EASY-TO-READ VERSION OF

Empowerment Outcomes:

Evaluation Of A Community-Based Rehabilitation (CBR) Programme For Caregivers Of Children With Disabilities In A South African Township

Afrika Tikkun
Developing Young People
from Cradle to Career

By Dr. JEAN ELPHICK
General Manager: Afrika Tikkun
Empowerment Programme

supervised by Prof Zosa Gruber
(nee de Sas Kropiwnicki)

and assisted by co-researchers
Rachel Maisha,
Maria Mashimbye,
Mpotse Mofokeng,
Elizabeth Ramakatsa,
Grace Tente,
Phumzile Vilakazi and
Phindile Xaba

submitted in fulfilment of the requirements for the degree
PhD in Development Studies at the University of Johannesburg

2017

Dedication

This thesis was dedicated to Bertie Lubner. His legacy lives on in our Afrika Tikkun family and all the caregivers and children of the Afrika Tikkun Empowerment Programme.

Acknowledgements

For your unflagging support and input: Carol, Kevin and Rosalind Elphick, Simon Grest and Jean Scrim, Zosa Gruber, Nellie Zembe, Paul Chappell, Elizabeth Ramakatsa, Grace Tente, Maria Mashimbye, Mpotse Mofokeng, Phindile Xaba and Phumzile Vilakazi and the rest of the Empowerment team, the Afrika Tikkun General Managers and our big bosses at head office- in particular Marc, Leonie and Onyi.

This study was funded by The University of Johannesburg's Centre for Social Development in Africa. The Disability Rights Symposium where this study was launched (16 March 2017) was made possible by the Lubner Family Foundation.

Suggested citation: J Elphick (2017), *Easy-to-read Version of Empowerment Outcomes: Evaluation of a Community-based Rehabilitation (CBR) Programme for Caregivers of Children with Disabilities in a South African Township*, University of Johannesburg and Afrika Tikkun: Johannesburg. Please contact jeane@afrikatikkun.org for the long version of the thesis.

Original Abstract (in academic language!)

This study evaluates the change in individual-level empowerment of caregivers of children with disabilities participating in a Community-based Rehabilitation (CBR) Empowerment Component intervention in the South African township of Orange Farm, near Johannesburg. In response to the call for evidence of the outcomes of complex, non-linear CBR interventions and the need for rigorous methodologies to do so, this study draws on existing frameworks and methodologies compatible with CBR principles, human rights and empowerment theory. Using a transformative research paradigm, the study develops a pragmatic yet robust approach to empowerment outcome evaluation that facilitates the meaningful participation of CBR programme clients. The study combines secondary programme data with participatory qualitative data and pilots an innovative, quasi-experimental quantitative tool developed in collaboration with seven co-researchers- all mothers of children with disabilities. By collecting data and analysing changes over a three-year period, this study argues that the caregivers- specifically those who participated in the CBR Self-help Group- exercised increasingly effective agentic strategies in an opportunity structure that gradually became more receptive to their influence. Subsequently, positive change with respect to the access of the caregiver's children with disabilities to human rights was evident. These findings conclude that the CBR Empowerment Component can inform an effective strategy for the promotion of empowerment and human rights among children with disabilities and their caregivers in low-income settings. From a theoretical standpoint, a flexible model of empowerment is therefore proposed centred around the reciprocal relationships between participation, agency and structure, and human rights. Moreover, this study argues that mixed methods should be used to evaluate empowerment outcomes, particularly transformative methods that are devised and implemented in collaboration with CBR clients themselves.

Contents

Introduction

In 2010 Afrika Tikkun asked: 'What is the situation facing families of children with disabilities, and what needs do families have?' After talking to families of children with disabilities in Orange Farm, Alexandra, Diepsloot in Johannesburg and in Mfuleni and Delft in Cape Town it was found that there were **lots of very complicated problems**. Many children with disabilities that lived near Afrika Tikkun were experiencing **human rights violations**. Although some caregivers advocated for their children, most felt powerless.

6 out of 10 children were staying at home and not going to school

Sexual abuse was common, but families didn't know how to report abuse and perpetrators were not arrested, tried or sentenced

Even though they qualified for the Care Dependency Grant to help with all the extra costs of raising a child with a disability, less than half were getting the Grant

Discrimination and prejudice was common, in many cases leading mothers to be abandoned by the father of their child

Children with disabilities were excluded and treated differently- even at Afrika Tikkun, the children with disabilities did not mix with all the other children their age

Caregivers of children with disabilities- mostly single mothers- were disempowered!

The caregivers identified the need for social change, inclusion and acceptance of children with disabilities and psychological support[1].

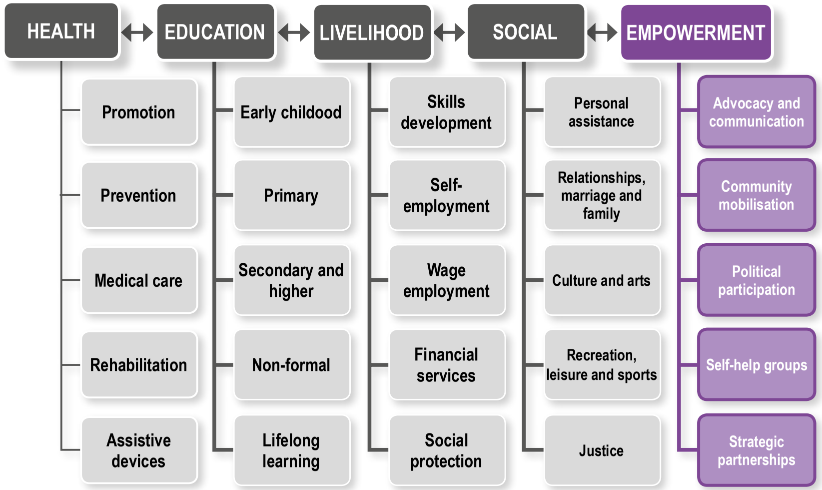
In 2011, Afrika Tikkun started the Empowerment Programme: Children with Disabilities and Their Families in Orange Farm. The Programme strategy was based on the Community-based Rehabilitation (CBR) approach.

> CBR is a strategy for inclusive community development that promotes the 'equalisation of opportunities, poverty reduction and social inclusion of people with disabilities'[2]. Individual ability, self-reliance and informal support are promoted by CBR. These kinds of programmes should provide the 'climate, relationship, resources, and procedural means'[3] for people to improve their own quality of life and pursue their human rights.

The Programme aims to provide a CBR Empowerment intervention to facilitate children with disabilities and their families to work together as agents for change within their homes, community and country, by providing the tools to support each other, access resources and opportunities, and campaign for social change and inclusion wherever services, systems and attitudes exclude children with disabilities. We hoped to achieve this by:

1. Providing educational workshops to empower disabled children and their caregivers to advocate for themselves, and raise public awareness about inclusion
2. Facilitating the development and capacity building of peer-led self-help groups, and strengthening the capacity of the groups to raise awareness and drive social change
3. Supporting self-help group members in the planning, implementation and evaluation of initiatives that promote inclusion of children with disabilities
4. Facilitating access to, and better service from, existing State and private service providers for children with disabilities by providing an advice and referral service
5. Introducing inclusion throughout the Afrika Tikkun organisation

After a year or two of piloting the Programme in Orange Farm, we had new questions about how the Programme was working: 'Does the Empowerment Programme really empower of caregivers of children with disabilities?' and 'Does empowerment make any difference to human rights for children with disabilities?'. These are not easy questions to answer, so that was why we did this study!



How did we define empowerment?

Empowerment is a word that gets used a lot, but is really difficult to define or study. We decided to look at empowerment in two different ways:

Agency and Opportunity Structure

We don't believe anybody, no matter how bad their situation, has no power at all. Everybody has some **agency** inside, that helps them to weigh up their options, make decisions and choose how to act. Agents set goals; plan what to do based on their circumstances; and use motivation and belief in themselves (efficacy) to take action (Bandura, 2009).

People can exercise agency in different ways- sometimes we exercise agency as individuals, but we can also use collective agency by acting as part of a group of people with a similar goal. Alternatively, we can get someone with more influence and power than ourselves to help us by exercising proxy agency.

Not everybody has total freedom to exercise agency. Agents need to learn from their past experiences, and think about the consequences of their actions. Some of these consequences are influenced by the world around them. Culture, beliefs, attitudes and behaviour (Seligman and Darling, 2009), and 'social and political structures' (Narayan, 2005, p.5) all make up the **opportunity structure**.

The 3 Dimensions of Individual-level Empowerment

Another way we can talk about empowerment is by understanding how powerful agents feel inside, if they have the information and skills they need and what powerful action they are taking.

Intrapersonal empowerment is how powerful a person feels (Zimmerman, 2000).

> Do you believe you have the power to influence people, services and systems?

Interactional empowerment is how people use their knowledge when interacting with people, services and systems (Zimmerman, 2000). Communication, mediation, negotiation (Zimmerman, 2000), compromise and persuasion (Field et al., 1998), critical awareness and self-advocacy are important tools.

> Do you know what services and support are available? How good are you at getting people and service providers to help you and your child?

Empowered behaviour is the empowered action that people take.

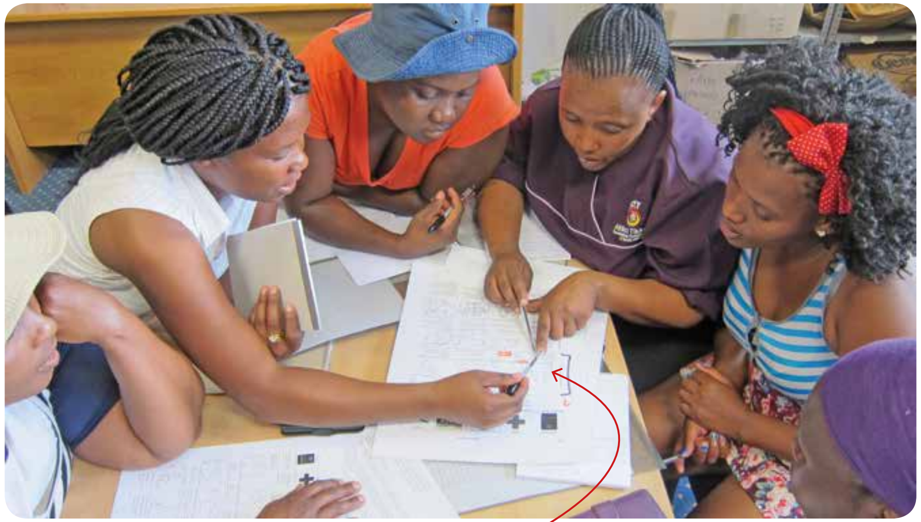
> What action have you taken? What are you doing to change your situation or the situation of your child?

The objectives of the study were:

1. To strengthen the Empowerment Programme by implementing a transformative research process.

> Transformative research actively promotes equality and human rights by doing research in partnership with people who are affected by social justice issues– working together to bring about social change[4].

2. To learn from what others have tried before in research about empowerment and CBR, and develop and test new ways of measuring empowerment
3. To evaluate the empowerment of caregivers of children with disabilities who are registered on the Afrika Tikkun CBR Empowerment Programme, by looking at
   - **a.** How caregivers participated in the Self-help Group started by the Programme,
   - **b.** How the agency of caregivers changed
   - **c.** How the opportunity structure changed
   - **d.** If there were any tangible changes in the access of the caregivers' children with disabilities to human rights



Co-researchers
hard at work!

How did we do the study?

The study used mixed methods, and collected information over time.
We used some information that we already had:

2010:
Baseline
study

2011:
3 Focus group
discussion
transcripts

2011-2016:
Monthly
reports

Then we collected new information to help answer our research questions:

2013/2014:
3 Focus group discussions
18 case study inteviews
81 EmpQ questionnaires

→

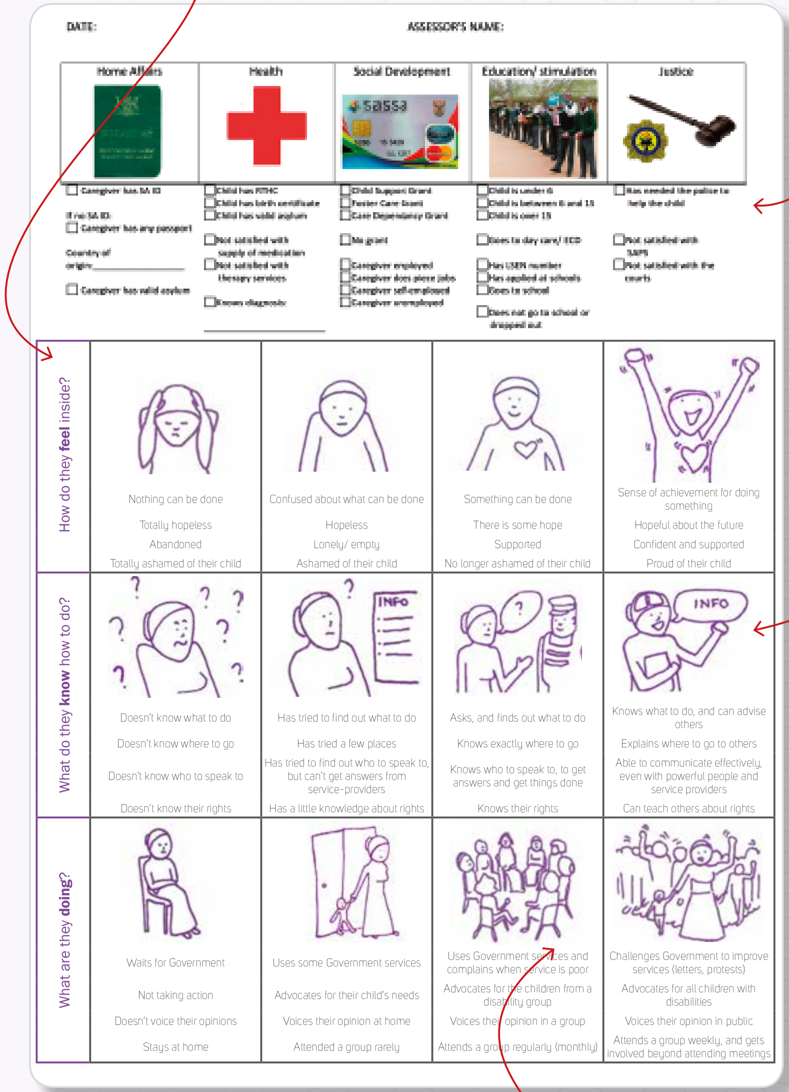
2014/2015:
3 Focus group discussions
18 case study inteviews
66 EmpQ questionnaires

We conducted focus group discussions with caregivers from the self-help group, Afrika Tikkun staff that did not work on the Empowerment Programme, and key informants from outside of Afrika Tikkun. We also did in-depth case study interviews with six caregivers. We interviewed the caregivers and two people that they chose who knew them and their children. We did the interviews in 2014 and again in 2015.

Together with 7 co-researchers (all mothers of children with disabilities from Orange Farm) we developed and used the EmpQ or Empowerment Questionnaire. The co-researchers each surveyed between 8 and 12 caregivers who were registered on the Programme in early 2014 and a year later in early 2015. In 2015, we were able to run statistical analyses on data from 63 caregivers of children with disabilities that participated voluntarily in the EmpQ interviews in 2014 and 2015. After the study, the co-researchers have continued to conduct the EmpQ with the cohort of caregivers each year.

This sections asks
how empowered
they feel

At the top it has check-boxes to
help us understand more about the
caregiver and her child's access to
services.



DATE: ASSESSOR'S NAME:

Home Affairs	Health	Social Development	Education/ stimulation	Justice
☐ Caregiver has SA ID If no SA ID: ☐ Caregiver has any passport Country of origin: ____________ ☐ Caregiver has valid asylum	☐ Child has RTHC ☐ Child has birth certificate ☐ Child has valid asylum ☐ Not satisfied with supply of medication ☐ Not satisfied with therapy services ☐ Known diagnosis	☐ Child Support Grant ☐ Foster Care Grant ☐ Care Dependency Grant ☐ No grant ☐ Caregiver employed ☐ Caregiver does piece jobs ☐ Caregiver self-employed ☐ Caregiver unemployed	☐ Child is under 6 ☐ Child is between 6 and 15 ☐ Child is over 15 ☐ Goes to day care/ ECD ☐ Has LSEN number ☐ Has applied at schools ☐ Goes to school ☐ Does not go to school or dropped out	☐ Has needed the police to help the child ☐ Not satisfied with SAPS ☐ Not satisfied with the courts

How do they **feel** inside?	Nothing can be done Totally hopeless Abandoned Totally ashamed of their child	Confused about what can be done Hopeless Lonely/ empty Ashamed of their child	Something can be done There is some hope Supported No longer ashamed of their child	Sense of achievement for doing something Hopeful about the future Confident and supported Proud of their child
What do they **know** how to do?	Doesn't know what to do Doesn't know where to go Doesn't know who to speak to Doesn't know their rights	Has tried to find out what to do Has tried a few places Has tried to find out who to speak to, but can't get answers from service-providers Has a little knowledge about rights	Asks, and finds out what to do Knows exactly where to go Knows who to speak to, to get answers and get things done Knows their rights	Knows what to do, and can advise others Explains where to go to others Able to communicate effectively, even with powerful people and service providers Can teach others about rights
What are they **doing**?	Waits for Government Not taking action Doesn't voice their opinions Stays at home	Uses some Government services Advocates for their child's needs Voices their opinion at home Attended a group rarely	Uses Government services and complains when service is poor Advocates for the children from a disability group Voices their opinion in a group Attends a group regularly (monthly)	Challenges Government to improve services (letters, protests) Advocates for all children with disabilities Voices their opinion in public Attends a group weekly, and gets involved beyond attending meetings

Here we find out if she
knows where to go,
what to ask for and
what to do to advocate
for her child's needs

Feeling powerful and having skills and
information are great, but now we need to find
out, is this caregiver taking empowered action?

What did we find?

Growing Participation

After the human rights course in 2012, caregivers were offered a series of workshops during which they developed 'collective identity'[5]. They agreed on a mission and objectives for their group, decided on a name, designed a logo and chose the colour purple for t-shirts that were printed. The Sidinga Uthando Self-help Group was started in late 2012:

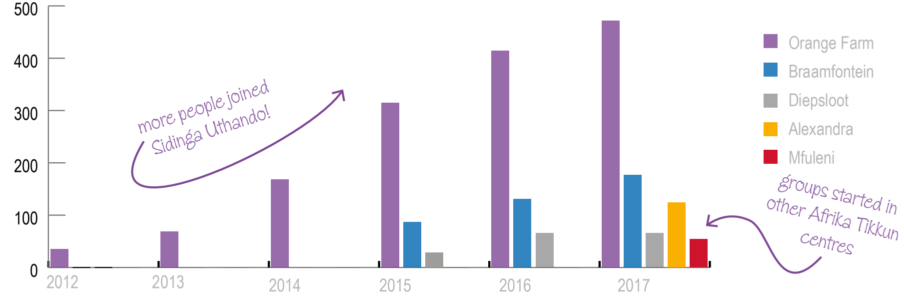
> *'We came up with Sidinga Uthando Self-help Group because, since I have my child, I realised that my child needs love...that is where the name came from...[Sidinga Uthando means] "our children need love"'* (M, CASE STUDY INTERVIEW, 2014).
>
> *'We have our own vision to fight for our children's rights especially equality, education and safety from violence and sexual abuse. We also want to become leaders in understanding our children and teach our community to accept our children as a part of the community and not to discriminate them'* (CASE STUDY INTERVIEW, 2014).

Community mobilisation resulted in the Group growing steadily. Existing members actively recruited new members.

'When I arrived, we were only 12 members but now we have more...there is progress compared to when we started. The achievements that I have seen are that there are new members. It is like every Friday I see a new face. It means that people are joining- they now know about us out there' (P, case study interview, 2014).

In 2017 there are 472 families of children registered on the Empowerment Programme in Orange Farm. The Programme has also been implemented in new sites, as shown in the table below:

Growing number of families of children with disabilities registered on the Afrika Tikkun Empowerment Programme



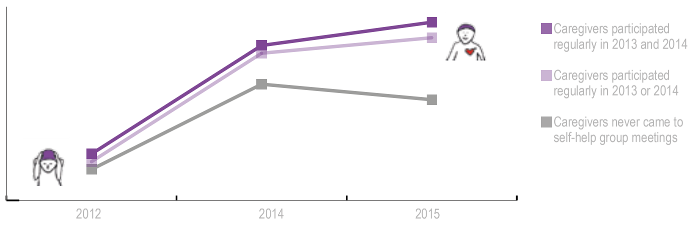
The EmpQ showed that not only did more caregivers register on the Programme, but that over time, caregivers who were registered participated more regularly and became 'involved beyond attending meetings' for instance, by taking up leadership positions.

Increased Agency

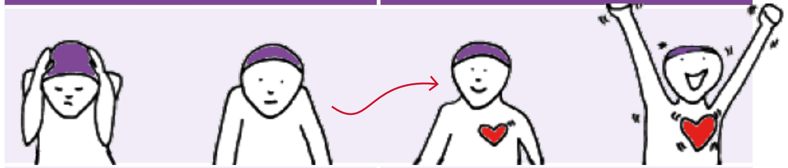
Intrapersonal Empowerment: Self-help Group members feel more powerful, proud, supported and loved!

Empowerment is a 'process' of developing critical awareness, 'courage' and 'inner strength' (Key informant, focus group, 2013).

Intrapersonal Empowerment Improved for Caregivers who participated



Significant changes[1] in intrapersonal empowerment were described by the EmpQ, but also by people that took part in focus groups and interviews. The EmpQ showed that when caregivers looked back on how they felt before joining Sidinga Uthando at baseline, they felt disempowered to a similar degree. Over time, those who participated in the Group began to feel better. Those who attended the Group the most felt the most empowered.



Baseline	After participating in Sidinga Uthando
Almost all caregivers who participated in the Afrika Tikkun baseline study in 2011 said that they did not feel powerful enough challenge the discrimination and exclusion their children experienced. **Some mothers blamed themselves**, believing their children's disabilities were because they did wrong in life or during pregnancy[6]	**'I do not tear up or feel ashamed of myself when I have to share my son's condition with other people. I have accepted my son 100 per cent and that is a very big change for me'** (M, case study interview, 2015). Caregivers also started to believe that changing the way children with disabilities are treated was possible: 'She went from being someone who just wanted to make it work for her child to someone who wants to make a systemic change' (FGD, 2015).
Caregivers were 'feeling hopeless' about their situations (Key informant, case study interview, 2015) and **'in complete darkness'** (Caregiver S, case study interview, 2014).	The Programme 'encourage[d]' caregivers not to lose hope and helped caregivers to **'see the light'** (Caregiver S, case study interview, 2014).
One mother said that before becoming involved with the Group, she was **'sitting at home...feel[ing] like a failure'** (focus group, 2015).	This changed when she became involved with the many activities of Sidinga Uthando making her **feel 'very happy' and like a 'confident person who feels like they can do anything'** (Caregiver, FGD, 2015).

---

[1] Full quantitative analysis available in the full version of the study

Afrika Tikkun staff members believed that the families of children with disabilities needed 'help' to 'manage the burden' of a child with a disability (focus group, 2011). Key informants observed caregivers facing 'social difficulties', 'stigma,' and having 'no freedom'. They observed feelings of 'frustration', 'anger', 'grief and remorse' (focus group, 2013).	The perceptions of people who observed the caregivers changed. For example, a key informant in the 2015 focus group said: **'It's very difficult to actually measure empowerment but watching the dignity change has been the most impressive thing for me. Watching these women, who ordinarily felt that their only option was to let things go, transform to having the self-confidence and the sense of dignity was powerful for me'**
Caregivers felt **'overwhelmed', 'stressed', 'worried'** and **'depressed'** (Caregivers, FGD, 2011). **'When you are alone, you kind of feel isolated and you feel no strength at all'** (Key informant, 2013).	By the end of the study, these words changed to **'confident', 'powered', 'motivated'** (Co-researchers, EmpQ, 2014), **'strong'** (Key informant, case study interview, 2014) and **'tenacious'** (Key informant, focus group, 2013). **'For me the obvious feeling is the confidence. My confidence has really improved and I think that it is the same for the other mothers as well. As I see them on a daily basis, I see that there is an improvement compared to the beginning'** (R, case study interview, 2015).

Changes in the way caregivers felt were linked to participating in Group. Sidinga Uthando expanded networks of 'peer support' (Key informant, focus group, 2015). 'Before every Friday meeting, we agree on the agenda of that particular meeting. We first pray, introduce ourselves and talk about 'good and bad stories' so that we can support one another better' (X, focus group discussion, 2015). The caregivers also supported each other by 'helping', 'comforting' and 'counselling' one another (Caregivers, focus group, 2015). Caregivers described how they could support fellow members by 'respecting her', 'talking positively', 'believing in her' and encouraging determination (Caregivers, focus group, 2015). These findings highlight the role of the 'Group's recognition' of 'individual achievements' as well as 'peer acceptance'[7]. **'What I love about the Group is the fact that we have a lot in common and we understand each other and no one gets judged'**, shared a caregiver in the 2015 focus group. 'If I have to cry I know that I can cry, and I know that I have got a shoulder to lean on' (W, case study interview, 2015).

Some described their friends from the Group as being 'like sisters' that you can 'share anything' with (P, case study interview, 2015). This ranged from 'anything bad' that happened to them, to 'the happier times' (Caregivers, FGD, 2015). P, for example, said she felt it was the one place she could share her 'deepest dark thoughts' (case study interview, 2015).

> 'Sidinga Uthando means everything to me- family, friendship and sisters' (M, CASE STUDY INTERVIEW, 2015).

Caregivers started to feel more 'comfortable' to talk to 'whomever' about their children and disability: neighbours, local children, people 'on the streets', and commuters on taxis and trains (Caregivers, FGD, 2015).

> 'When I go on a train and they will ask about my son [with Autism Spectrum Disorder]. They will ask me: "Why are you so brave about this?" and I tell them about the Group' (B, CASE STUDY INTERVIEW, 2014).

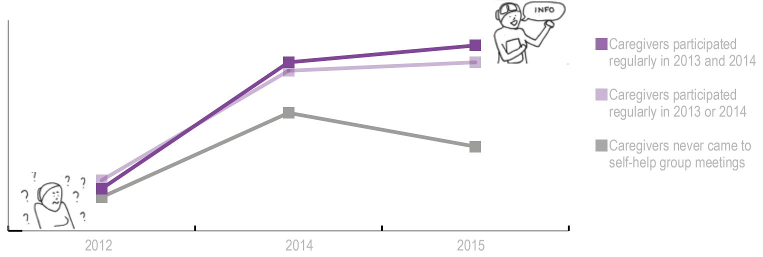
> 'I have changed a lot. You know it was not simple at first, just to talk about your child's condition to people that you do not even know and just to stand up for those people with disability and to go to their house and to speak to them to [invite them to] come to the Group. I was not like that and now I feel I have more power and confidence to do that'
> (W, CASE STUDY INTERVIEW, 2014).

Empowerment did not just help caregivers with respect to their children, the way they felt about exercising agency spilt over into other spheres of life:

> 'Now I know how to make decisions for myself despite what people think. I do what makes me happy now. I used to be a victim of abuse and every time I wanted to make a decision, I would think of my husband and my parents. 'But now no-one can tell me what to do... In 2012, I knew that I had rights and every woman has a chance to live her life, but I didn't realise that I had the power to change things'
> (W, CASE STUDY INTERVIEW, 2015).

Interactional Empowerment: Self-help Group members gained knowledge and skills needed to advocate for themselves and their children

Interactional Empowerment Improved for Caregivers who participated



When the Programme launched in Orange Farm, caregivers were invited to participate in a course on human rights and disability. The workshops encouraged participants to decide what parts of the South African Constitution they wanted to learn more about. Learning did not end there, as this mother described:

> 'We did the human rights course and had some ladies from Autism SA came to talk to us about Autism... A lot of people came to talk to us about how best we can communicate with our children...In 2013, we had the sexuality education course... We had a disability dialogue at the Constitutional Hill...This year we did the new START course[2] and the CP course[3]. We also had the disability dialogue again this year'
> (P, CASE STUDY INTERVIEW, 2015).

The Programme also provided a service for caregivers offering advice, support and referrals for individual children. Most caregivers needed help to access State health, social development and education systems for their children. Networks of referral, processes and recourse protocols were established over time as caregivers and Programme staff learnt from experience and built relationships.

Sidinga Uthando members placed great importance on 'learning opportunities' as 'a building block for the parents' (Key informant, case study interview, 2014). New skills and knowledge included:

1. **Human rights literacy**

   Having encountered so many closed doors when looking for services for their children, learning about what the law said about the rights of children with disabilities was a revelation. Caregivers used this new knowledge to fight for their children's rights:

   > 'When people would say your child has a right to go to school I always thought that they meant 'normal' children and not my child. The first time I heard that my child had a right to go to school was at Afrika Tikkun. I promised myself that I would take my child to school no matter what' (P, CASE STUDY INTERVIEW, 2015).

---

[2] The START course is offered by the Sunshine Centre Association on typical childhood development.
[3] The CP Course is a peer-led course. The carer-to-carer training and resources were provided by Malamulele Onward.

Caregivers highlighted the comprehensive sexuality education course they had completed, saying it was the ‘number one’, ‘most important’ educational opportunity that they had accessed through the Programme (M, Case study interviews, 2015). Self-help Group members learnt how and to whom abuse should be reported.

> *‘We were also taught to make our children aware that people are not allowed to touch their private parts. This has made a huge difference because our children are not being sexually abused any more’* (CAREGIVER, FGD, 2015).

2. **Understanding disability**

Caregivers learnt about disability and skills for raising their children from each other, and from training. This resulted in some caregivers trying new things with their children that helped them in their everyday lives. Caregivers spoke of asking for ‘advice’, engaging in collective problem-solving and talking about ‘solutions’ to problems they were having with their children during Self-help Group meetings (L, FGD, 2015).

There were many examples, but one that stood out was a mother who shared that her daughter was ‘falling a lot’ during a Group meeting (Key informant, case study interview, 2015). Through talking, the Group worked out that the child was having seizures several times a day. The child did not have a South African identity book or Road to Health Card (RtHC) and paying for medical consultations was difficult for the mother because the family was extremely poor. Furthermore, the Group discovered that mother didn’t believe in the seizure medication that had been prescribed: ‘She told us that she didn’t want to give her child medication because it is not right for her child. She thought it would be better if she took the child to a sangoma[4] or to prophets’ (Key informant, case study interview, 2015). To persuade the mother, a caregiver from the Group shared that she and her family had also tried ‘the sangomas and churches for prophets and pastors’ but they ‘didn’t see any difference’ until they learnt to understand her diagnosis with the help of medical professionals (Case study interview, 2014). On the advice of the Group, and using referral letters from the Programme’s advice and referral service, the mother got an appointment and was granted hospital fee exemption. Although she was ‘not OK’ with administering her daughter’s medication at first, she started following the instructions from the hospital’s doctor (Case study interview, 2015). **‘Now we see big changes with her child because she doesn’t fit anymore because she started taking medication for epilepsy,**’ reported a key informant (Case study interview, 2015).

3. **Skills to manage and lead the Self-help Group**

In early 2013, the Self-help Group held a democratic election to appoint 13 members to fill a variety of leadership roles. By 2015 the Sidinga Uthando Self-help Group was established, peer-led and engaged in a variety of activities. Some members voiced the desire for Sidinga Uthando to become an independent organisation: ‘I want Sidinga Uthando to be on a different site- a site just for Sidinga Uthando. I want for it to be registered and to be a stand-alone [organisation]. If we are to get help, I want us, as Sidinga Uthando, to apply for the help by ourselves’ (B, case study interview, 2015). People outside the Group said that the members had the competence to ‘handle’ the Self-help Group and that they would be able to run as a voluntary association (K, case study interview, 2015).

> *‘Even when [the Programme manager] is not here, they are able to handle things. It would be sad if [the Programme manager] was to leave but I believe that the mothers would be able to carry the Programme forward. [The Programme manager] comes [to Orange Farm] sometimes, but they are able to arrange their own functions and they make sure everything is in order’* (KEY INFORMANT, CASE STUDY INTERVIEW, 2015).

> *‘In the coming years, I see the Group doing everything that [the Programme manager] is doing for us, by ourselves. For example, finding people from the relevant [Government] Departments where we need something from. I can see us doing that for ourselves and helping other moms’* (P, CASE STUDY INTERVIEW, 2015).

Leading members of Sidinga Uthando- all individuals with their own agendas and priorities- to become a ‘cohesive working unit’[8] was not easy and did not happen overnight. Conflict and tensions that arose within the Group were often caused when things could not be equally shared among all individual members. For example, some caregivers and their children became enrolled in school before others. This was an issue throughout the study period, however, they were largely overcome as the Group matured. Gradually, the Group demonstrated that they were capable of ‘performing’[9] and achieving their mission:

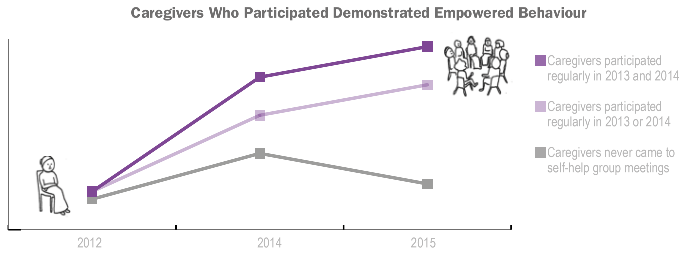
> *‘Our mission is to become leaders in understanding our children with disabilities and fighting for their rights- especially the rights to equality, safety and education- by teaching our community to accept and include our children’* (E, CASE STUDY INTERVIEW, 2014).

Leadership emerged from within the Group: ‘I see [Sidinga Uthando leaders] as people who are very understanding and they are very patient. They have a very good way of working with people. And if there is a fight, they always have a good solution’ (L, case study interview, 2015). However, it was also acknowledged that the Group leadership was not invincible: ‘You know when you build a house the foundation has to be strong because if the foundation is weak the house will fall. I feel like the foundation of our Group is not strong enough,’ said a caregiver (FGD, 2015). She, like others, felt that although the Group was strong, and there were people who had been ‘trained to lead’ (Caregiver, FGD, 2015), the leaders would only be successful if the members ‘supported them’ and ‘respected each other’ (Caregiver, FGD, 2015).

In summary, the caregivers found within the Group a wealth of advice, helpful contacts and support. As individuals and a collective, caregivers were able to identify problems, discuss possible strategies to tackle them, and had support to take action by exercising agency directly, or through a proxy. Many of the issues they encountered were practical problems, and caregivers learned from others in the Group about what worked for others in similar situations. Caregivers also felt inspired by others who had succeeded, and this motivated them to take action themselves.

Empowered Behaviour: Self-help Group members started doing more to advocate for disability rights and challenge the status quo

Just getting involved and participating in Group meetings on a regular basis is a demonstration of empowered behaviour. Of all three dimensions of empowerment that the EmpQ measured, the most dramatic change was shown in empowered behaviour. Once again, those who participated in Sidinga Uthando became significantly more empowered than those who never participated.



Even formerly ‘shy’ Self-help Group members who used to ‘take a backseat’ started ‘really getting involved’ and ‘doing something’ (B, case study interview, 2014). Some of the important ways that caregivers took action are summarised below:

1. **Mobilise the community**

In the Participation section above, we described how participation in the Group grew. The members of Sidinga Uthando were largely responsible for this by using word of mouth:

> *‘We are always raising awareness everywhere we go about the support Group here. We invite people that we see need the support. And if I invite a person, that person will invite someone else and it goes on and on like that. The new members are from everywhere: the hospital, clinics, malls and churches!’* (M, CASE STUDY INTERVIEW, 2015).

---

[4] A sangoma is a traditional healer.

Although the caregivers increasingly mobilised and participated in the Group, not every Group member became 'involved beyond attending meetings' (EmpQ, 2015). As one key informant put it: 'They have different personalities. Not everyone is a leader and some people are just happy to go along' (FGD, 2013). Overall, however, and certainly within the EmpQ cohort, caregivers were not passive recipients of services, and many took a lead in mobilising caregivers like them to join forces with the Group.

2. Provide peer support

The support caregivers received transcended the weekly meetings in several ways, and provided concrete examples of 'bonding social capital'[10]. The caregivers made 'social connections'[11] outside of the weekly meetings and events. For example, one mother shared that when she didn't understand English-speaking guest speakers who came to the Group, she would call another mother afterwards to 'explain nicely' to her (Case study interview, 2014). Another mother used her free airtime minutes to call Group members when she missed meetings. She described how she used the Group's WhatsApp chat group, pictured below, to keep 'in the loop' and to 'know what was going on' (P, Case study interview, 2014).

Im impressed..and touched at the same tym..dis is amazing 11:32

Well done phumzie and mxo 11:33

Maria Mashimbye
Phum we are really proud of mxolisi 19:00

2 DECEMBER 2015

+27 74 088 0284 ~Bra.I
Phumzie we are very proud of u for what u has done mxolisi keep on supporting ur child 00:25

Elizabeth Ramakatsa
Morning ladies! 08:53

There will be a Child Protection Road Show on Monday the 7th at Mkhabela's Place at 09H300. Let us join hands to fight for our children's rights

Self-help Group members assisted each other in practical ways- including babysitting for one another when they needed to go somewhere, sharing assets and providing physical presence and support for Group members going through difficult times. A key informant described the peer-support she witnessed. She recounted how 'every single one' of the Group members had sat through a rape trial at the Vereeniging Magistrates Court with 'immense dignity' to support a complainant who had Cerebral Palsy (FGD, 2015). She felt that their support and their public condemnation of the defendant's actions was 'more empowering than the actual process of the justice system, which [wa]s actually quite disappointing' (Key informant, FGD, 2015).

The support caregivers provided each other was not necessarily directly related to disability. The Group members recognised the difficulties that unemployed non-South African caregivers faced, for example, especially if their children were not eligible for social grants. Fellow Group members helped some families by sharing food and clothing. One non-South African mother said that one of the other Group members had a daughter just older than hers, so outgrown clothes were passed on to her daughter. Another caregiver bought her family a food parcel and other groceries at Christmas time.

3. Persevere

Caregivers did 'not give up' when they 'hit walls' whilst advocating for their children (Key informant, FGD, 2015). They took on complicated and dysfunctional Government systems and often experienced disappointment, unfair discrimination and injustice.

> *'I worked so hard to find a school for my child in 2011 and I found a school in 2012. My child is attending a school now and I am trying to help other moms and give them advice because sometimes they lose hope and some are not patient. I always tell them that I failed to get my child into more than ten different schools but I didn't give up'*
> (CAREGIVER, CASE STUDY INTERVIEW, 2015).

> *'S is not the kind of mother who just sits and does nothing, she is always pushing'*
> (KEY INFORMANT, CASE STUDY INTERVIEW, 2014).

> *'After fighting for the school and winning the fight, I realised that nothing is impossible for people who work together and do not give up'* (CAREGIVER, FGD, 2015).

Even if they weren't always successful, they had the resilience to keep trying: 'I didn't really get help from the Police but at least I now feel comfortable enough to approach the Police when I have a problem that needs their attention' (FGD, 2015).

4. Raise awareness and address attitude barriers

> *'I always talk to people even when I meet with people on the street. This thing of teaching people is the biggest thing, by talking to the people and keep talking, we can change attitudes and we can win this'* (CAREGIVER, CASE STUDY INTERVIEW, 2014).

The awareness campaigns emerged as an important activity among most Group members. The Clinic Awareness Campaign and Paint It Purple was initiated by the Group and the Group maintained ownership of the initiatives. 'Going out' and 'doing something' reinforced self-efficacy and encouraged the caregivers to exercise agency with respect to other issues in their lives (Caregivers, FGD, 2015):

> *'When we went to the clinic to raise awareness, that was the biggest thing for me. Truly speaking, we can be fancy but if we do not go out and speak about our children, we are not doing anything'* (P, CASE STUDY INTERVIEW, 2015).

The Group used Campaigns and speaking opportunities to make people aware that children with disabilities have rights, but rights are sometimes 'not really true in their lives, they are just taken away from them' (Case study interview, 2014).

> *'I think the mothers themselves are spokespersons within their communities, they can advocate for their children'* (KEY INFORMANT, FGD, 2013).

Self-help Group members addressed audiences which increasingly included influential figures. These included: local ward councillors; the mayor of Johannesburg; members of the Department of Women, Children, and Persons with Disabilities and the Department of Social Development; university students; school and youth groups; other support groups for parents of children with disabilities; prosecutors and legal aid workers; human rights activists; researchers and journalists (Programme monthly reports, 2013, 2014 and 2015). Towards the end of 2015, three Self-help Group members prepared and delivered three oral presentations at two different conferences (Programme monthly reports, 2015).

4. **Organise campaigns and events**

The Group members took initiative and responsibility for arranging events and campaigns, like the **Clinic Awareness Campaign**. Another example that stood out was The Annual **Afrika Tikkun Kopano Kematla Inclusive Fun Run** that the Self-help Group organised from 2013 onwards.

A highly successful campaign was called the **Paint It Purple Campaign**. Using the colour of Sidinga Uthando as a symbol of the Group's mission to promote equality and inclusion, Group members began in mid-2015 to paint their houses purple:

> *'We went to paint at the children's homes and wrote the names of the children and the types of disabilities they have on the wall so that people may ask what is happening there. We use that as a chance to explain to them and teach them about the conditions of our children'* (CAREGIVER, FGD, 2015).

The Group uses one meeting per month to gather at a fellow member's house to paint together.

To date 25 houses around Orange Farm have been painted, and the Campaign has been recognised by the community, and the local and international disability community alike. During Disability Rights Month in 2016, the former minister of the Department of Women, Children and People with Disabilities, and current Deputy Minister of Social Development, Henrietta Bokopane-Zulu joined Sidinga Uthando to paint.

5. **Voice dissatisfaction**

Caregivers and the Group used effective communication and self-advocacy to make their voices heard. For instance, they complained directly about unsatisfactory service and asked questions 'when they didn't understand' (Co-researcher, EmpQ, 2014). Some said that they were willing to be 'stubborn' when people did not accommodate their children (Caregiver R, case study interview, 2014).

> *'Sometimes we blame the Government and say they are not doing anything when we are the ones who don't go out to look for help. Being part of the Group has opened my eyes and I now know which doors to knock at when I need of help. The clinic campaign also taught me that I can also be the change that I want to see– I shouldn't sit down and complain. I must do something about my problem'* (FGD, 2015).

Caregivers used their collective voice to assist fellow Group members' children by recognising the power of 'representation, collective identity, solidarity and...recognition'[12]. The caregivers discovered that if they returned to a service provider who had treated them unfairly, accompanied by a few other Self-help Group members, they were treated differently.

> *'At first they didn't want to help me but when they realised I had support from the Group, they ended up helping me...unlike before'* (CAREGIVER, FGD, 2015).

Caregivers didn't just use their self-advocacy skills for their children, they applied them in other areas of life too:

> *'I think she is now empowered. Before she was even afraid of her husband when he abuse her, but right now she is able to tell the husband if [he] can do any kind of abuse [he will] regret [it]'* (CO-RESEARCHER, EMPQ, 2014).

6. **Hold duty-bearers to account**

Self-help Group members 'worked together' in an 'amazing way' to advocate for the rights of their children (Caregiver, FGD, 2015).

Caregivers had the courage to ask difficult questions. For example, when an official from the Department of Basic Education visited the Self-help Group a mother stood up and said, **'We've done all these things [to enrol our children in school], what are you going to do?'** (Key informant, FGD, 2013). In doing so she demanded accountability and held the duty-bearers responsible for the implementation of inclusive law and policy. She 'really put the woman from the Department of Education on the spot' (Key informant, FGD, 2013).

To further advocate for their children Sidinga Uthando got organised. They actively found new members with out-of-school children and established a list of children to demonstrate the 'extent of the problem' (Key informant, FGD, 2015). They also did other things like writing letters and 'dr[awing] up a petition,' (Caregiver, FGD, 2015). Caregivers mobilised and used 'strength in numbers'[13] to exercise collective agency with a 'unified' voice (Staff members, FGD, 2015) which was 'better heard than when they work as individual parents' (Key informant, FGD, 2013).

7. **Engage with 'the experts'**

The caregivers began to recognise their 'insider's expertise'[14], and the value of their experience of raising a child with a disability. This had an impact on fellow caregivers, but also on the professionals that they came into contact with, leading a social worker to remark:

> *'She has taught me a lot...You know I have been a social worker for many years but I had never worked closely with parents of children with disabilities. This is for the first time and what I can say is that I am taking note of what I am learning every day from Caregiver M... [She] is my reference'* (CASE STUDY INTERVIEW, 2014).

Sidinga Uthando members also started teaching others about disability and human rights: 'I can see that we are growing because Jean used to be the only one teaching us before, but now the other [Self-help Group] members are teaching us' (P, case study interview, 2015). In addition to peer education, caregivers were able to teach people usually seen as 'the experts':

> 'I was amazed...the [mothers] had this belief in themselves...They answered questions that they were being asked by social workers and other professionals, what I found is that they actually trusted their judgment more...They have used their status as mothers of children with disabilities to show people that life goes on. They have really embraced it, especially in a teaching environment, they have the confidence to talk about the different experiences that they have gone through and they present it with so much belief in themselves'
>
> (KEY INFORMANT, FGD, 2015).

Changing Opportunity Structure

Empowerment 'operates within the social, cultural and familial context' of the caregivers'[15] lives. These contexts are the opportunity structure. They have the 'potential to empower and to oppress'[15]. Several big changes made it easier for caregivers to exercise agency- the most important ones are summarised below:

1. Attitudes changed

The caregivers noticed some changes in the attitudes of the people and service providers they encountered. Attitudes of Afrika Tikkun staff changed too. In 2011, a staff member said, 'Sports deals more with physical activities and children with disabilities cannot participate, obviously' (FGD, 2011), in 2013 a staff member said, 'Obviously we can't leave them out' (FGD, 2013).

This response from the 2013 focus group discussion shows empathy not pity which was not demonstrated by staff in 2011:

> Q: 'How would you feel if your child had a disability?'
> A: 'I would feel scared, stressed, alone and lastly, blessed. I would be scared for my child because I do not know if she will be courageous enough to face the negativities of the world, but I would not be worried what people will say. I would also be worried about if he or she is coping. I would feel alone because I have never been in this kind of a situation before but blessed because I believe that every child is a blessing' (STAFF MEMBER)

Staff members also helped to show that the attitudes of caregivers themselves had shifted, allowing their children to live fuller lives:

> 'Before joining the [Self-help] Group, whenever they would mistreat him, I thought they were doing the right thing. Since I joined the Group, I know that no one has the right to abuse my child or beat him up. [Now] I got used to allowing him to play outside and our neighbours now understand his condition better and the children in the community no longer bully him'
>
> (CAREGIVER, FGD, 2015).

2. Inclusion was introduced at Afrika Tikkun

New opportunities for children with disabilities became available. A highlight was the inclusion of children with disabilities and other barriers to development and learning in the Afrika Tikkun Early Childhood Development (ECD) programmes. Of the 215 enrolled children from Orange Farm in 2016, 33 children had developmental delays, representing 15 % of the children enrolled. On follow-up assessment by an occupational therapist 8% of the Orange Farm ECD children were found to have disabilities (Programme quarterly report, 2016). Four children that graduated from Grade R in 2016 had disabilities.

Although not all staff welcomed inclusion, it became increasingly recognised. Staff said that they wanted more training- especially for ECD practitioners- to help them to 'give them ideas of which programmes can include people with disabilities' (Staff member, FGD, 2013).

3. 'Professionals' started taking caregivers seriously

Caregivers gained skills, competence and confidence, so they could engage better and communicate more effectively with doctors and other professionals. The Programme facilitated this by supporting caregivers to collaborate with people who could help them. This included, 'obtaining the assistance of lawyers; presenting memoranda to relevant officials; and raising awareness amongst the police and various professionals'12. Most of the time these professionals were different from the caregivers in terms of socio-economic status, race and home language, but caregivers started overcoming these differences and building alliances.

> 'The way they were conversing with other people and with the other professionals was very much on an equal level. They did not see themselves as inferior to the social workers or the forensic psychologists. They saw themselves as being on an equal footing'
>
> (KEY INFORMANT, FGD, 2013).

Shifting power dynamics was highlighted by a key informant as being particularly significant because of South Africa's history. 'You know historically, we always being told what to do, never allowed free thinking in terms of what we want and asking for what we need' (Key informant, FGD, 2013). When caregivers started asking for help, the people they relied on for professional services were able to engage better and be more helpful.

4. **Advice and referral made it easier to access services and systems**

Having documentation of a diagnosis is the first step towards accessing systems and support services for children with disabilities, but in 2014, 10% of the children registered on the Programme did not have medical diagnoses. Even after getting a diagnosis, there are so many other steps in the process. Some of these steps include:

- Accessing mediation, therapy and assistive devices
- Applying for a Care Dependency Grant
- Enrolling in school

Depending on the child's needs, there can be dozens of steps, each with complications and confusing detours. 34% of children had Cerebral Palsy (CP). This can be a very complicated condition because it involves multiple impairments and complex needs. Caregivers often need to use services from lots of different departments, often in multiple districts and jurisdictions. Having the support of the Afrika Tikkun Empowerment Programme's Advice and Referral service helped map out the steps that caregivers needed to take for their children, making the process easier. It also helped put caregivers in touch with the right people, instead of them going 'up and down' until they found what they needed for their children (V, case study interview, 2015):

> *'I didn't know where to start looking for a school and how to do that until I joined the Group'* (CAREGIVER, FGD, 2015).

> *'It was so easy because of the help that we received here. When we arrived at the school, they said they needed an LSEN number. But because we are a part of this Group, our children had all been assessed by the Gauteng Department of Education and so we already had LSEN numbers'* (E, CASE STUDY INTERVIEW, 2015).

Better Access to Human Rights

Children with disabilities became more equal citizens in the Orange Farm community

Access to human rights is difficult to measure, just like empowerment. Although we cannot say that changes in human rights access were caused by the Afrika Tikkun Empowerment Programme or Sidinga Uthando, the study did take note of changes in how caregivers and children experienced the following rights:

Section 9 Equality: 'the right to be free of unfair discrimination'

In the early parts of the study, discrimination, stigma and prejudice were the norm. Even in 2014 a caregiver said: 'I can say I am still fighting for equality because it is not an easy road, even for example to the clinics, to the hospitals and to everywhere, even the taxi rank...I feel it is not yet solved' (case study interview, 2014).

Over time, children were treated more equitably, got more opportunities to leave their homes and access important services.

'I remember that before joining the Group I would hide my child in the house in fear of what other people would say and my child had no freedom like other children. I thank God for this Group and the support I got from Jean and other ladies because the Group has opened doors that were closed' (Caregiver, FGD, 2015).

Section 12 Safety and Freedom: 'the right to freedom and security of the person, which includes the right…to be free from all forms of violence; not to be tortured in any way; not to be treated or punished in a cruel, inhuman or degrading way'

An audit of violence perpetrated against children with disabilities registered, showed that by mid-2015, 17 cases of abuse were reported to the Programme's Advice and Referral Service. Abuse affected girls more than boys. Emotional and physical abuse, child marriage and kidnapping were reported, but rape and sexual assault were most common[13].

Caregivers said: '[Violence] is still a problem in the community but not amongst members of our Group' (Caregiver, FGD, 2015). They felt that they were better able to prevent abuse, and knew what to do if something happened. Although they had done other things, including participating in the launch of a Disability Desk at the local police station, the caregivers attributed the biggest difference to the comprehensive sexuality and life skills education they received:

'I feel like my child is safe now because I know his rights and I have been taught about rape and how to fight for my child's rights' (Caregiver, FGD, 2015).

Section 27 Access to food and water, healthcare and social security

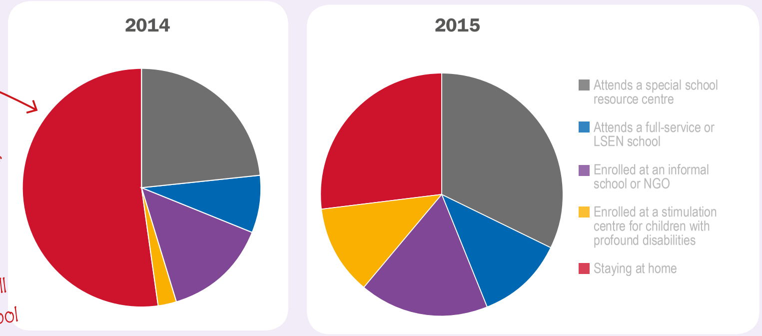
The Afrika Tikkun Empowerment Programme's assistance and the clinic awareness campaign changed the way caregivers experienced healthcare services. In 2011, caregivers said that they were 'scared to go back for other follow-ups...because they know they are not gonna be treated the same as other parents' at the clinic (Caregiver, FGD, 2011). By the end of the study, caregivers said:

'I love the fact that we are no longer discriminated against in clinics and we are respected like other people. In the past we were treated differently' (FGD, 2015).

'I took my child to the clinic last month. Before the [Clinic Awareness] Campaign, were done, the nurses would ask you a lot questions including why you kept the child at home until they got so sick. Having to explain to them that your child had a disability was very annoying and that made me feel uncomfortable. After the Campaign, I noticed that they attend to our children as soon as we get to the clinic wearing our Sidinga Uthando t-shirts. We don't even ohave to queue up. They now give our children better care and treatment' (Caregiver, FGD, 2015).

In 2014, 48% of children with disabilities were accessing the Care Dependency Grant. A year later, 62% were accessing the Grant. 60% of those not accessing the Grant in 2015 are not South African citizens and are therefore not eligible (EmpQ, 2014 and 2015).

Section 29 Basic Education:



In 2014 more than half the children were staying at home. In 2017 just 19 out of 473 children are still not enrolled in shchool

Many children became enrolled in school, and a new school, Duzenendlela LSEN School opened in the community.

First day at the new school!

'This year 13 of our children got a school very easily when before you would have to fight and wait for a very long time before your child could get a school. There were no problems and no discrimination' (Case study interview, 2015)

'I want to talk about education. When I joined the Group my child was not going to school and would always cry when his brother was getting ready for school. It used to hurt me a lot when he asked me why he was the only one not going to school. [The Programme] has helped me find a school at Duzenendlela for him. They said they will call me after the tenth of February for me to buy uniform for the child and send the child to school once they have moved to the place across the road. I am very happy about that' (Caregiver, FGD, 2015).

Factors that continued to disempower

Even if the findings were positive overall, some disempowering issues remained, and sometimes held caregivers back from participating, exercising agency or challenging the opportunity structure:

1. **Poverty**

> 'I cannot do anything...I feel terrible because I do not [have money to provide] for my child' (L, CASE STUDY INTERVIEW, 2014).

2. **Gendered social norms surrounding childcare and disability**

97% of caregivers were women.

> 'Because men are mostly traditional, they don't want to deal with [disability]' (STAFF, FGD, 2011.).
>
> 'Probably the man is gonna blame the wife. Or the mother-in-law will blame the mother. They will say: "This is your child. You need to take care of her"' (KEY INFORMANT, FGD, 2011).
>
> 'She need[s] a social worker. She is a victim of abuse. She is stressed. Poor attendance in Group because her husband is not supporting the situation of the child' (CO-RESEARCHER, EMPQ, 2014).
>
> 'He refused to attend because he thinks that these Groups are mainly for women' (L, CASE STUDY INTERVIEW, 2015).

3. **Personal setbacks**

Even among resilient, 'strong' and 'persistent' caregivers, setbacks frequently occurred and forced caregivers to re-evaluate their assets and capabilities (Key informant, FGD, 2015).

> '[The mother] was more powered but after her husband died she is feeling down again. She is not happy. She won't afford school fees because she is not working and her husband passed away. She is not OK about everything' (2014).

4. **Citizenship**

The impact of citizenship on empowerment was frequently referred to in the co-researcher's comments on the EmpQ. One mother, who occupied a leadership position in the Self-help Group, was described as 'so strong' and 'powerful' (Co-researcher, EmpQ, 2015). Despite 'knowing her rights' and 'wanting to go forward' a co-researcher said that she needed 'more support because [she had] no identity book from South Africa' making her 'powerless' (EmpQ, 2015). For some, the situation impacted on how hopeful they felt about the future:

> 'She is not happy at all because she does not have identity book. The child doesn't have birth certificate. He has no grant. She is still looking but there is no hope' (CO-RESEARCHER, EMPQ, 2014).

5. **Slow-changing structural barriers in State systems**

Although many children gained access to some fundamental rights and things were 'better than before' all problems with service access and service delivery were not solved, nor did every child access the services they needed (Caregiver, FGD, 2015). For example, in 2017, 19 out of 473 children are still not enrolled in the education system. They range in age between 7 and 13 years old.

> 'The problem I still have is the fact that I can't find the right school for my child... When it comes to education, the Group still hasn't helped me as much I want it to' (CAREGIVER, FGD, 2015).

What can we learn from all this?

Transformative Research was a helpful and empowering approach

The study purposefully worked towards building an authentic 'partnership with research participants as both individuals and as a group'[14] by collaborating with caregivers of children with disabilities in a 'joint effort to bring about social transformation'[15]. The most successful part of the study was the collaboration with the co-researchers on designing and using the EmpQ- an effective and useful tool that the Programme now uses with every Empowerment Programme client.

What did co-researchers say?

Quotes are from co-research de-briefing meetings held in February 2014 and January 2015

> 'We were looking for evidence to see if there is a difference by coming to the Group, to understand if the Programme is helpful,' explained Mpotse.
>
> In 2014, Phindile said, 'I heard some tragic stories. Some were very personal stories so I had to be strong not to cry...They hit close to home.'
>
> Elizabeth reflected, 'Doing this and seeing other caregivers' situations made me thankful for to have what we have.'
>
> In 2015 Maria said, 'I saw empowered caregivers as those who are brave enough to stand by themselves, have the information and knowledge to know where to go for help, and do things for themselves.'
>
> Phumzile said, 'This research gave me perspective about my own life.'
>
> Grace said, 'It was super to have a job. I gave it my all.'
>
> Rachel said: 'Doing this research makes me feel like a more decent and important person.'

At the time of the first co-researcher workshop, all seven mothers were unemployed. Today all but one have jobs. One has qualified as an Auxiliary Social Worker with a second enrolled on the course. Each in their own way, they continue to act as role models in their community and within Afrika Tikkun.

We can't show causality, but the findings suggest that empowerment outcomes (participation, increased agency and changing opportunity structure) promoted human rights in Orange Farm

This study on its own can't prove that the Afrika Tikkun Empowerment Programme led to empowerment, but the findings do suggest that the CBR strategy used by the Programme does help promote empowerment of caregivers of children with disabilities and the enjoyment of human rights among their children. In South Africa, where there are implementation gaps for many government services, the State needs to be held to account for essential service delivery, policy or legislative implementation- especially among those who often get excluded. This study showed that a small group of agents who worked together were remarkably effective in bringing about tangible changes in their children's lives. Our next challenge is to find out if the Afrika Tikkun Empowerment Programme can produce replicable outcomes in other communities and if the strategy can be effectively scaled to provincial or national level.

---

1 Narayan, 2005, p11
2 Elphick, 2010
3 Gulati et al., 2011, p72
4 Dalal, 2010, p.423
5 Tuckman, 1965, p.396
6 Narayan, 2005, p.11
7 Bates and Davis, 2004, p.196
8 Narayan, 2005, p.11
9 Narayan, 2005, p.11
10 Carter et al., 2007, p.529)
11 Fazil et al., 2004, p.396
12 Rule et al., 2015, p.19
13 Elphick and Siziba, in press, p.6)
14 Marshall and Batten, 2004, Article 39
15 Mertens, 2014, p.21

EASY-TO-READ VERSION OF

Empowerment Outcomes:

EVALUATION OF A COMMUNITY-BASED REHABILITATION (CBR) PROGRAMME FOR CAREGIVERS OF CHILDREN WITH DISABILITIES IN A SOUTH AFRICAN TOWNSHIP

This report was created by the Afrika Tikkun Empowerment Team to share what we learnt from a study that we did in Orange Farm. The study is over 300 pages long and the language it uses is not easy to read. That is why this version offers a simplified version, so that caregivers of children with disabilities can learn from the study they took part in. The full version of the study is available on request from Afrika Tikkun.

AFRIKA TIKKUN
EMPOWERMENT
PROGRAMME