids cannot stay by themselves here, but then I’ll come and visit the kids here. There’s water now. And they dig [sic] the pit latrine. When they see me there, they ask why I’m not coming to visit. Dineo, my friend, is there.

We ask Lerato where she would rather stay, and Lerato says here in Nellmapius. Judith laughs and supports that.

It’s boring here. My friend gave me the curtains. I’ve got a tuckshop, about a month, two months ago. I haven’t put my stock outside, they just come in and buy here. When the school is out, then I’ll put it outside. I’ll buy the stuff that the kids need, [like] airtime, [but] I don’t know where to buy.

We suggest that she goes to Kitkat and finds out.

Molefi, my boyfriend, he built it outside [the tuck shop stand outside]. He also made the washing line. It cost me R45 to buy the planks. The top one I got from the dumping site for R20.

Reflexive note: October 2019

This was to be the last time I would see Dikeledi. At the end of 2018, I received two missed calls from her. I was personally not in a good place, and I never answered the phone. January arrived and I had to finish my own work at the University of KwaZulu Natal (UKZN) in preparation for new work at the University of Pretoria (UP). It was later that I found out she had thrown a party at her house, and she wanted to invite us – this had been the reason for her calls. In February 2019 I started working full time at UP. It started off very difficult, since I injured by back at the end of January and again ended up in the emergency room at the hospital, with a bulging disk in my lower back. Starting straight away in the deep end with community supervision in Mamelodi of 10 students, I found that I had very limited time. It was a steep learning curve. Although I drove often into Mamelodi, I did not take the responsibility to check up on my research participants and find out how they were doing. Judith had received a bursary for her Bachelor’s degree in Development Studies, and had moved to another province.

^{bbbb} Pseudonym used; Dikeledi’s cousin

I then contacted Ontiretse, the CHW manager of the community health centre, again in May, hoping that our second group of students would be able to work with her team of CHWs. We met at the Mamelodi community hall on Monday the 18th of May. We were chatting, and I was excited to see her. She then asked me, "Did you know Dikeledi died?" My heart sank. I considered what this loss would mean to the children, wondering what could possibly have happened, feeling incredibly guilty for not having been there, and wondering what I could have done to prevent this from happening. I couldn't break down in front of the students, but I felt just wanted to disappear. It all seemed so surreal, so unreal, so unfair. I thought about all this time that I had not contacted them and wondered, what had happened?

I asked Ontiretse to please find out what had happened, and to arrange with Martha for us to go and visit Lerato. In May, Ontiretse confirmed, "Evening Helga. Dikeledi passed on last year December [sic] and the older child Lerato is the one who stays in the house and, the other kid, the family members took them. Still waiting for Martha to give me Lerato's numbers and I will send them to you as soon as I get them." I read the message over and over again, trying to let this sink in.

I did not receive Lerato's contact details, even with follow up in both June and July. It seems that Martha was on sick leave and Ontiretse was unable to get hold of her. Ontiretse said she would contact the CHW responsible for the current area that Lerato was living in and ask one of them to go and find Dikeledi's daughter.

It was a long time of waiting with unknown delays. Eventually, everything was arranged, and I was able to visit Lerato together with Martha. The two of us went there, and when I saw Lerato, I just hugged her very tight, and held her, whilst she was crying. I couldn't believe that this girl had now been left behind here. What we had been worried about had, in fact, happened.

I tried to figure out with her where all her documentation was, and what had happened to the death certificate. I tried to encourage Martha to assist her to be able to get an income for the shack so that Lerato will be able to have a more sustainable source of funds. Lerato said that she had left school and I tried to find out what the name of the school was and where it was, but it did not make sense.

Lerato told me that her mother had died in December already. They were not sure what had happened. She had been sick, and she died. The family came from Maganeng and took her sister away. She had not had contact with her sister since then, and was having nightmares as she recalled her mother at night. Martha was translating and trying to understand what had happened.

I remember thinking, what is she living off? Where is she getting money from? I need to do something.

Together with Martha, we brainstormed several aspects that needed to occur. Martha wrote down that she should assist Lerato with her ID, and assist with transferring her to the CHW team here in this area. Over the next few months, I visited Lerato a few times. Sometimes when I went, there was no-one there. I spoke to one of the neighbours, who said that she knew Lerato and she sometimes gave her food. I also

met two young girls whilst looking for Lerato – the one told me that she was not friends with Lerato, because Lerato was allegedly sleeping around with too many men. The other one said that she was her friend, and she would be supporting her. I tried to get Lerato back into the vocational school where she had been. Not knowing where it was, I drove around Mamelodi and eventually found it. Once there, they were less than forthcoming to assist us. They said I should return for an appointment with the principal to explain the situation.

Reflexive note: March 2020

This continued into early 2020. When I visited Lerato again at the beginning of March 2020, she had a boyfriend. I urged her to ensure she was taking protection. She indicated that she previously had received injections, but was not currently. I tried to explain how important it was for her to do this, so that she could complete her schooling and try and find work. But, when I visited her again, she told me that her breasts were swollen, and her period had stopped. I asked her to please go to the clinic to see if she was pregnant, and when I returned, she told me that she was. Judith had been away studying, and when she was available, we went together to Lerato to try and make sense of what had happened with Dikeledi, and to see what the future held for Lerato.

Reflexive note: September 2020

Lerato and Mpho were together when we arrived. I reminded Lerato of when we first came, that we were conducting research to try and understand her mother's life. It would be helpful if we could hear from her side and from Mpho's life, to make sense of the bigger picture. Their lives being so intertwined, one could not separate it. They both consented to this.

Lerato explained that Dikeledi was not sick for very long. They had given her a new wheelchair and she was taken by an ambulance to the hospital. Before she arrived at the hospital, she was dead. She had not been eating, she had been in pain and had been crying – her children did not know why. The pain that she had was in her stomach. We asked her whether it may have been a bladder infection again, since that was the previous reason for hospitalisation. However, Lerato indicated that there wasn't anything red in her urine. When asked whether the doctors told her what happened, she replied, "She actually died immediately when we got to the Dagga hospital, and then they sent me outside and when they came back they said, "No that woman has passed on". They showed me her body and then gave me her clothes, and then I stayed the whole night in the hospital, and then in the morning I came back here. I didn't know how to tell Naledi that my mum had passed on. She was outside playing. Someone had stayed behind to look after her." It is unclear, but it seems that through some measure of good fortune the CHWs came to the house on that day. They did not come regularly, but on that day they were there. She said, "I explained to them that my mum passed on and I do not know how to tell Naledi". Then the CHWs proceeded to tell

Naledi and Lerato called her family in Maganeng. She said, “Naledi cried and she was otherwise; she was not good.” I asked her whether anyone at the hospital supported her, or whether the nurses spoke to her. She said, “They just told me that because I was strong to care for my mum, I must keep on caring for Naledi, and I must not care what the family does or whatever, I must just be strong.”

Lerato is unsure of how the arrangements after that worked. She saw them bringing the corpse to the house of her mum; she passed by the house and then they took her to Maganeng. Her aunt came and stayed with both Lerato and Naledi for a few days in Mamelodi, to clean the house and do the laundry. A few days later they went to Maganeng. After the funeral they returned with their uncle’s taxi. They came to remove the school documents, and then they took Naledi back to Maganeng. Lerato said, “Naledi actually wanted to run and go somewhere until they leave the house and come back later, but I told them she must just go with them, just to listen to them and then, when I have money, I will come back and get you.”

It is unclear exactly what followed and the extent to which Lerato had engagements with her family in Maganeng, or what exactly everyone thought. It seems that Lerato’s uncle indicated that people [and the cousins] had told him that Lerato had said he wanted to steal the house. Badiri [Dikeledi’s cousin] was also upset and left the house without his key. He had been staying with Lerato, and told people that the family in Maganeng wants to steal her mum’s house. It seems, however, that the miscommunications have been clarified now, and that her family in Maganeng wants her to come and have her baby at home. After this, she thinks she will return, but she does not know.

We asked her what she wants. Lerato said, “The only thing that I want is to go there and see Naledi, have a baby and then come back here.” She is nervous that she will not be able to return to Mamelodi after having her child. “They said they are going to come and get me, so I don’t know if they’re going to come and get me and bring me back here, or if they are going to insist that I stay that side.” Lerato had indicated that her wish was for the three of them (Mpho, Lerato and her baby) to live in the house together as a family. Mpho stated that he will ensure that if the family refuses for Lerato to return, he will arrange with his parents and ask Lerato’s family to release her to return to Mamelodi. Both Mpho’s parents are still alive, but they are divorced. Mpho’s mother, sister, brother and a younger sister are all living in a house, and Mpho is living outside in an outbuilding or a shack [it is unclear]. This is where Lerato and Mpho have been staying together since there is electricity there. Therefore, even though they come to the house and chat, after a while they return to where there is electricity. Previously, Lerato had told me that it had been difficult with Mpho’s family, because they did not want to accept her. But since the pregnancy, it seems that the family is happy and supportive.

Judith explains the cultural process to me, “Culturally, when someone is pregnant, it’s the first pregnancy, her family has to go to Mpho’s family and report the pregnancy. It’s a cultural thing. They must sit down and discuss the pregnancy.” Judith elaborates, “They [Mpho and Lerato] have to report to Mpho’s house

and say the baby is born. Mpho's mother has to go to Lerato's uncle where Lerato is [Maganeng], Mpho and his mother have to go there and buy the first outfit. The first outfit that is a gift from the mother. They have to go and dress the child; it's like you are blessing the child with this. And bring gifts for the father's



Image above: Lerato and Mpho

side. But first the family of the girl has to go to the father's house and report there is a girl. Since their religion, they are Zion Christian Church (ZCC), they don't do that. The Zion Christian Church, they follow the Christianity thing. They are not on rituals; they are praying for the child. When the child is born, the child goes to the hospital; come back home."

"Lerato will be staying indoors for almost a full month. The child will be indoors for almost three months; no sexual intercourse during the three months until the child, they believe a child must be a little bit matured, three months, before you can have sexual intercourse with the father. No one is allowed to visit

the child, only the family can bring clothes. After three months you can come and visit the child; it's their culture. A month full [sic] she has to stay in the house. She sleeps on the tummy; they must flatten the tummy, unless she has had an operation. And then you sleep on the tummy for a whole month on the ground and then they cook for you. You don't do anything, they will bath the child, they will treat you, they will feed you, every day they will take hot water and they will massage you... the treatment after pregnancy, you are tired, so now they use hot water bottles, they put on you, they treat you and they take care of you and the baby. Then after a month now they will tell you, now you have to exercise, you must walk around and you can go to the shops. But the child still remains indoors, according to the culture and the religion. The child stays at home until the child is three months old. After three months there will be a big celebration. It can be only families coming to celebrate that the child is strong. They believe that if the child manages to be three months, she has made it in life or he made it in life. Community can come to that, it depends how much you can afford. So me [Judith] and my child, we didn't have money, it was just me and my uncles. However, we cook wors^{cccc}. And her uncle's wife will take the child out of the house and then people will bring gifts. Lerato is Northern Sotho. So now, because they are not married, they cannot consider his culture, they consider the mother's culture. Whatever happens in Maganeng, it doesn't affect Mpho's family, until she comes this side. They can only marry if Mpho pays lobola^{dddd}. But they can come and there is a naming of a child. Mpho's family has to come up with a name. Lerato's family has to come up with a name, then they will be sitting down and discussing it [sic]. The child will be named this person, and then they speak to the child and say from now on you will be called this."

Mpho and his family has to go and buy clothes. Even though his parents are divorced, both his mother and father, as well as his siblings, will come to Maganeng. Judith queries, "I don't know if they have to pay the money, the damage? 'Impregnated my daughter, it's like you caused damage in my household. You have to pay some amount'. So if the uncles come, they have to go to Mpho's house. When they go there, they tell the mother, 'Your child has done one-two-three to our daughter, and we need this amount.' His parents will say, 'Okay, we will come and bring the money to Maganeng.' This is for the maintaining of the child." However, Lerato says they have not indicated anything about this cultural protocol. Judith queried whether they will be able to pay the money if required, and Mpho states that they will. His mother works as a domestic worker. Mpho says he will have to raise the money first to pay for the damages, and then he will raise the money to pay for the lobola.

Mpho receives a disability grant. Mpho seems to have cerebral palsy and impaired hearing (he wears a hearing aid). Lerato does not know what caused it. But Mpho says, "I just got injured, I don't know how. But I think it's, like, witchcraft. So, my ears just got damaged. I'm not sure if I can say witchcraft injury. It just got damaged in 2000." He is currently 32 years old. Therefore in 2000, he would have been 12 and

^{cccc} Colloquial term for sausage

^{dddd} This is a traditional customary "bride price" in which the prospective husband and his family gives his prospective wife's family property, for example livestock, as a payment of allowing the husband to marry their daughter.

still in school. Mpho was born in Maganeng as well, but on the other side of Maganeng. When he lost his hearing, he had to change schools. He passed grade 7 and then went to a school in Saulsville^{eeee}, where there is a school for children with hearing problems. He said he was in Grade 12 when he started having ear problems, “I didn’t even go and get my certificate after passing my matric, because I was severely sick with my ear problem. I went back to Maganeng and stayed with my grandparents. They were taking care of me, my grandparents. They will clean my ears with soap and warm water. They were white works [sic] coming out of my ears. Then my grandfather passed on whilst I was having ear problems. Then I came back to stay here [in Mamelodi]. Then I started taking the medical treatment for my ears, from the community health centre. From the community health centre they send [sic] me to Steve Biko^{ffff}. They assessed me at Steve Biko and then they sent me back and give them the results that they must get some devices to help me with sound.”

Mpho and Lerato met at the neighbour’s house. The neighbour was a friend of Mpho’s. According to Lerato, Mpho had noticed her before her mother died, but they started dating only after her mum passed on. It was only when they were dating that they realised they were both from Maganeng. In December she visited him and his family, and they found out that one of Mpho’s family members knows Lerato’s father.

I asked Lerato whether she has any contact with her father. She says that she knows where he stays, but she will not go to him. He stays in Mamelodi. The last time she saw him was after her mum passed away. She said, “After my mum passed on, I went to his house, but I really regret why I went to that house. My mum once asked me, “Can you go to your father’s house?” Yes, I regret going there. I told my mum that I wouldn’t go to his house, because he doesn’t care about me.”

Lerato continues to elaborate that her father is not the same as Naledi’s father. Her mother was married to Naledi’s father, and they were divorced. They never had the proper traditional wedding; they went to home affairs and signed for the marriage there. It sounds as if Naledi was born after the divorce. Lerato’s father came from the same village as her mother. She does not know where her mother met the Erasmus man^{eeee}; she doesn’t know where they met, but that is where they were staying.

I wonder about this, “the Erasmus man”. We are describing Dikeledi’s partners according to where she was living with them, as opposed to by their names. Also, there seemed to have been these alleged continuous cycles of abuse. We ask Lerato about her father. She says, “No, he was not nice to me. He abused my mother. He hit her sometimes. He never touched me, but it was so odd.” When we queried

^{eeee} Name has been changed; this area is in Pretoria West.

^{ffff} Steve Biko Academic Hospital is a tertiary-level public hospital in Tshwane

^{eeee} This is Naledi’s father

about Naledi's father, she says, "Naledi's father and my dad, they are the same. He never took care of Naledi. Same as my dad. He never took care of me."

The person Dikeledi was with when we first met her was the man that she was with after Naledi's dad. Lerato says that after moving from Naledi's father's house, they moved to that man's house, "He was okay, and my mother was able to walk until my mother fell and then he changed. But, before then he was a nice man. He would even go and visit the village. Then things changed when my mother started getting sick and being in the wheelchair."

From here she went home over the Christmas period. She decided to leave that man, and in Maganeng she met another one. She returned to Mamelodi with that man, and, as Lerato says, "They start being nice, then as time goes they change." I asked her how she feels about her mother having had many different partners. Lerato says, "That thing wasn't nice. I think she was trying to find someone that was good." Lerato does not believe it ever had to do with security or finding money; Dikeledi was one person who would do things for herself. This is what we realised as well. She was always making a plan, even having the spaza shop outside and selling things. We asked what other things they used to do to make money. Lerato spoke of a group that did singing and dancing. Apparently, the group was doing really well, but it was very far for them to get to, so she stopped going.

I asked Judith to enquire why she stopped going to school. Lerato says, "I was confused. I had lots of memories when I went to school about my mum's life. How we were living, and the way how she left me. It was not long after she left. We buried her in December, then in January school starts. So, it was just short time. And then I was alone in the house. Since my mum died, even her room, when I got into her room, I got very hot. This heat comes on me. Sometimes I sleep here. I will sleep with the Bible, but I get this heat. I will sleep on the couch here with the Bible and when I'm sleeping, sometimes I will feel like sometimes when you bury someone going down, I will see the bright light but with an orange perception, that I'm going down slowly. Then I will stop sleeping when that happens. That happened once, otherwise. I used to get those nightmares. I was alone. I had no-one; it was just me.

I proceeded to ask Lerato about the neighbour who had previously indicated she gave Lerato food. Lerato said that she did care for her. She would not go to bed hungry because there wasn't any food, but only because she "...don't like food. I would stay three days without food, but I wouldn't worry, because I don't care about food. The food was there, but because my mum passed on, so I was not feeling like eating [sic]." After she finished the food that she had from her mother, who always used to buy in bulk, she would obtain food from her neighbour, Auntie Margaret. This neighbour apparently said to her that whenever she needs food, she must come to her. She would also come and check to see whether Lerato was okay.

I ask her what she likes about Mpho. She says there are many things. He's cool, and every time they talk, he understands her. He's caring, and they have fun together.

I ask her about Maganeng. What kind of an area it is. Apparently, it's a rural area, where many people from the city have houses. It is governed by a chief. The houses are mostly brick houses. For example, her uncle who lives there, has taxis in Mamelodi. The other uncle that lives in Mamelodi is not her uncle, but Dikeledi's uncle. They talk with him, and she spoke with him about Extension 22. They are trying to assist Lerato to obtain the money from the shack, but it does not sound as if anything is happening. According to Lerato, regarding the shack, "they told me that there is no documents and then I got confused, that my house doesn't belong to anybody. People that are staying there, they told them that. They told my uncle that they spent R3000 in that house to build a fence, so they want that money. But nobody told them to do that. Since they started staying there, they haven't paid even that R300." The neighbour's daughter has moved into the shack, and so they would not want to vouch for Dikeledi having lived there and paid for it. It will be difficult to get the shack back into their ownership. Judith says that she needs to go to the social workers, because someone is trying to steal from them. We tell her that if she would like us to witness that the shack belonged to her mother, we can do that for her. Lerato insists that they are trying to steal the property, but she is not going to do anything now before her baby comes. We suggest to her that she speak to her uncle. We give her our numbers again and she can ask her uncle to contact us so that we can assist. Lerato says she thought that they were going to pay every month.

I just want to clarify with Lerato, again, the different plans that her mother used to make to be able to source money for food. One of the examples is that she used to buy food in bulk. It doesn't seem like Lerato understands. She liked to do things for herself. We share a talent / gift – we both like to sing.

I ask her how she wants her child to grow up, and what she wants to teach her child... what the most important values are for her. Lerato says, "I want her or him to grow independently, do things for him- or herself, study further and finish school, work for herself. If she's a woman, she mustn't depend on men. She must just depend on herself and do things for herself. If it is a boy, he must work hard to be independent."

Judith asks about her health and wants to check whether they tested before they were intimate. Lerato says she only tested when she was pregnant. We ask whether she tested positive, and she said no. Judith just wanted to know, if it happened that she was positive, what she was going to feel, and Lerato says she would accept it. Judith is trying to understand what makes her so strong to accept it, and Lerato says, "There is nothing I can change, you must be strong and accept your situation."

I explain that if she is positive and pregnant, there is a lot they can do to prevent the virus from going to the child. She says they test now and then to keep the child safe.

Judith asks what Lerato's plans are going forward. Lerato says, "If possible, I want to go back to school. Because, even Naledi is growing, I don't know what she wants. I want to go back to school to further my studies. I want to go back to the school where I was, but I don't think they will agree to take me back."

I ask her what practical things she did there. She says mainly hospitality and sewing. It seems she didn't do woodwork, needlework or computer skills, which is unfortunate. I ask Mpho whether he ever learnt any skills at school, but it is difficult to ascertain what he learnt. His entire right side is affected – to me it sounds like he has cerebral palsy, so I check with him, and he agrees. His right side is not that strong.

I ask whether it limits him in anything that he wants to do, and he says no, he doesn't experience any limitations. He can do anything. We find out that she is due in October. She isn't sure when. I ask if we can phone the uncle and find out how her baby is. It sounds as if she will like that.



Image above: Lerato

Reflexive note: September 2020

Today Lerato called me... she has had her baby! I couldn't believe it. I was so very excited about this. I asked her where she was and she said she was still in Pretoria. She had her baby at Mamelodi Regional Hospital. She indicated that her family were going to come from Maganeng to fetch her. She had a normal birth. I asked her a couple of questions about what happened, where she was when the contractures started. She said she had been at Mpho's house, and everything was fine. She's had a girl! I remember her talking about the name she would give her daughter, if she was having a girl. She had wanted a girl... I am so thrilled for her. And exactly the names that the two of them had chosen – Sindi Kaboentle^{hhhh}. Such beautiful names. I told her how happy I was for her. Unfortunately, because of COVID-19 lockdown regulations at the hospital, Mpho was unable to be with her. She was still in pain, but she was happy. They were going to show her what to do in order to be able to breastfeed the baby. I said good luck to her and asked her to let me know how it goes.

Note: During 2021, the researcher experienced significant events and therefore was unable to continue engagements.

Reflexive note: April 2022

After Lerato left for Maganeng, we maintained contact through occasional messages, both on Facebook and via WhatsApp. Lerato sent me photos of her daughter, and of her and Naledi. Her child is beautiful. She seemed much better. But twice in this time she indicated that she wanted to come back to Mamelodi to stay in her mother's house and that she wanted to take care of herself. I tried to advise her that she needs to have a plan, and she will have to have support if she returns. I foresee the difficulties she would encounter trying to find work currently, especially considering the high unemployment rate, and having not completed her schooling. She does not receive any grant, except probably a childcare grant of a few hundred rand – definitely not enough to support the two of them. Even with Mpho's disability grant, it would probably not be enough. At least now she is with family, and they can ensure that she and her child are looked after.

^{hhhh} Pseudonym used



Image above: Mpho and Lerato's daughter, Sindi



Images above: From left to right – Naledi, Lerato, and their cousin's daughter; Lerato in her uncle's home

Reflexive note: September 2022

There are some things I am concerned about, as I have been finalising Dikeledi's narrative. The biggest regret is that I realise we ourselves should have gone to the police and reported the alleged abuse of Dikeledi and her daughters. At the time, we were naïve. It felt like we were talking to social workers, to those in authority, to everyone we could, – but there were so many gaps in the system, and the proper intervention was not occurring or not accessible.

Another aspect that concerns me, is the services that were being provided through our University clinics, namely Itsoseng and Siyathembaⁱⁱⁱⁱ. I now understand what happens on the other side. Occupational therapy students used to run the Siyathemba clinic next door to Itsoseng clinic and children who had been assessed [and treated] at Itsoseng by psychology master's students would have been referred to Siyathemba. When the surrounding schools referred to the clinic, because of the long waiting list it often took months until the assessment was able to take place. The recommendations on Lerato's report seems meaningless, because there are no qualified occupational therapists offering paediatric services in Mamelodi that Dikeledi could have afforded at the time and no educational psychologists. I wonder about the referral to the social worker. Why did they not find out who the existing social worker was? Or why do the social workers not talk to each other. It makes me realise how our assessments and interventions are so far away from the context. I do not know whether our clinics with standardised assessments really make a difference. Fortunately, Lerato went to the prevocational school, but I am not sure how much of a role the clinic played in this, or whether it was the insistence of the teachers at her school.

I also wonder what happened at the prevocational school. Could there not have been more specific training and vocational placement facilitated, not just prevocational training. Why did they not follow up with Lerato, when she stopped coming? It is so important to keep children in schools and work with them to prevent their paths from going a certain way because of their vulnerabilities. It is a problem we need to address as a community.

Reflexive note: October 2022

A short while ago, I asked Judith to call Lerato to find out what she and her sister would like their pseudonyms to be in the story of their mother, considering I was compiling this final e-book version and I did not want this request to be confusing by me asking it in English. I envisaged this to be a good aspect of ownership. Lerato replied that she would first have to discuss this with her sister and she was unaware that her mother had been involved in research. I was confused and concerned. I know we had continuously indicated that our work was part of a research project and, when I had seen Lerato after her

ⁱⁱⁱⁱ Occupational therapy services were previously offered through the Siyathemba clinic on Mamelodi campus

mother had passed away, I had indicated to her again that we were involved with research and whether we could have permission to continue speaking with her and recording the information.

When Judith called them again, she indicated that she had to ask her uncles for permission, since that was the correct line of authority in the community. We were apprehensive that information might be misconstrued, so we decided the best would be to drive to Maganeng to discuss with the family how we knew Dikeledi, and to ensure that we had done everything we could to follow through with the required ethics of their family and community. I discussed the situation with a colleague who had insights into their culture and thoroughly prepared myself. I printed out several photos of our journey, for example of Dikeledi and Judith in Dikeledi's new house, and bought a frame with a picture of Dikeledi for Lerato. I knew Lerato's daughter was two years old by then, and I found a beautiful dress for her too.

We left early in the morning and, after approximately three and a half hours drive, arrived in Maganeng. Along the way we bought two live chickens. This is an appropriate cultural form of building relationships.



Image above: It took us a while before we found a home selling live chickens

The family was very happy to see us and they invited us inside. When Lerato came, she looked beautiful. It was wonderful to see her looking so well.



Image above: Judith holding our gift

Judith explained our situation in detail in Sepedi to ensure that everyone would be able to understand. With us were Dikeledi's brother (Kweda), his wife (Khauhelo), their daughter (who already has her own three children), and Lerato and her other aunt (Lineo), who both left the room at various times. We shared with them that Dikeledi had consented to be in a research study. I took out a copy of the document she had signed, on which I had blurred out the title of the study (considering it said that this was a study involving women who had HIV and disability regarding their food security). I also showed where Dikeledi had indicated that she wanted her pseudonym to be Dikeledi. I had taken a look at what this name meant, and saw, "one who is filled with a lot of tears". I wish I had looked up this name four years ago, when she first asked us to use it.

We explained aspects of the study to the family, namely that Dikeledi had chosen to remain anonymous and that we had promised to keep her information confidential. We, thus, were unable to share with them everything she had told us. Similarly, when we chatted with Lerato, we were supporting her as health care workers, and were, thus, bound by confidentiality. I had printed out an example of one of my reflexive notes of when Lerato had called me to tell me that her daughter had been born. I passed the piece of paper around for them to see what I had written. I had chosen this entry because it did not disclose any vulnerable information, and I used it to explain the process of how we collected our research data. I gave Lerato the framed photo of her mum, which she clutched onto.

They were very forthcoming with information about their relationship with Dikeledi. They explained that Dikeledi had always called them from the different places that she was living, and had discussed her situation with her different partners with them. Lerato's aunt appeared to know a lot about Dikeledi's situation, which matched what we knew about her.

It seems as if this family wanted to be involved in Dikeledi's life. Dikeledi would call Khauhelo frequently and report to her about the situations that she was in. On two different occasions Dikeledi had called Khauhelo and told her that on that day she found her boyfriend trying to sleep with her daughter, or she found her boyfriend in her daughter's room, and she did not know what was happening. According to Kweda and Khauhelo, they tried to reach out to her, even visiting her several times in Mamelodi, trying to convince Dikeledi to return to Maganeng. Khauhelo said she found a stand for her in the area where she would be able to build a house and life. Apparently Dikeledi refused. Kweda and Khauhelo thought that Dikeledi preferred to remain in Mamelodi because of her different boyfriends, and, if she were to return home, she would be judged for this. Hence, they felt, Dikeledi distanced herself.

We were all equally concerned about Lerato. The family members were worried that Lerato was possibly abused by Dikeledi's various boyfriends. They felt that she is "mentally not functioning well [sic]". According to them, she often dresses her daughter incorrectly (for example the clothes are upside down, or her left shoe is on her right foot). They said that Lerato started changing after the alleged abuse, and

she needed to move to the prevocational school. According to them, the way in which Dikeledi was talking, all the men were abusing Lerato. However, they never confirmed that she had been raped.

When Naledi came to live with them, she struggled initially with the change of language from seTswana to Sepedi^{jjjj}. They said, however, they have seen great progress with her. She even received an award for getting the highest marks in Sepedi. They feel this shows that her academic learning has improved. The aunt said that she has been to the school and was in communication with the school, and both the teachers and the family are supportive.

The aunt said that she wants to fight for the house to belong to Lerato and Naledi. She said that Naledi can then live in the house in Mamelodi when she attends the university after school.

Judith thinks that the previous impression we had of the family is not what we observed today. They do not appear to be selfish, but rather they do want the best for Dikeledi's children. She said that they are staying in a good house, Kweda owns taxis, and they are doing well. She is unsure of why Dikeledi did not want to have a relationship with them. Dikeledi had refused to give us her family's contact details, but it is now clear that she used to call Khauhelo whenever she was in a stressful situation.

Their impression about Dikeledi's physical health is that she had TB (tuberculosis). They think that her disability was worsened by her not taking her medication. Khauhelo said that she would visit Dikeledi in hospital, and she would find pills [medication] under her pillow. She said that Dikeledi used to say to her that she did not want to take them, because she could not swallow them.

According to Kweda and Khauhelo, Lerato and Mpho have separated. They suspect that this is due to Mpho's parents. According to them, whenever Lerato has attempted to discuss that Mpho should contribute financially to child maintenance, Mpho's mother has spoken negatively towards Lerato, shouting at her, and "crushing her"^{kkkk} when she wants to speak with Mpho or when Lerato asks Mpho to come and visit Sindi (their daughter). The only time Mpho was able to communicate with Lerato was when he came to visit his family close to Maganeng and one of the uncles sent a message asking that Lerato and Sindi could come and visit them. However, Khauhelo then said that Mpho should rather come and visit Lerato and Sindi at their [Kweda's] house. Culturally, Judith explains, considering they completed the appropriate rituals when the child was born, they cannot refuse him access to his child. However, Mpho did not come to the house. Lerato is apparently always crying and worried, because she grew up without a father, and her daughter is also going to grow up without a father. Khauhelo also suspects that they (Lerato and Mpho) are still in love with each other, but because Mpho cannot hear properly, Khauhelo thinks 'his ears are his mother's'. And therefore, he does not receive the messages that Lerato sends, and they are not communicating well.

^{jjjj} Sepedi and seTswana are similar languages

^{kkkk} A colloquial way of indicating that they are humiliating or belittling her

I asked what the chances are that Lerato and Mpho could live together in Mamelodi. Khauhelo feels that when Lerato is ready, she can go and stay in Mamelodi. However, they are worried that Mpho will want to take over the house and be the man of the house. But they are concerned that Lerato will be robbed of her house, because they realise that she is “struggling mentally”.

Judith advised them that they need to discuss with Lerato what will happen if she decides to get married. It would be wise to sign an affidavit that the house belongs to Lerato and Naledi. She explained to them the benefit of getting married out of community of property with Mpho, especially since the house should also belong to Naledi.

According to the aunt, Lerato has only recently become like their daughter. For a long time, Lerato would be in communication with Mpho’s family and had taken the legal documents of the house to Mpho’s family. Badiri (Dikeledi’s cousin), had to fight with Mpho’s family to have the documents returned to them. They suspected Mpho’s family was conspiring in changing the ownership of the house to Mpho. They are relieved that Badiri now has the documents.

They would like Judith and I to see whether we can get the decree of Dikeledi’s divorce, so that they can have a will that says the title deed belongs to Lerato and Naledi. Apparently, they have no proof that Dikeledi divorced her husband (Naledi’s father). And without this, they are unable to ensure that the house belongs to Lerato and Naledi. However, Khauhelo says she will fight to ensure that the house belongs to Dikeledi’s daughters.

The family would like Mpho to be involved in the life of Sindi. Judith suggested that they meet with Mpho’s mother, and that they discuss the importance of Mpho having a relationship with his daughter.

According to Lineo, Lerato has recently changed significantly. They said that she has now become a Christian, they see her as a “prayer warrior, she is listening to them, and the church is grooming her to become a better woman”. Judith encouraged the aunt to ensure that Lerato receives counselling through her existing support system, with the pastor, as well as through social services.

According to the aunt, Lerato used to be “naughty” and “stubborn” and did not want to listen to anyone. Judith tried to explain the responsibility that she took for her mother and that she “carried a lot of load”. She would ensure that Naledi was prepared for school, she assisted her mother with cleaning, she would assist Dikeledi with her nappies, amongst others. At this, Lerato teared up and left the room.

According to the aunt, they are concerned about the man that Dikeledi stayed with, who fetched her from Maganeng after she became disabled. Initially they thought that he was a “nice man”, however, now they are concerned that he took Dikeledi back to Mamelodi only so that he could “have Lerato”. They do not know whether he was doing it out of “a good heart” or why.

Lerato and Lineo returned to the room with tea and bread with butter. The milk seems to have been freshly obtained, since it was still warm. I ask Judith whether they have agreed and all consented to us continuing with our work and the dissemination of the story, as well as finalising the research and she says yes. We are about to leave when Lerato asks whether there is going to be any money involved in sharing their story. My heart sinks.

Judith explains everything again in terms of how Dikeledi consented to participate in the research study. About how she knew that there were not going to be any financial benefits to participating, but how the story can make a difference to others who may be in a similar situation such as them. How important it is for people to understand what happens 'on the ground'. Very often, when people work in hospitals, they do not always understand the situation of the patients, and what happens in their homes. We try and explain that the story is so important, so that policies can be developed in a way that is context specific.

We further explain that this is not like a book where there are royalties and the author gets money from the people who pay to read it. Their story will remain anonymous, using Dikeledi as the chosen pseudonym. And that we really hope that others will be able to learn, grow, develop, help, and assist with improving the healthcare services, so that the suffering can be reduced.

I can see everyone agreeing to what Judith is saying. Lineo is busy video-recording Judith as she is speaking, using her cell phone. Judith goes through great length to explain, answer any questions, and clarify. The nods continue. Finally, she stops speaking. I can see that everyone is satisfied. We thank them again for their time. They want to take photos with us and we all gather as someone comes in and proceeds to take a number of pictures.

Lerato explains how sad Naledi will be that she missed us. I wish we could stay, but it is still another three hours for us to drive back. We will need to try and get the documents that confirm Dikeledi's divorce so that we can ensure the house in Mamelodi is transferred into Lerato and Naledi's names. There is more to be done, such as ensuring counselling for Lerato, and potential vocational training.

We hug everyone as we leave. They thank us again and direct us the way to drive back to Pretoria. On the way, Judith and I discuss the many important lessons we have learnt from this visit. It seems to us that our current research systems are based on westernised notions of consent. This, however, is an African community, which requires community consent to proceed. I completely understand why Lerato was hoping that there would be money involved. When you are living in poverty, you need to try and find any possible means of income. If your story is the only thing you have, then that becomes your asset. It becomes something you can potentially gain from. I think, in the future, we will need to take video recordings of getting consent from individuals involved in qualitative research. We can then show this to the family members in case the person passes away. If the individual's story involves the lives of the other family and household members, then we need to ensure we understand the kind of consent that he or she has obtained from others in the household to be able to share information. I think, going forward,

one has to always obtain consent for interviewing the entire family. You cannot guarantee that when you are in someone's home, you will only be speaking to one person. Others will come in and go out, things will happen, important and relevant information will be shared. This is an ever-changing dynamic that cannot be controlled by strict regulations.

The most important aspect being that, during ongoing longitudinal research, we always have to remind those with whom we are interacting that there are no financial benefits, if this is the case. Because expectations change and there should be ongoing calls for consent.

My heart is sad, as much as it is grateful. There is so much that I have learnt. I wish I had known many things before already, but I do really, really hope, that this story will indeed make the difference that we envisaged, as we explained to Lerato and her family.



Image above: Lerato and her family, with Judith and myself



Images above: Sindi and I; Lerato and Sindi