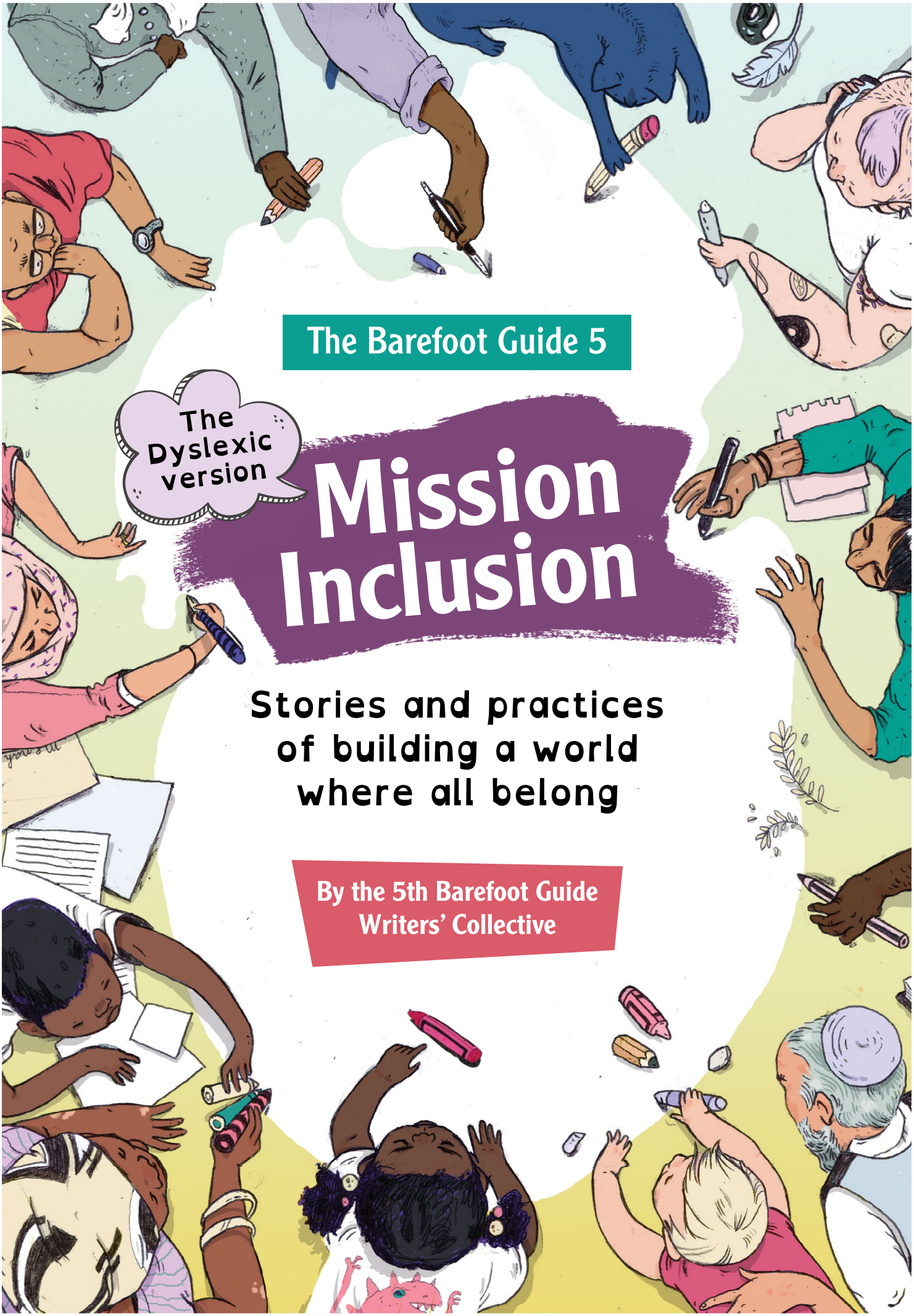

The Barefoot Guide 5

The Dyslexic version

Mission Inclusion

Stories and practices of building a world where all belong

By the 5th Barefoot Guide Writers' Collective

This publication has been made possible through the valuable support of these partners of the Barefoot Guide Connection

MISSION INCLUSION

Stories and practices of building a world where all belong

By
The Fifth Barefoot Guide
Writers' Collective

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How this guide was developed

From 2011 until 2016, a multi-actor programme was run in five countries to improve the life chances and living conditions of people experiencing exclusion and marginalisation of various kinds. This programme worked with local leaders, organisations and movements as well as various institutions and authorities focusing on older people, those with mental health issues, people with disabilities, ethnic minorities, people displaced by war and youth at risk. Many initiatives were developed that had lasting effects on the ways in which these groups valued themselves and in which they are valued by society.

The experiences gained through this programme were distilled in a publication called *Embracing Practices of Inclusion* (published on the Barefoot Guide Website). It was written by a number of those who had themselves participated in the programme. The publication revealed a great number of interesting lessons that aroused further curiosity about the work that was being done on inclusion around the world.

The Barefoot Guide, Mission Inclusion was born at a writing workshop of inclusion practitioners in May 2016 in Alkmaar, the Netherlands. Practitioners from Kenya, Bangladesh, Vietnam, India, Georgia, Lebanon, Uganda, the United Kingdom and the Netherlands gathered there to produce amazing stories and poems on inclusion. These were further developed, peer reviewed, and then handed over to the editorial team. New writers, from several more countries, including Madagascar, Argentina and South Africa, who hadn't attended the workshop, were invited to contribute their stories too.

The editorial team then discussed the patterns that emerged from this rich and varied material and wove them into a coherent whole. This joint effort has led to this wonderful mix of stories, case studies, poems and vignettes – all of which we believe add greatly to the discussion about inclusion.

After an editorial team meeting in the Netherlands in May 2017, and a last flurry of activity, including collaboration with illustrators from across the world, this guide has now been published to join the four previous *Barefoot Guides*. It is a free downloadable resource available to all. We hope that all readers will enjoy reading this guide as much as we have enjoyed developing it.

A note on the Dyslexie typeface used

Dyslexie is a typeface/font designed to mitigate some of the issues that dyslexics experience when reading. It was developed by Dutch graphic designer Christian Boer while in college to help combat his own dyslexia.
Two versions of this Barefoot Guide have been produced, one with and one without the Dyslexie typeface.

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We are Able

So what if I can't hear the rain
Don't we all get drenched the same?
What does it matter seeing the sun,
When I feel her touch upon my arm?
Why should I jump, climb or run
When I can smile and joke for fun?
So what if you can speak and talk
Don't actions speak louder than words?
I need not worry to have a hand
For you, friend, are my helping hand

We all feel sad, we all feel joy
We are all human, girl and boy
So why then are we so unfair,
Don't we all breathe the same air?
Why do we not seem to care,
letting each one their burden bear?
Why don't we all embrace each one
For surely all together we can.
Let's rid the world of barring labels
For though we are different, we are able!

– by Brenda

PERSONAL STORY 1

Anita gets lost, Alejandra does not

– by Carolina –

In 2010, I had a once in a lifetime experience: I had the privilege to accompany Alejandra Manzo, an actress with Down Syndrome, and Victoria Shocrón, a social entrepreneur, to the San Francisco Jewish Independent Film Festival. The film "Anita," starring Alejandra, had been publicly voted as best film. This account reflects a moment during the awards ceremony that moved me deeply.

Vicky, Ale and I get comfortable in our reserved seats at the Castro Theatre, and I can feel the looks and hear the whispers of the audience. We are accompanying "Anita." In a few minutes, she will fill the screen. The director of the Film Festival welcomes us. His voice conveys pride and admiration when he reads the words of Marcos Carnevale, the director and writer of the winning film, who is not with us that night. "I invite you to look into the eyes of Anita and to feel the world through her."

The lights obey Marcos, and Lito Vitale's music submerges us in this fictional tale, which could so easily be true. Following the attack on the Argentine Israelite Mutual Association building[1] in 1994, a young person with Down Syndrome gets lost in Buenos Aires. In the next 120 minutes, we see Anita experiencing solitude, failure, and discrimination. Anita simply lives, she does not judge, she does not discriminate, she doesn't even try to find her way back.

I am completely fixated on the screen. The coming explosion draws near. Alejandra anticipates it and takes my hand. She knows what Anita will suffer. So much so, that when the explosion comes and the entire theatre jumps, Alejandra tightly squeezes my hand and begins to cry.

Is this really happening? Am I, Carolina Tocalli, in San Francisco, surrounded by Jews who are moved by the memory of another attack on its community, with my hand being held by the chubby hand of the lead actress, whom I just met yesterday and who now cries inconsolably?

> ***"I invite you to look into the eyes of Anita and to feel the world through her."***

---

1 The **AMIA bombing** was an attack on the Argentine Israelite Mutual Association building. It occurred in Buenos Aires on 18 July 1994, killing 85 people and injuring hundreds. It was Argentina's deadliest bombing ever. Argentina is home to a Jewish community of 230,000, the largest Jewish community in Latin America.

The experience is very intense. I search for words to describe this moment, but can't find them. They are trapped in my heart, and for now, they want to remain there. They are cooking on a slow flame. It's clear that I am still not ready to write them now but I know they will come – or stay hidden, like a treasure.

In such moments one grows, and I am growing.

The film continues and viewers get lost with Anita. We laugh, we get cold, we want to dance, we want to run, get wet, grow sleepy and it seems that we even snore with Anita. Alejandra has stopped crying, she lights up. The happiness of a day spent in the sun at the zoo, with Anita saying hello to the elephants, returns us, with hope, to the present. Life goes on waiting for us to live it.

Life in the Castro Theatre continues with a standing ovation. Alejandra and Vicky climb the stairs to the stage to share the movie making experience. I have the privilege of filming these 24 minutes in the life of a 37-year-old woman with Down Syndrome, who had the opportunity of a lifetime.

To the last question of the interviewer on the similarities between the character and the actor, this woman responds, sure of herself: "Anita gets lost, Alejandra does not."

I turn off the camcorder, thinking that I shouldn't lose reality, nor lose myself in life.

MISSION INCLUSION

An invitation to all

Welcome to all

The UN is talking about inclusion. The World Bank is talking about inclusion. The Sustainable Development Goals refer to equality, access for all and "leaving no-one behind." Conferences are held and working groups formed. They all agree that inclusion is hard, that reaching the poorest and most marginalised is difficult. They talk about the importance of finding out who is excluded and why, and what we can do about it.

This is good news. But it is easy to feel overwhelmed and forget about the good work that many people have been doing over the years, even decades, to slowly address marginalisation and exclusion, to enable people to access services, speak out, and to participate fully in their families, communities and societies.

As *Barefoot Guide* writers, we wished to take a look at what people have done and what they are doing now to change things. We hope that by reading stories of change, success and failure, and by asking questions and seeking to understand, we and other practitioners can gain a deeper understanding of what it means to be inclusive in our practice and work alongside those who are excluded in bringing about change. We believe we can all start to address exclusion right now.

All the people who share their stories in this book are on a mission to end exclusion and to create truly inclusive societies. We invite you to join us in exploring how change happens and how we can make a difference. The doors are open, so please come in.

> *We believe we can all start to address exclusion right now.*

A journey through this *Barefoot Guide*

You don't need to read this book from beginning to end. In this chapter, we provide an overview of each of the subsequent chapters. Though we believe the order in which the chapters are presented is useful, you may read them in any order. Each stands alone, so go where your energy and interest takes you.

Personal Stories

In between the chapters there are personal stories. These accounts are complete in themselves and are not linked specifically to the chapters prior or subsequent to them. The stories are offered for you to reflect on: what do they teach us about inclusion and exclusion, how do they illustrate the ideas found in other parts of the book, how do they relate to your own experience and your own challenges? Read those whose titles intrigue and excite you.

We invite you on a journey of (self) discovery. There is no right way to read the book. We all bring different things to the mission and we all have different roles to play. Find the way that is right for you.

THE CHAPTERS

CHAPTER 1 Reclaiming the Power

"Understanding power and how it works to exclude, is what gives those who are excluded the power to change things."

– JASS

Chapter 1 describes in detail how HIV-affected women in Malawi created a movement to bring about change in order to get access to effective antiretroviral treatment.

You can't understand exclusion without considering power. The story shows that everyone has power, including those who are excluded. It illustrates how one can learn from one's own experience. Surfacing this knowledge is part of the work of inclusion. The "power within" enables people to believe that their lives have value and their voice is important.

As the women talk to each other and share their experiences and aspirations, they begin to see the power of working together. They start to organise. They develop "power with."

The "power within" and "power with" are both important, but on their own will not lead to change: people need to know how and where to direct this power. What issue do they want to address? And how? The women start to understand how the society they live in systematically excludes them, who has "power over" them, and why. Though their experiences may differ – one woman may have lost her land, another her family – but the root cause is the same: systemic discrimination and exclusion. This insight strengthens their will to act.

Armed with this understanding and shared power, excluded people have the "power to" bring about change. This is not an easy journey – there is pain as well as joy, there are defeats as well as successes. But the women in Malawi achieve their aim. Read the chapter and find out how.

CHAPTER 2

Rewire the System

"How is it possible that some children exist physically – I see them right in front of me – but not for the law, not on paper?"

– SARA'S STORY

Chapter 2 reflects on how exclusion is systemic, built into society, in the structures and systems that we take for granted. By understanding the system, we can see how people are excluded and we can start to challenge that system.

Sara finds it difficult to hide her frustration as she tries to help a child who is excluded by the very systems that could help her. She begins to understand how so many children remain invisible because of complex, generational forms of exclusion. She sees the many interdependent layers that are preventing change.

In her quest to address discrimination against children with intellectual disabilities in Bangladesh, Shamsin reflects, "When society fails to accommodate a certain condition of a person, that society is the disabled one." She motivates us to reflect critically on our own assumptions and beliefs, ones that are often unconscious and unintentional, as well as those of the society to which we belong. She argues that we need an inclusion revolution.

To challenge the system in the way that Sara did takes courage. It requires us to go against the stream and defy societal norms and ideology. Biraj also did this, on air, in India, by asking one single question and acting on it.

"I believe in the power of awkward situations, but would give my life to avoid one."

– Biraj's story

Read this chapter to find out how the systems in which we all live can perpetuate discrimination and exclusion, and how, even when change seems almost impossible, we can make a real difference.

CHAPTER 3 Heal the Wings and Learn to Fly

Chapter 3 focuses on how strengthening accountability can increase inclusion. When marginalised people engage in relationships that strengthen accountability, they can improve their access to services. The stories in this chapter address a number of questions. How do we encourage self-reflection in the different actors involved? How do we change the assumptions that government officials and citizens have about each other? How can communities and governments engage in an answerable relationship in contexts in which the citizens do not feel safe?

"Civil servants have told me that it is as if they are looking into a mirror, and it is not always nice what they see. They feel they can and should do much better. Community leaders have also done some soul searching: they know that they can and should do much more to make sure everyone can be served. When they come together, the service providers with their bosses, the community, NGOs, businesses and everyone else they can think of, they can and do find local solutions"

– Lucia's story

Lucia tells how, in Ethiopia, by bringing citizens and civil servants into the same room to listen to each other, they began to address the problems poor communities face. She describes how, when trust is built and people connect to each other as human beings, they can start to make small changes that seemed impossible before.

Praveen explains how simple technology helped to overcome the remoteness and systemic inertia that was causing women and children to die through lack of access to medical care and state benefits in the state of Orissa in India. In Madagascar, Yvonne takes us through the learning process that enabled communities and government officials to talk to each other through radio shows.

In all three stories, when people see that they have a way to hold government officials and service providers to account, they realise they can change things. When government officials and service providers see that there is a way they can meet people's needs, even with limited resources, their willingness to do so also increases. When both sides understand each other's challenges better, inclusion begins.

Excluded by the excluded

A blind woman needs help. She goes to the local women's organisation and asks to join.

"We can't help you here," they tell her.

"But I'm a woman."

"You should go to the disabled people's organisation. They can help people like you."

The woman visits the local disabled people's organisation. There are only men there.

"You can join our women's wing," they say. "They'll help you."

She joins the women's wing and makes new friends. She discovers that, like her, they feel vulnerable to sexual abuse. She asks if the organisation can do something about it. Her friends are doubtful.

"The committee decides what issues we should focus on."

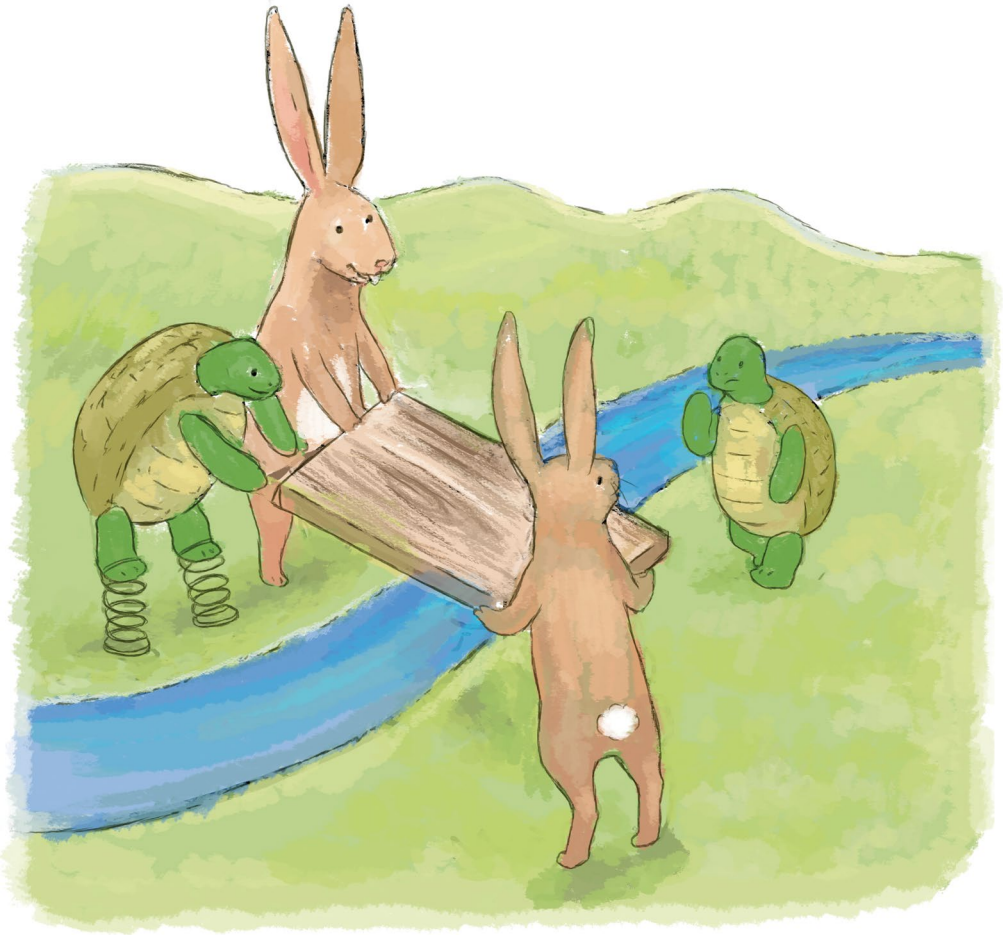
"So, we can ask the committee to consider raising awareness about sexual abuse."

"We can but they won't approve it."

"Why not?"

"Well, we only have one vote. The women's wing representative's vote. All the other representatives are men and they're not interested in tackling sexual abuse."

CHAPTER 4 Walk the Talk



How is it that even organisations of excluded groups sometimes exclude those they should be welcoming? How can our experiences and struggles to be a truly inclusive organisation inspire us and guide us to work more authentically and, therefore, more effectively?

We can learn much from our own struggles to be inclusive: we are more likely to earn the trust of those we support if they can see us trying to practise what we preach (though it is better never to preach). In chapter 5, we find practical guidance for practitioners and organisations trying to be inclusive in all they do. This chapter does not present a recipe for instant success, neither that it is an impossible mountain to climb: rather, it is a process of seeking guidance from the people who have experienced and understand exclusion, of slowly but surely improving and adding to what one does, and learning to be authentic in what one does and who one is – "being the change you want to see in the world."

In "Walk the Talk" we engage in making our organisations more inclusive because "living" inclusive practice strengthens our ability to facilitate tough processes of inclusion.

CHAPTER 5 Walking Alongside

In the final chapter, we hear from people reflecting on how they can facilitate inclusion and inclusive processes. This practice, of accompanying fundamental change in individuals, organisations, communities and societies, runs through most of the chapter. Here we tease out some of the frameworks used by inclusive practitioners to make sense of "exclusion," and to envision a more inclusive society. This final chapter studies a diverse set of inclusive practitioners.

"Many of my students felt they belonged to a kind of 'them,' branded as misfits and failures. My quiet being with their painful memories made them less afraid . . . Hope does not emerge in effortless, colourful Hollywood moments – it comes from a profound and costly process of change."

– Ed, teacher, the Netherlands

Victoria, an artist, and her collaborator, Woods, a businessman, started working together in 1993. They have enabled hundreds of people with intellectual disabilities in Latin America to find employment. New people arrived and others left, but Victoria and Woods' commitment as leaders, provided the energy that fueled the ongoing commitment required to sustain the work.

Victoria and Woods learnt that if everyone takes responsibility, everyone benefits.

"I grew up on a farm, and my father never tolerated anyone looking down upon him. I think this is where I developed the ability to relate to everyone as they are. This is one of the most basic capacities we need to cultivate and develop as facilitators of inclusive development processes."

– Jürgen, agricultural development specialist, South Africa

Jürgen was concerned that only better-off farmers were benefitting from the input of extension workers. He tells how an approach known as "facilitation for change" enabled farmers to form groups based on their own needs and interests to solve their own problems. In this way, everyone was included and everyone could benefit.

These practitioners describe a range of different practices: what they have in common is that they all bring a presence to their work. Their stories illustrate what it means "to be the change".

So . . .

Exclusion is complex. While this makes it difficult to tackle it effectively, it also means that exclusion can be approached from many angles. We can find our own ways of working towards an inclusive world. What is yours? Find a chapter or a story that captures your imagination or arouses your curiosity and begin.

PERSONAL STORY 2

The experience of poverty

One of our co-writers, Pauline, felt unable to continue writing her story after an incident happened that she found terrible.

"[My story] was centred around a childhood friend I christened Ras, and how in my earlier career of working on poverty issues my drive was the desire to tip the odds in favour of individuals like him. Ras was shot two days after I submitted the piece. I have spent the past couple of months trying to make sense of his death, wanting to avenge it, and for the first time in a long time I have been allowing myself to grieve the loss of dozens of my childhood friends."

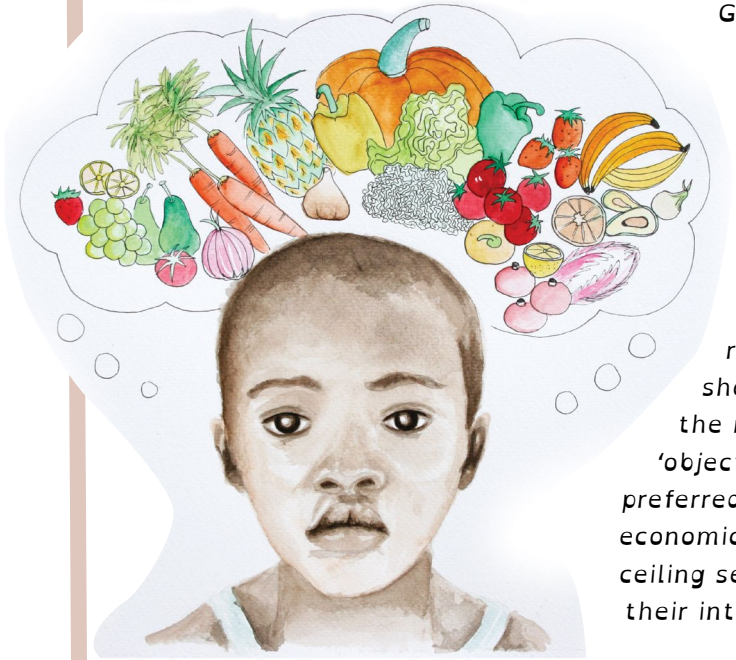
Instead of her story, she sent us an exchange of letters between herself and a friend, Kepha, who she asked to help her write about their experience of poverty. We include here some excerpts from the letters as they so eloquently tell what it means to be poor and excluded.

"The word 'poverty' itself is a sweeping word, a generalisation. Let us call it hunger."

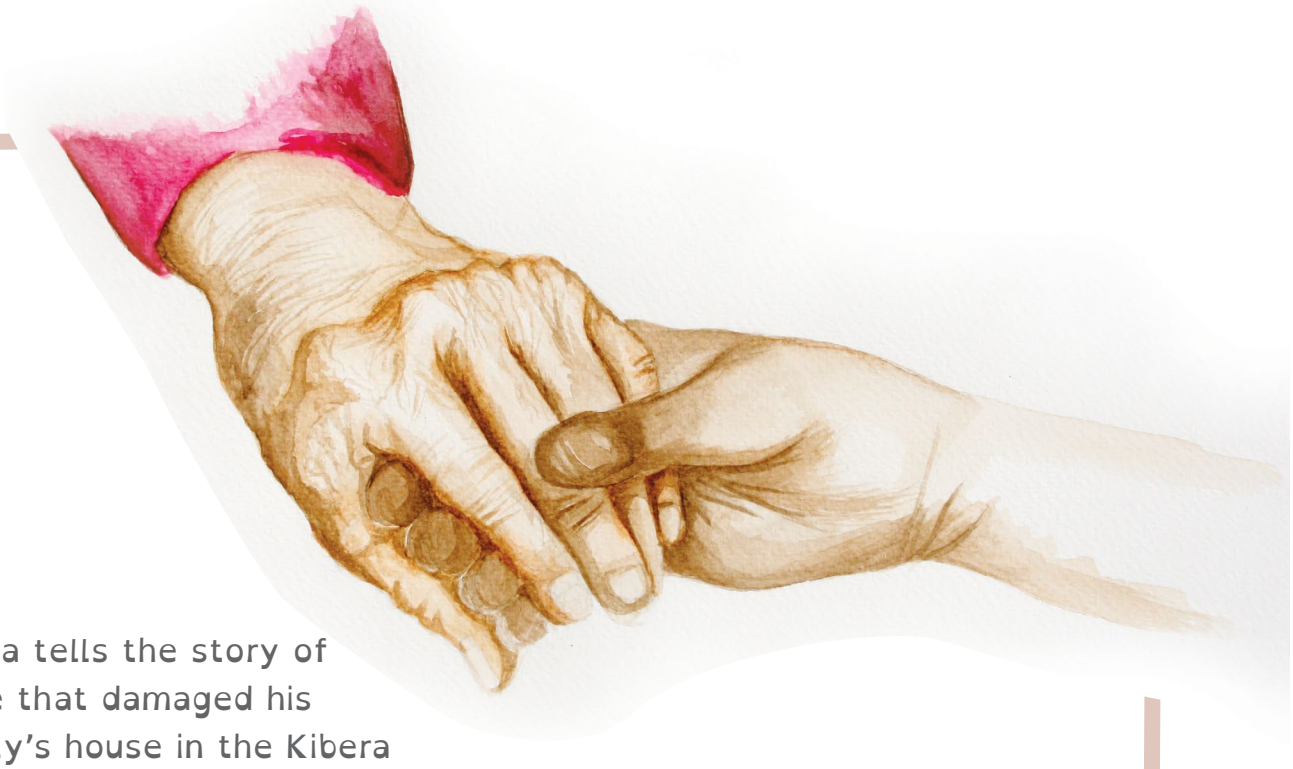
"Without food, one becomes an animal and everything human becomes secondary. This is not even a question of dignity, it is one of existence. Nobody can appreciate human rights on an empty belly. If hunger has animalised me, how can I see you as human? How can I respect your rights? From this alone we see several connections with violence and conflict. The human instinct to escape hunger is so strong that one finds any profession agreeable so long as it generates some income to get food."

And what it can feel like to be on the receiving end of development interventions . . .

"Often the expert is from another world and is divorced from our own realities . . . Statements such as 'Below one dollar a day' or 'residents use dirty water' are out of character and reduce local communities to mere victims and spectators in processes that touch their lives. Sometime last year, I filled an evaluation form for a project in Kenya designed by someone seated in Geneva who has never been to Kenya. I was tempted to lie for my answers to fit the already set expectations of the form. I developed a headache afterwards."



"Once there was a foreign reporter who rejected the interview material I gave her about my life in a slum, because I was too close to the situation to offer an objective input for her research. In her quest to be 'objective' she missed out on what I had to say about the real situation. I did not fit her idea of an 'objective source of knowledge.' She might have preferred speaking to a university professor of economics rather than listen to me. This is a glass ceiling set to prevent poor people from expressing their intricate experiences of poverty."



Kepha tells the story of a fire that damaged his family's house in the Kibera slum and injured his mother. They and their neighbours managed to control the blaze.

"Questions crossed my mind as I helped pack our few belongings. They are all summarised into one big question, were we part of this country? If we were, why couldn't the fire department even show their presence?"

He comments while waiting with his mother in the hospital: "She raises her hand to hold mine as if to signal me to get my ear closer. Then she whispers something: "Do not tell them you are my children, tell them I have no one to take care of me and they will not ask you for money."

But he tells the hospital the truth . . . "I can't deny my mother in any circumstance. The thought that she is more worried about the hospital bill than her own situation makes me tremble with shame."

They cannot afford the treatment and his mother does not survive. Nevertheless, Kepha believes there is a way forward. "I do believe it is important to shift the debate from the poor to poverty itself. Terrible stories of indignity of poverty are all over the world. We must begin by reaffirming our humanity to each other and seeing one another as humans above everything else."

"In many ways, most of the action will be the responsibility of the poor. They must learn to organise, learn advocacy techniques and employ non-violent pressure on duty-bearers. The psychology of poverty is that those who exit tend to forget and they must always be reminded that there are many others suffocating behind them. In many places around the world, people are taking charge of their own destinies, connecting their hardships to their grievances and making sense of the government's role in it. This is a key step in fighting poverty, making it a tangible issue, seeing it as a scientific consequence of omission and not fate."

"Many solutions to poverty are bottom-up but we cannot turn a blind eye to the irresponsibility of the powerful. Top-bottom responsibility must be taken as well and those in positions of power and authority must be compelled to use their offices to enable more equitable distribution of resources."

PERSONAL STORY 3

Brenda's life story

From social exclusion to social inclusion

It was a sunny morning, I was four years old, when my parents received the most heart-breaking news. "Your child will never be able to walk", the doctor said. My mother began to cry and my father looked confused.

Back at home, grandma got the news. She was dumbfounded. "How can this curse befall our family?" It was so hard for her to believe. She called for a family meeting. "Something is wrong, who offended the ancestors? Who annoyed our Kamba gods?" No response. She continued, "Our traditions, beliefs and practices view disability as a curse and I believe one of you (pointing at mum and dad) offended our gods. Can anyone explain or say something about this child?!" she yelled. Dead silence. Tears started flowing from my mother's eyes. Her body started shaking. Grandma looked directly into dad's eyes and said, "It must be your wife." The blame of a disabled child – me - was shifted to mum. Grandma gave her a month to come up with a reasonable explanation. Mum was told to take me with her to her parents. She could not stay a day longer with her husband, who did not utter a word against his mother's decision.

> ***"Tears started flowing from my mother's eyes. Her body started shaking."***

Life changed completely. Mum did not know what to do. "Why am I the one to blame?" she asked. While packing her clothes, dad stretched out his hand and touched her. He said, "It's hard for me to see you frown, it's even harder for me to see you cry but the hardest for me is to see your heart broken and I cannot do anything about it." She did not respond. She carried me on her back, took the bags and went to her maternal home where she explained what had happened. They comforted her and promised to help her to get me a good school.

After being in that home for one week, a close friend of my grandfather (father to my mother) came to visit, and he was baffled by what he heard. "How can one do that to a child?" he asked; "This is unbelievable, I will help you to get a special school for your grandchild" he said. "Education is the only thing that can change this girl's life" he concluded.

The following day he came with all the details of Port-Reitz primary school for the physically handicapped and handed the details to mum. She smiled and hugged the man. "You are a godsend, you don't know how I have suffered since my daughter contracted polio."

I was taken to a boarding special school a week later. Mum was happy and at the same time confused. I was too young to be in a boarding school. I remember she hugged me and said, "I love you my daughter; I will do all that it takes to protect you. I will visit you and I will call the school every week, just to know how you are doing." I cried when she left, but the matron comforted me and all was well.

When dad heard I was taken to school, he lamented "why is this woman wasting money on a cripple, someone who will never amount to anything?" Mum chose to turn a deaf ear and continued to support me with weekly visits as promised.

At the age of 7, when mum visited she explained everything to me. She cried a lot when she was narrating the case to me. I cried too. I felt helpless; I knew my world had taken another turn. I started having so many questions. Why me? What did I do?

Who said disability is a curse?" I could not get to all these questions. My heart was broken. Mum gave me a hug and said "being happy doesn't mean that everything is perfect. I want you to be happy and work hard because as long as I am alive, I will support you my girl."

Why me? What did I do? Who said disability is a curse?

> *but he said, "I cannot marry a cripple, how will I socialise with people?"*

After mum left, I had to encourage myself to be strong. Now I had a true picture of why I was being discriminated and marginalised at home. I promised myself to work hard and be a better person in the future. This was a dream which did not go up in smoke. I finished my primary and secondary education. I could not continue further because of my mother's financial situation.

In secondary school, I had an opportunity to do office practice and typing. I chose to go to the capital city Nairobi, to look for a typing job. I took my few clothes and left. I went to live with my aunt who did not want to host me for long. In my busy search for a job, I met an Italian woman, Paula, who directed me to an organisation where they needed someone with a high typing speed. After the interview, I was given the job right away. When I went back to my auntie's place, I told her I got a job and I thought we would celebrate together. But I was mistaken. She told me to leave her house immediately.

So, the following day, I took a paper bag with all I had: two dresses and two panties. I reported at my new work place, not knowing where to go after 5pm in the evening. Around 4pm, I spoke to one of my colleagues, a lady, and she accepted to host me until I was able to have my own place.

After two months, I moved to a small rental house. I was very happy because my life was improving now. During my leave days, I wanted to go to my rural home, but the situation was still the same. I was not wanted there.

After settling at work, I fell in love like any other woman. Little did I know that the man was a product of our African culture. When I discovered I was pregnant I gave him the good news, but he said, "I cannot marry a cripple, how will I socialise with people?" He left me for a 'normal' woman. He also said, "my mother cannot accept you in our family. Sorry, but I have to go." This was another blow in my life. I comforted myself, "it is okay, you will make it". Since then I am bringing up my son, alone but happy.

Why should one be rejected, discriminated against or marginalised because of disability? This was the question I kept on asking myself. To understand the situation better, I chose to carry out some interviews with both men and women with a disability. I visited different self-help groups, introduced myself and asked them to share their life experiences. Oh! I remember Jane saying, "I cannot share my story; it is

filled with pain and sorrow." She said that, though she cannot read nor write, she has a small business that puts food on her table. Seated on his wheelchair, Isaac said he was told by the villagers from my home area that he was thrown in the bush to be eaten by wild animals. Shepherds saw a wrapped bag with baby Isaac. They took him to a mission children's home that he now calls his home. And with fellow persons with disability, he always feels at home". Mmmmm! Kathini started that she thought she was the only one who was marginalised and discriminated against. With the stories of peers, she feels a bit comforted now. She continued: "Life is hard but we will journey together and possibly one day, we will have smiles on our faces". "Yes, we will smile," Tata responded. For those of us who have physical disabilities, stairs can be large barriers. Our daily struggle.

> ***Seated on his wheelchair, Isaac said he was told by the villagers from my home area that he was thrown in the bush to be eaten by wild animals.***

Many stories, many voices.

I concluded, "to tackle these difficulties we have to remain united and one day our voice will be heard; policies will be implemented and we will be able to live independently."

I can attest that I enjoyed listening to all these people. They all experienced exclusion in one way or the other. We are many who culture and society have discriminated against and marginalised because of disabilities. We are many who have been denied our basic rights because of disability. Why disability? Is disability a curse? I looked at their faces. Their body language said it all. I discovered that words cannot express what we feel. We die on the inside simply because we cannot show the world what we are really are going through. The pain inside us is not always seen but instead the weak smile on our faces.

Growing up in isolation is the worst thing that can ever happen to a child. According to the interviews, it was clear that disability caused social exclusion to the lives and families of those living with disability. Inclusive development calls for the change of our mind set; our socialisation and our relationships. Is this possible?

Yes, it is.

I champion for the rights of persons with disability. I was privileged to get a scholarship to pursue a Bachelor of Arts in Sustainable Development and a Masters of Art Degree in Social Transformation. This is what has empowered me and I know it can do the same for others. I agree with Nelson Mandela when he said, "Education is the great engine of personal development: It is through education that the daughter of a peasant can become a doctor, that the son of a mine worker can become the head of the mine, [Nelson Mandela] that a child of a farm-worker can become the president of a great nation. It is what we make out of what we have, not what we are given, that separates one person from another. Education is the only tool or weapon that an enemy cannot snatch it from you. Education is a companion which no misfortune can depress, no crime can destroy, no enemy can alienate, and no despotism can enslave."

> ***"It is through education that the daughter of a peasant can become a doctor, that the son of a mine worker can become the head of the mine***

Mandela was right. As much as I struggle because of physical barriers, these days I rarely experience social exclusion.

The majority of persons with disabilities are frustrated with life because society has no proper mechanisms for understanding, let alone fulfilling their needs. I am hoping to team up with others to see if we can help lighten the load of despair amongst fellow persons with disability. I have been volunteering with Action Foundation based in Kibera focusing on improving the health of children with disabilities and supporting them to achieve their maximum potential. They promote social inclusion rather than dependency. I also organise self-help groups. One in Nairobi and the other one in Kitui. My focus is to advocate and lobby for the educational and health rights of persons/children with disability.

I will never tire of saying this. I know success is not measured by how high we go up in life but by how many times we bounce back when we fall down. It is this 'bouncing back' ability that determines success. We are all products of our past, but we should not become prisoners of it. mbracing inclusion is possible because Henry Ford said, "Coming together is a beginning; keeping together is progress; working together is success."

"Exclusion is never the way forward on our shared paths to freedom and justice."

– Desmond Tutu

It's night again. I never really liked sleeping. Probably because every time I closed my eyes, I was afraid of the next day. I did not know who would insult me next. When I woke up, my eyes were all cried out. It is different now. I sleep like a baby. No worries. My family members appreciate me. My brothers and sister want to be associated with me. They are proud of my life achievements. They are also happy because I forgave them. My grandma and dad never lived long enough to see this change happen. Before my father's demise, we reconciled. He tried to knit the family back together but their cultural behaviour was too rooted. It needed time. The time is now. My brothers and sister view the world differently, not through a cultural worldview, as disability is no longer a curse to them. The society in our home area views me differently, as a skilled and a talented woman, not a curse anymore. I feel great to have moved from social exclusion to social inclusion.

> ***The society in our home area views me differently, as a skilled and a talented woman, not a curse anymore.***

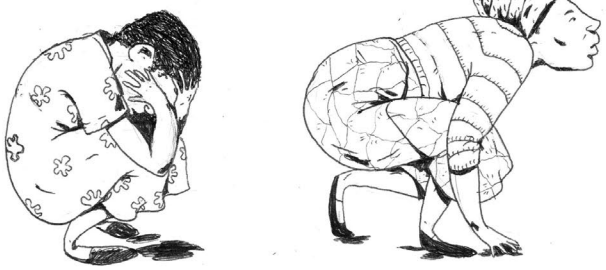
INCLUSION

To be a part
And not stand apart
To belong
And not to be isolated
To have friends
And not just companions
To feel needed
And not just a person with needs
To participate
And not just be a spectator
To have responsibilities
And not just enjoy rights
To have opportunities
And not favours
Is to be really included.

– by Dipti Bhatia

Release the Power

Creating a movement to end exclusion



"If there's anything that the experience in Malawi taught me, and taught many of us, it's that the work of organising and mobilising starts with very small efforts. You know, sometimes it's one woman at a time, talking about the issues that they care about, no matter how small or insignificant those issues might appear to you as an outsider. It's about taking the time to support them through that journey of self-awareness and self-consciousness, that's where it begins, right? Without a sense of self, without a sense of rights, without a sense of 'this is what I'm entitled to as a human being,' you're not going to move."

– Everjoice Win, Action Aid

Projects can bring about small changes, but to bring about big changes, to change the way a system works you need a movement – with large numbers of people who are prepared to work together to challenge the system. But what if you want to create a movement of people who are excluded two or three times over, whose own sense of self-worth and agency have been severely undermined by stigma and discrimination? Where do you start? How do you support them to believe that by working together they can make a difference? Let's look at a real story and find out.

Back in 2007, despite enormous amounts of money being directed towards HIV and AIDS-related work in Malawi, rates of infection were still rising. Just Associates (JASS, www.justassociates.org), a global feminist movement-building organisation, together with allies at Open Society Initiative for Southern Africa (OSISA) and ActionAid in the region, were concerned that HIV-positive women, particularly poor black women in rural areas, had the least access to treatment, support and information. Not only were they excluded from public discussion and decision-making about HIV and AIDS, they were also stigmatised in their own families and communities. The stories of these women were being used to show the impact of HIV and AIDS to the world and to raise money, but their specific needs were not being addressed and their organisations were not being supported.

Recognising and building the power within

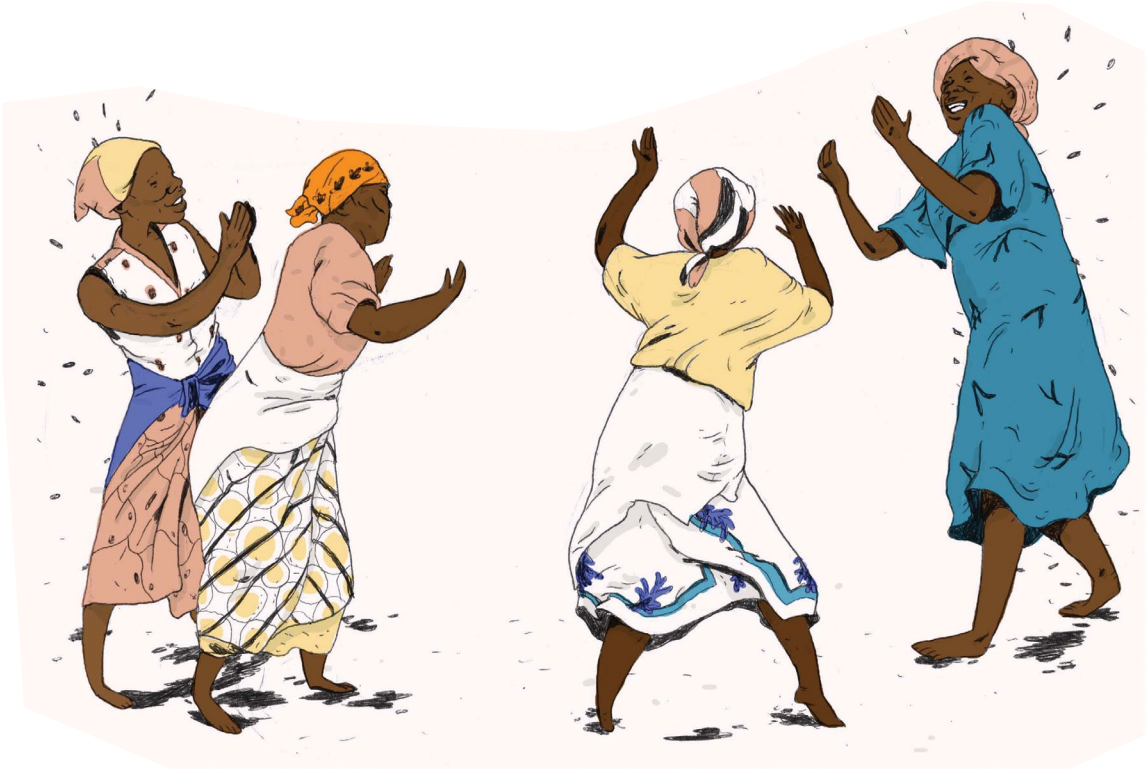
JASS started by going out to meet and engage with the women, *listening to what they had to say*. Many organisations had already run workshops to provide information and involve women. These workshops tended to have a set format, be quite formal, and women knew the role they were expected to play in them. JASS wanted to do something different, to engage with women on their own terms. They called their gatherings "get-togethers" and made them fun and engaging. There was food and dance and song. They aimed to create a safe space where women could talk about their lives and not be told what to think and do. Participants were encouraged to laugh and to cry, to share their hopes and fears, to be themselves. They were asked about the challenges they faced and how they were coping with them.

The focus was not just on problems. Through the gatherings, women discovered they had vital knowledge, experiences, ideas and survival strategies to share. They came to realise they weren't alone and they weren't to blame. They began to see themselves as resourceful survivors who deserved to thrive, to have a voice and to be heard. They began to understand how the systems and power relations in society were leading to inequality and exclusion. This they understood as discovering their "power within".

"Our bodies, our lives"

JASS used a feminist popular education approach – popular education informed by a feminist analysis of power and how knowledge interacts with power. The approach recognises that the dominant patriarchal system influences what knowledge is valued; privileging male experiences and perspectives while excluding the experiences and insights of women. This system underpins the way society works and how it affects women and men. By unpacking this way of looking at things and enabling women to learn from and value their own experiences and knowledge, they begin to see the world quite differently. They see how the system in which they live impacts on their lives, their opportunities and their relations with others. They also see how they can begin to change that.

By unpacking this way of looking at things and enabling women to learn from and value their own experiences and knowledge, they begin to see the world quite differently.



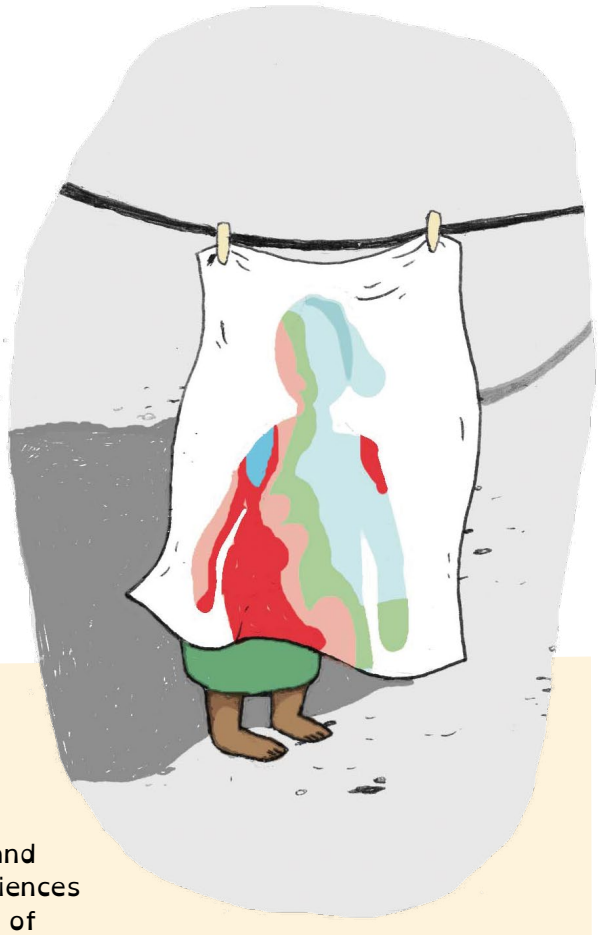
In the first phase of movement-building work, JASS supported women to understand the connection between their individual pain and the systems and structures that excluded and oppressed them. Women felt this in their own lives and in their own bodies.

Rather than ignoring women's experiences of their bodies, JASS used the body as an entry point, as a source of knowledge and political analysis, using a process called body mapping. This activity allowed women to explore and discuss their stories, some of them quite painful, leading to insights about the negative impact of the second-rate drugs the government was currently providing. This put women's lives and bodies at the centre of movement building.

We sat down and thought about what name could really suit this campaign, and we came up with the name 'Our Bodies Our Lives: the Fight for Better ARVs' because what we are fighting for is our own bodies and our own lives.

– Sibongile Singini, woman activist, JASS Southern Africa In-Country Organiser

"Women's bodies bear testimony to the idea that the "personal is political."



Body mapping

Women's bodies bear testimony to the idea that the "personal is political." Oppression and joy plays out in women's lives physically, mentally and emotionally. This simply means that their experiences of the system can affect their health and sense of wellbeing. The body is a symbol and physical manifestation of our experiences of power. In patriarchal systems women's bodies, often do not "belong" to them but are controlled by the men. The body is also a site of contested ownership, internal tensions, and conflict.

How does *body mapping* work?

1. Working in pairs, one person lies down on a piece of paper (or fabric) and the second traces her partner's body onto the paper. Participants then fill in their body maps, using different colours, based on the question: *what parts of your body give you pleasure or pain?* (With pain understood as a way of naming the way our bodies carry experiences, scars and trauma.)
2. In plenary, they share their body maps and discuss these with each other. Each woman speaks to her own body. Participants are urged to be open and honest, as this process is an important part of developing trust within the group. In the first part of reporting back women talk about the ownership of their bodies, then the parts of their body that give them pain.

3. In the second part of the activity, women discuss the parts of their body that give them joy and delight; this is a stage of affirmation, of valuing their bodies and, so, themselves.
4. At the end of the process, the facilitator reiterates the power of the body, that is, the power of the experience each body carries. She speaks to how the desire to control women's bodies is central to patriarchy and how, as women, our experiences are common and how our personal problems do not need to be, and cannot be, solved alone. We need to work together. She speaks of the need for self-care to reclaim our bodies and wellbeing.

This requires sensitive and thoughtful facilitation. Facilitators must be able to address painful issues which emerge. It is not something that should be done until the women in the group are comfortable with each other.

For a more detailed description: https://werise-toolkit.org/en/system/tdf/pdf/tools/Heart-Mind-Body-Mapping.pdf?file=1&force=

Credit: JASS SNA with Hope Chigudu based on the work done by HIV and AIDS treatment and literacy activists in Southern Africa.

This is the groundwork, the foundation of the movement. It cannot be done quickly or skipped. Take the time it needs.

This first stage of movement building cannot be rushed. This is the groundwork, the foundation of the movement. It cannot be done quickly or skipped. Take the time it needs. In Malawi, JASS worked with an expanding circle of women over six years – supporting them in breaking their fear and silence, building trust and community, developing skills and community leadership – until an organising campaign emerged and they were ready to move to a "standing up" stage.

At a certain point, you will know, you will feel, when you are ready for the next stage. Don't be stressed with project or donor deadlines. This is the women's process, not the donor's process. Crucially, JASS was prepared to put in the time and effort that was needed. Above all, they were willing to listen to what the women needed to move forward and to help them to recognise their own *power within* and discover *power with* others.

Power within

The women had a safe space to talk about their own lived experience. They saw the barriers that were facing them and the ways in which they had been coping with and overcoming them. They saw that their experiences were valuable in identifying where change was needed and that they had resources within themselves to change their lives. They had agency, the will to act, and they felt that agency and celebrated it.

For how to create safe space go to: https://werise-toolkit.org/en/system/tdf/pdf/tools/Creating-a-Safe-Space.pdf?file=1&force=

The women were encouraged to take action in their own communities. They gained confidence by implementing their own ideas, running their own projects, individually or in small groups. While they had small successes, there was no single issue that united them and while they made small gains, they could not individually tackle the system that was oppressing them. They needed a movement and to create the movement these individual efforts needed to be connected.

Making the connections to create the *power with*

The JASS sessions created opportunities for women to explore working together to develop the "power with" – the power that comes from working collectively. However, during this exploration, cracks emerged between them: they started to form allegiances and cliques based around their differences, rather than looking at what bound them together. How did this happen? The social messages, which had disempowered and excluded them and pitted women against each other, seeped back in. Ideas of how society identifies and judges women as good or bad began to surface, specifically, that of stigmatising women who exchanged sex for money and food because they had no other way to survive. Women were re-stigmatising each other. The facilitators realised they needed to dig deeper and to really surface what keeps women divided and silent. They devised ways of unpacking the social norms and judgements that women internalise and use against one another. Remember that one of the ways patriarchy dominates women is to divide them, to use them to judge and control each other.

> ***The facilitators realised they needed to dig deeper and to really surface what keeps women divided and silent.***

"A movement cannot be built on stereotypes."

– Hope Chigudu

Good women/bad women exercise

This is an exercise that can be used to explore and challenge stereotypes.

Purpose

To help women to explore how society uses them to judge each other and how these judgements divide and weaken them all. To help them to understand how women often have little choice about what to do to survive, to stay alive, to feed their children, and rather than judging each other, to look at why and how women could unite to help each other and work together to change the system. To help them to discuss what to do about this.

Resources

a. Two empty boxes labelled "good women" and "bad women."

b. A set of eight statements for each group of four-to-six women. If the workshop is only a few women, you can give each woman a set.

The Statements

Each statement is written on a different strip of paper (these can be changed or adapted to suit the situation and culture of the women):

- This woman does not work outside the family home.
- This woman always has sex when her husband wants her to.
- This woman had never had a sexual partner before she got married.
- This woman works outside the family home.
- This woman sometimes disagrees with men in public.
- This woman has had sex for money.
- This woman might have been infected by a man who was not her husband.
- This woman was raped.

Process

A. Group work: after explaining the exercise, the facilitator divides the workshop into groups. The groups each read out the statements and decide which box the statement goes in, discussing why. (If a group can't agree, they put the statement to one side.) When they are finished, they put the statements into the chosen boxes.

B. The women then come together in plenary and discuss what the group task was like. How did they feel about dividing women up based on one thing that they do? Were there any that were difficult to agree on/decide?

C. The facilitator opens the boxes and reads some of the statements, asking the following. How do you think the women in this box feel? Why did you put this woman in this box? What if a woman does one thing from the good box and another from the bad? Are all the women in the good box okay? Which box would you put yourself in? Why? Which of these women do we need to work with? Let the discussion happen.

D. When enough has been said, summarise the key points of the discussion, including how social norms and judgements divide us by establishing sets of rules about what we should and should not do. We are made to feel bad or different if we do not follow the rules – even if this is not our own choice. How do we punish those who do not follow the rules? The rules create stereotypes and these create divisions that make it more difficult for us to work together based on what we have in common. Stress that movements need to make space for everyone and not make judgements about them, this makes us stronger.

For a complete description of this activity go to: https://werise-toolkit.org/en/system/tdf/pdf/tools/Good-Women-Bad-Women_0.pdf?file=1&force=

Credit: Anna Davies-van Es and Patricia Ardon, with inspiration from Hope Chigudu and Youth Vision Zambia.

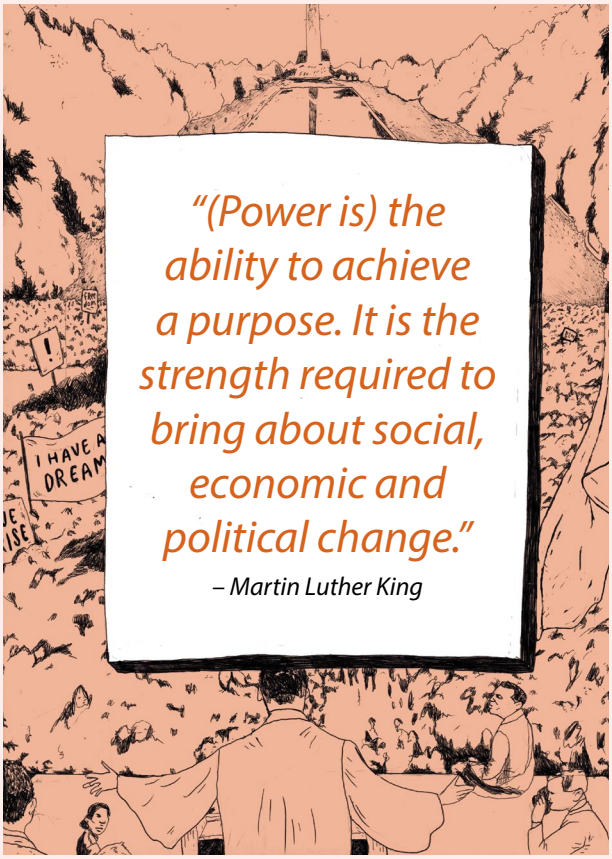
Understanding Power

When you are excluded from decisions which affect your life and you feel unable to change your circumstances for the better, power can seem unattainable. It seems as though some people have all the power, some have none. And without power, how can we change anything?

Power is not one thing, but many.

Power over: The power to control the lives of others by force or by making rules and enforcing norms that give advantage to one group over another. This can be done visibly (as part of the political process), in the shadows (through networks of influence), or invisibly (through social norms and ways of working).

Adam Kahane writes that we see power and love as mutually exclusive and challenges us to connect the two. Power without love is abusive and unjust; love without power is sentimental and weak. Power and love together enable us to act to end injustice in a way that does not perpetuate and create injustices.



"(Power is) the ability to achieve a purpose. It is the strength required to bring about social, economic and political change."

– Martin Luther King

The first step to taking action to change the way things are is understanding that there are different forms of power and that we can claim power for ourselves. Power can be used constructively as well as destructively.

Power within: A person's sense of self-worth and self-knowledge, the realisation that they have power, their capacity to hope, imagine, think critically, question assumptions, say no or yes, respect others, collaborate.

Power with: Refers to the power in numbers of people acting together to achieve a common goal. It is about people unified across differences by shared purpose and multiplying their individual talents, knowledge and resources to make a larger impact. It is about the collective power found in community and common ground.

Power to: The unique potential of everyone to shape his or her life and world, the ability to speak up or take action, for instance, to join a protest, write a banner, organise a meeting, scream, remain silent or defy that which is being dictated to someone. This is about the ability to act and comes out of power within and power with.

Power for: Refers to the combined vision, values and agenda of change that inspires us and informs the work we do. It builds on the other forms of transformative power and encourages us to create strategies and alternative institutions, relationships and ways of living that reflect our beliefs and hold the seeds of the world we seek to create.

More reflections on power can be found in *The Barefoot Guide to Organisations and Social Change*, Chapter 3.

[Adapted from JASS, Making Change Happen: Power https://justassociates.org/sites/justassociates.org/files/mch3_2011_final_0.pdf]

After this conversation, the women realised that they could not create a movement if they were only willing to work with those who were "like them." They also saw how, by appreciating differences and seeking to understand others, they were stronger. They could present a united front to those who they were seeking to influence.

JASS worked with women all over Malawi. By this point, there were hundreds of women all over the country who were starting to feel organised, trusting each other because they had shared so much of what had been hidden, and who were preparing themselves to work together to bring about change.

> *the women realised that they could not create a movement if they were only willing to work with those who were "like them."*

These spaces started from our respective areas, building to a place where it involved many women countrywide. It was about a combination of powers – the power within a person, and the power to. This combination enabled us to come up with the campaign: because of the power in me, together with the power of other women, we managed to hold others accountable."

– Kwangu Tembi Makhuwira, COWLHA, Malawi

Building Alliances

JASS started its work in Malawi talking with other women's organisations and networks, slowly growing a web of women's groups across the country. As the work with the Malawian women grew, they recognised that they needed to broaden their relationships and to forge alliances, including with some unlikely allies. Of particular importance was the relationship with an organisation of progressive religious leaders initiated in 2011 – MANERELA+ (the Malawi Network of Religious Leaders living with or personally affected by HIV/AIDS). The alliance with MANERELA+ was critical, given that many religious groups often perpetuated stigma and blame, especially by blaming "loose women" for the disease's spread. MANERELA+ could bring validation and the political legitimacy of an alternative religious organisation. However, building relationships with mixed-gender organisations in a conservative context to build women's leadership is not always straightforward, and this required skilful negotiation and the building of trust. The effort was important and well worthwhile, bringing visibility and legitimacy to the movement and providing opportunities for changing the attitudes and beliefs of influential people.

Finding a unifying organising issue

Women living with HIV and AIDS faced so many hardships and injustices – poverty, lack of access to land, abandonment, poor health – that it was difficult to find one issue that the movement could rally around.

This was not an intellectual decision, as such, but came out of their direct experience and feelings. They felt it in their bodies.

JASS went back to the women's bodies, to the source of their pain, and the source of their strength and resourcefulness. They now focused on working with women leaders from across the country who had emerged from the initial gatherings.

During a relaxed evening of candlelight, storytelling and song, women talked with honesty about the pain and shame they felt in their bodies. Women began to speak about the changes in their bodies caused by the poor quality anti-retroviral drugs (ARVs) that most of them were receiving from the government. The Malawi government continued to distribute these older ARVs although newer and better ones were available, claiming that they could not afford to immediately roll out the new drugs nationwide. The older drugs caused redistribution of fat in the body and debilitating nerve pain and numbness in many women. This resulted in many women looking physically different, which led to increased discrimination. The chronic pain often meant that women could not do the things they needed to do for themselves and their family in order to survive.

It was the physical changes caused by these drugs and the resulting stigmatisation and mistreatment that became the focus of women's anger. This was not an intellectual decision, as such, but came out of their direct experience and feelings. They felt it in their bodies. As a result, the demand for alternative antiretroviral drugs was a cause that all the women could sign up to.

This single, galvanising issue – that of toxic drugs – brought together many elements of the work: it tapped into women's anger over the government's and pharmaceutical companies' disregard for people, it generated a clear demand – better drug treatment for HIV-positive people – and it activated women's "power to" demand change. This was the spark that focused the organising effort to win governmental responsiveness to and accountability for women's needs through a campaign for access to treatment using the latest antiretroviral drugs.

Empowering evidence gathering

The women knew in their own bodies the damage the old drugs were doing, but in order to launch a campaign they needed evidence that decision-makers would listen to. Rather than just doing a literature review (something that would have been alien and intimidating to the women), JASS wanted the process of gathering evidence to build people-power and community leadership. They therefore used a participatory research process. Sixty women learnt how to collect data in their own communities. They surveyed 846 women across Malawi in two months, reaching out through their networks and support groups.

The findings were clear: 70% of the women were using a combination drug containing Stavudine, which can cause bodily deformities and other major side effects. When these effects became visible, they suffered shame and exclusion, their husbands often blaming them unjustly for getting the disease. Many women stopped taking the drug because of the changes it caused, risking their health in consequence. Others were not able to access treatment at all.

The data showed that these were not just isolated cases but that huge numbers of women were affected. It showed that the policy of using a low-quality drug was harming women in many ways, physically, emotionally, socially, and economically.

The collection of the data was important in movement building. Because the women had taken on public roles in the community research, their communities began to see them as emerging leaders. This also helped build a network of women across the country who were aware of the issues and ready to get involved. The method of collecting data was therefore as important as the data itself.

With a large group of emerging community leaders, strong evidence, diverse allies and a network of over 1,200 women, the foundations of the movement were in place.

"Come into the circle and join with us"

The women were ready to go. Now an opportunity was needed for the women leaders to get noticed, to put their demands on the table and to start the process of change.

The alliance with MANERELA+ had proved critical in gaining access to political leaders, but the movement also needed to become visible in its own right and to show its own power.

The opportunity they needed came in 2012 in the form of the SAVE Conference, a high profile national HIV and AIDS advocacy conference where governments and agencies wanted to show their work in a good light. JASS and the women activists organised their own event parallel with SAVE, the National Women's Dialogue. More than 120 women turned up, double that expected. Powerful speakers and dialogue helped women to share their stories and use this space and energy to formulate their demands.

The National Women's Dialogue began with a press briefing that brought together 20 journalists from national and community-based media houses, including the national broadcaster Malawi Broadcasting Corporation (both radio and television), Zodiac, Capital FM, The Nation, and Radio Islam. The women leaders put together a press release about the dialogue and fielded questions from journalists. This resulted in feature articles in two national newspapers, daily news clips on national news, as well as a twenty-minute in-depth news special.

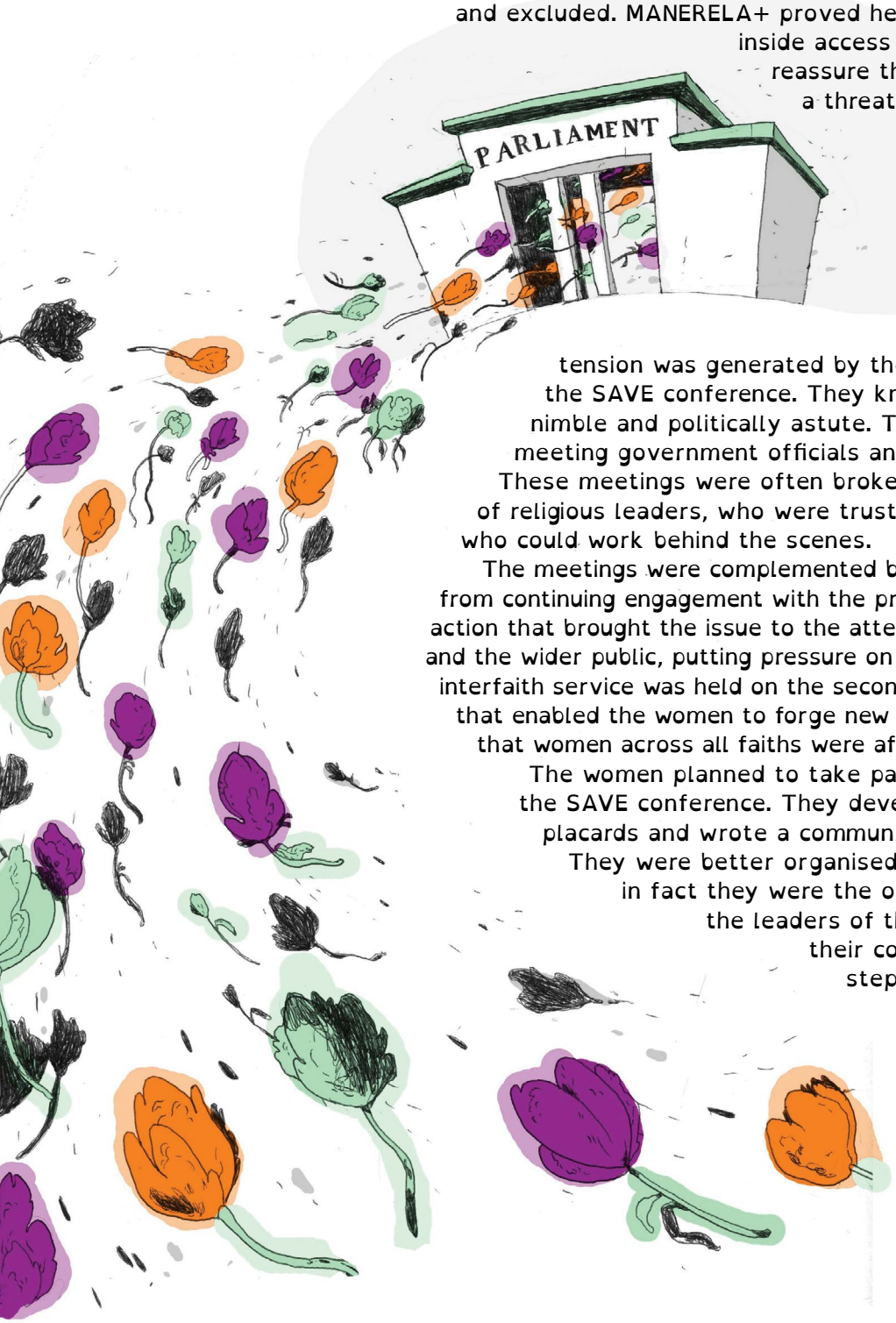
Then, later in the week, at the SAVE Conference, the Head of the Ministry of Health's HIV Unit arrived to deliver his presentation. He was greeted by powerful and well-prepared women with their own agenda.

"We want you to come into the circle and we want you to talk with us," they said.

The women presented their demands calmly and clearly. They wanted immediate access for all women to quality antiretroviral drugs.

"We want you to come into the circle and we want you to talk with us," they said.

The women were breaking the expected silence of stigma and making their voices heard in ways hard to ignore. This created political tension and there was concern that there could be reprisals against the women who had previously been so vulnerable and excluded. MANERELA+ proved helpful again, as they had inside access to those in power and could reassure them that the women were not a threat.



Inside/outside strategy

The women had got themselves noticed. Good tension was generated by their presence and actions at the SAVE conference. They knew they would need to be nimble and politically astute. They worked on the inside by meeting government officials and explaining their demands. These meetings were often brokered by MANERELA+'s network of religious leaders, who were trusted by the government and who could work behind the scenes.

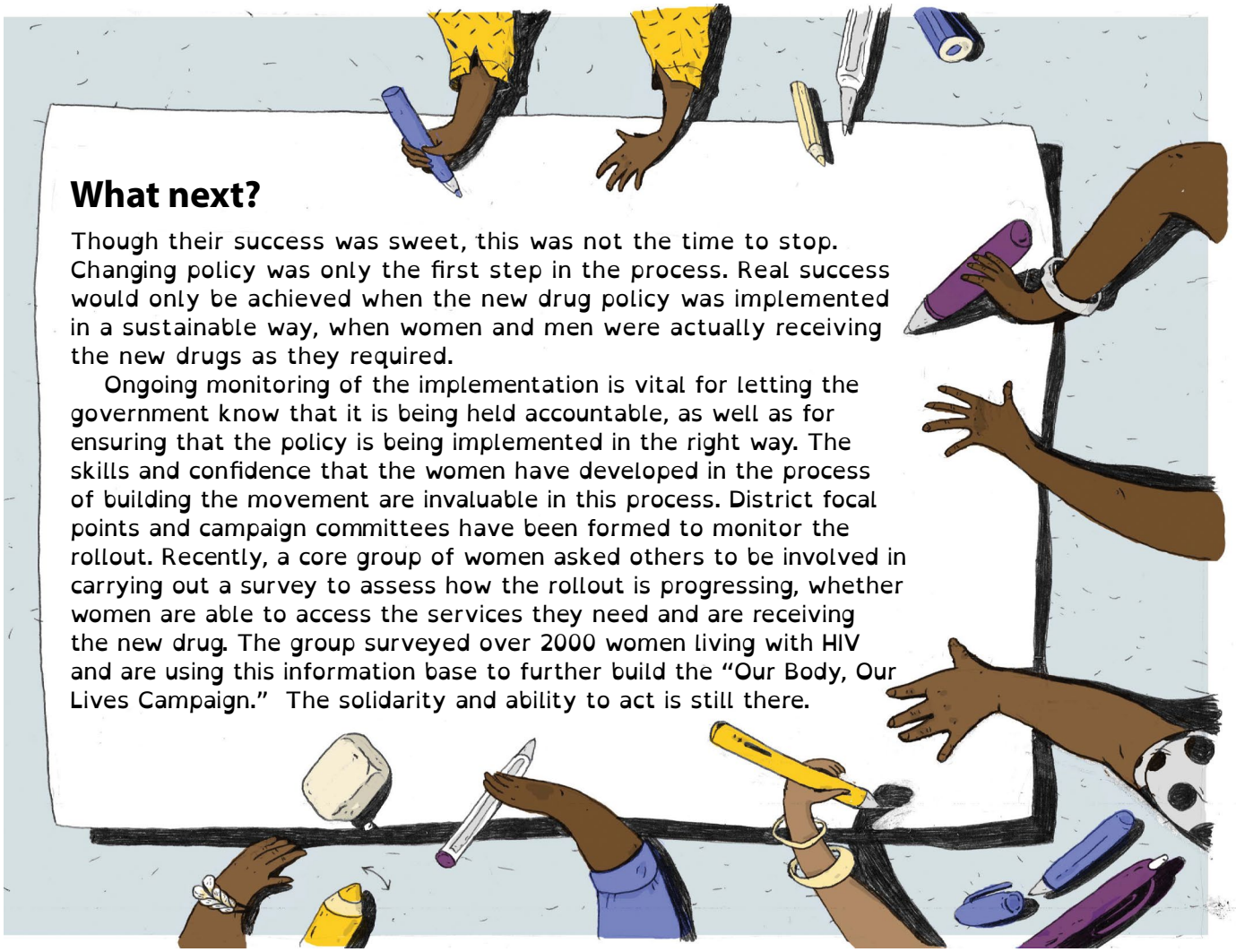
The meetings were complemented by work on the outside. Apart from continuing engagement with the press, they embarked on direct action that brought the issue to the attention of decision-makers and the wider public, putting pressure on the government to act. An interfaith service was held on the second day of the National Dialogue that enabled the women to forge new relationships and demonstrate that women across all faiths were affected by the drugs.

The women planned to take part in a march at the end of the SAVE conference. They developed powerful feminist placards and wrote a communique outlining their demands. They were better organised than others on the march – in fact they were the only ones with placards – so the leaders of the march drew heavily on their communique and read it on the steps of parliament.

Success

The women kept up the momentum of the campaign and were able to meet the then President of Malawi, Joyce Banda, as well as the principal secretary of the Ministry of Health. They had power in directly representing their communities and in being able to place clear evidence for their demands on the table. Their community-based research showed the devastating effects that the drug was having on women's lives and the multiple injustices that women were having to face as a result. The visibility of the campaign in the press and the President's public commitment to women's issues were among the factors that contributed to the campaign's success.

Victory was at hand: the Malawi government changed its policy and agreed to accelerate the rollout of new ARV drugs and to address barriers to access. The rollout began in July 2013.



What next?

Though their success was sweet, this was not the time to stop. Changing policy was only the first step in the process. Real success would only be achieved when the new drug policy was implemented in a sustainable way, when women and men were actually receiving the new drugs as they required.

Ongoing monitoring of the implementation is vital for letting the government know that it is being held accountable, as well as for ensuring that the policy is being implemented in the right way. The skills and confidence that the women have developed in the process of building the movement are invaluable in this process. District focal points and campaign committees have been formed to monitor the rollout. Recently, a core group of women asked others to be involved in carrying out a survey to assess how the rollout is progressing, whether women are able to access the services they need and are receiving the new drug. The group surveyed over 2000 women living with HIV and are using this information base to further build the "Our Body, Our Lives Campaign." The solidarity and ability to act is still there.

Learning for our practice

"If you have come here to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together."

– Lilla Watson, activist, academic and artist

"The solidarity and ability to act is still there."

In this story, JASS functions as an external organisation working to help women, who were excluded, to bring themselves into the political processes required to bring about change in their own lives. This raises a number of questions to reflect upon:

How were they able to be so effective? How did they build trust with and among the women they were working with? How did they ensure that the agenda belonged to the women and not to JASS? How did they support marginalised women in becoming powerful actors in their own context?

Before reading on, think about your answers to these questions. Better still, get some colleagues together to study the story and then discuss these questions amongst yourselves.

There are several things we can learn from this story about the practice of organisations like JASS that wish to support marginalised people in creating a movement.

1. It is vital to carry out the initial research to gain a thorough understanding of who is excluded and how they are excluded. This is best done by people who are familiar with and preferably belong to the society or community with whom you plan to work. Developing an understanding does not mean, at this stage, deciding what to do – only the group of people affected can do that. Keep an open mind about exactly how people are experiencing exclusion, what the key issue is for them, and what they may want to do about it.
2. Start by building trust. Like the women in Malawi, many people have already had experience of people who want to help them. They may have definite expectations of what such processes involve and what they can expect to get out of them. They may be also be suspicious, having found from past experience that outsiders come with their own agendas. Find ways of making people feel comfortable and building their trust in you and in each other. What do people like doing? In what places and circumstances do they feel safe?
3. People who have been discriminated against and excluded may not value their own experiences and opinions. This is part of their self-stigma. They have been told that they are not important or have been shown that the society they live in does not value them. By starting with their own experiences and by allowing space and time for them to share these and acknowledge them, people can begin to build their power within again – to feel that what they feel and think is worthwhile and that they deserve to be listened to. Don't hurry them: work in their time, not the donor's time.
4. Power analysis is fundamental to the JASS approach. This is not an academic exercise done in an office far away from the action. It is done by the excluded women themselves in their own communities. Developing this understanding of power and how it is working to exclude them is what gives those who are excluded the power to change things. Respect their own ability to understand exactly what is going on and what to do. This is important to empowerment.
5. Recognise that we are all influenced by the society in which we live and that even when this society excludes us, we often internalise the beliefs and prejudices that have led to our exclusion. This causes us to discriminate against each other. It divides excluded groups and increases powerlessness. It is important to help those so excluded to recognise this when it is happening – as when, during the early stages of movement building, the women started to form allegiances and cliques based around their differences, rather than looking at what bound them together – and then to work with this, rather than just ignoring the processes of exclusion, or to support one group rather than another. It is important that our approach is inclusive, at every level and stage, and works with diversity, actively encouraging people to recognise how excluded people themselves may also be excluding and discriminating against each other.

PERSONAL STORY 4

Red Riding Hood from Georgia

– by Maia –

In my work with internally displaced people I met Mari, a 14-year-old girl from a war-affected village, who set up a youth organisation to help her fellow villagers survive after the war in 2008. Her own experiences gave her a strong determination to help others.

"It was as if I began to love and appreciate my mom, dad, grandmother, grandfather and, in general, all people around me absolutely differently."

As a displaced person in Tbilisi, she was helped and supported by strangers who provided war-affected people with food, clothes and all necessities. This inspired her to assist those who were in need of help after she returned to her native village, Karaleti.

The village was almost empty as most war-affected families preferred to stay in the capital. The situation was even worse in neighbouring mountainous villages – young people had left the villages and only a few elderly inhabitants remained. The new border had divided the villages into two separate parts. Russian representatives advised those who remained to leave.

Mari took pity on her grandparents left alone in the village and started to support them, doing the housework, cleaning and cooking, farming and gardening. She shared her worries and concerns with her friends.

"It was as if I began to love and appreciate my mom, dad, grandmother, grandfather and, in general, all people around me absolutely differently."

Sometimes she took them with her to help other elderly people in neighbouring villages. The reason for her doing so was simple – compassion and sympathy. "On the one hand, we tried to relieve their pain caused by loneliness, and make their life easier by helping them physically; and on the other hand, to become an example for those young people who left their native land."

The elderly people told their returned relatives how the young people helped to make their lives easier and how they supported them to show them that they were not alone. Every day they waited for the children because they made their lives happier. They brought new life and hope.

The children's efforts resulted in definite positive changes. Gradually, displaced young people started to return to the villages to spend time with their grandparents. Mari decided to establish an organisation. "We had free time . . . So, I decided to fill it with a new activity, tree-planting and cleaning up in the other villages throughout the region. With the support and involvement of different organisations – local government agencies as well as private enterprises, we organised large-scale actions. My house turned into the gathering place for our voluntary group."

The children had even greater ambitions – to establish a cultural centre in Karaleti for the socially vulnerable, for those who were unprotected or internally displaced.

The group designed a project and won a contest organised by the Ministry of Sport and Youth Affairs. They financed the project and a Literature Club was set up in the village. Young writers and other celebrities regularly visited the club. The children organised many events and parties, sports contests and cultural activities. They launched a project for children who had cerebral palsy.

A Georgian television company "Imedi" filmed a documentary about them. They became role models for many other young people. After two years there were 47 children in the organisation, now there are around one hundred.

There is a settlement for internally displaced people in Karaleti. Before the youth organisation was founded, the young people in the settlement were estranged from other local youth. The youth organisation decided to make friends with the displaced young people through their cultural centre to break this isolation. They helped the young people there to organise and set up joint activities. This cooperation enabled the displaced youth to open their own youth centre in the settlement.

Mari, now 19 says, "We are young people wounded and scarred by the war. We perceive and look at the world differently. Realising the peacekeeping nature of women, we concluded that the more young people are involved in public service, the more guarantee of peaceful life we will have in future. We would like to strengthen our youth organization even more. We strongly believe that every young person has the right and chance to develop and enjoy his or her rights. Our goal is to serve this purpose."

Rewire the System

Changing the rules for inclusion

The impact of discriminatory systems on an individual

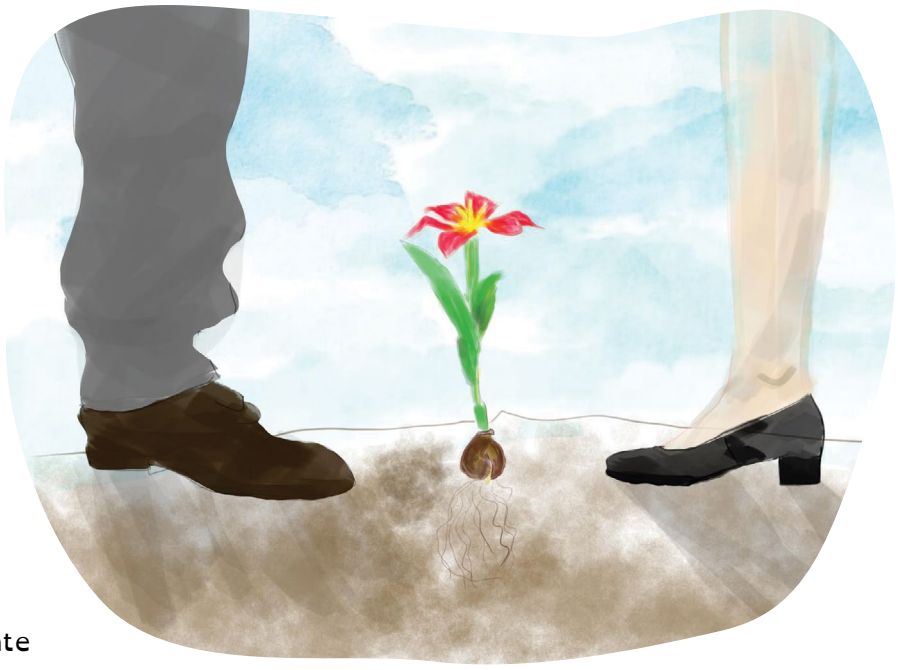
Visualise yourself as a 17-year-old girl. What does your life look like at this very moment? What will life have in store for you? Please take some time to think about this.

What is the picture that you've created? This is a difficult question to answer, isn't it? If we were sitting face to face I could see you arguing that you need to have a lot more information about the girl in order to form an opinion. Information about the country she lives in, the school she is frequenting, friends she might have, the neighbourhood where her family resides. You will no doubt have even more questions to understand the environment the girl is growing up in. Even if you are not familiar with the term, what you have been trying to do is to understand the "socio-ecological systems" that shape the girl's life and have an impact upon her.

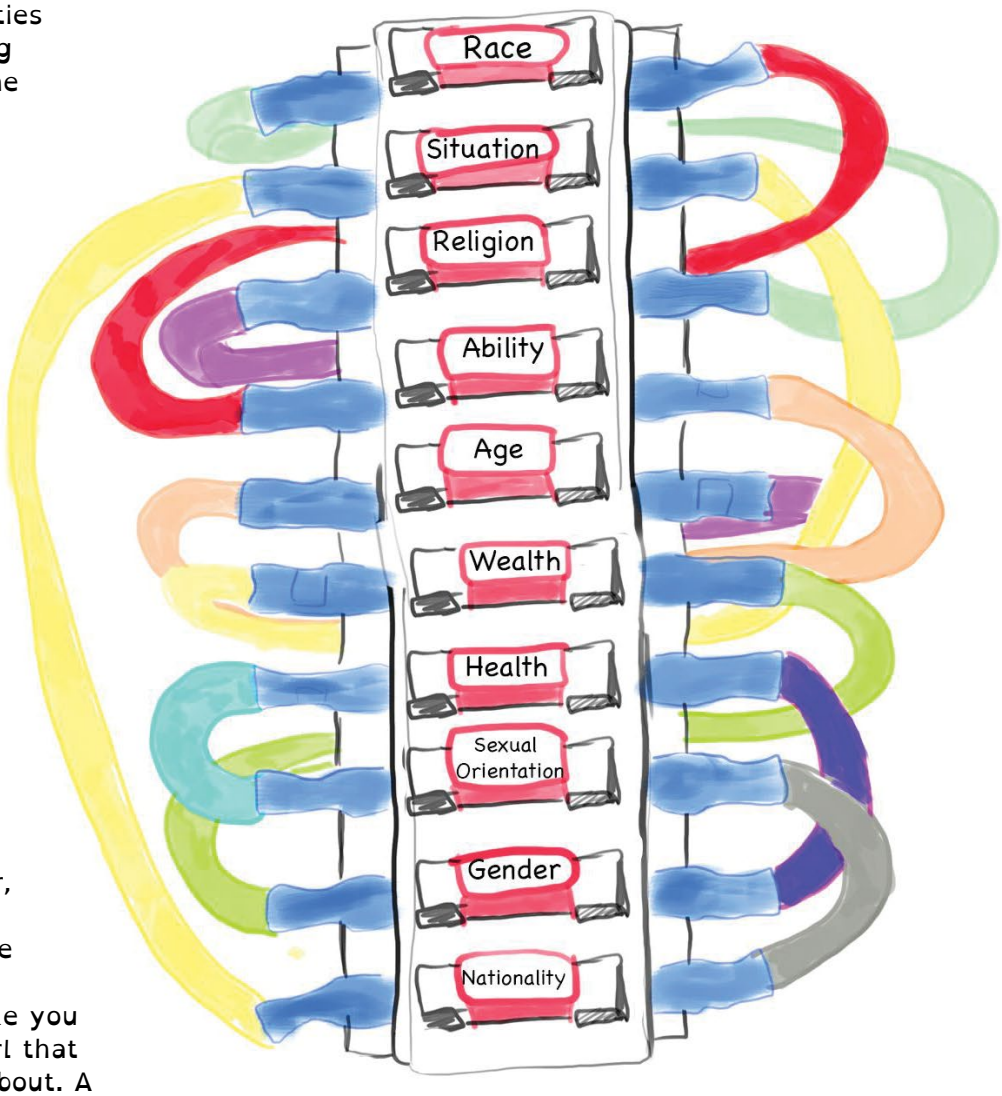
There are many definitions of what comprises a socio-ecological system: commonly, such definitions have characteristics that include multiple tangible and intangible components, both interdependent and connected; these include people, services, resources, relations, values and principles. Such systems are complex and often challenging to fully understand.

Socio-ecological systems exist across societies and influence one another. In our complex world, they provide structure through a set of written and unwritten rules and regulations. They influence our attitudes and behaviours and the way we organise. Such systems can either support you, discriminate against you, or ignore your existence completely. The way these systems cater to you or not, depends upon their characteristics as well as one's own specific identity, such as race, religion, nationality, ability, gender, age, wealth, health situation, and sexual orientation. If you – because of who you are – deviate from the norm to any great extent, your society may deliberately or unwittingly discriminate against you, or make no provision to acknowledge or support you. We call these effects "systemic" because they exist within the system and are not solely the responsibility of one or more individuals.

> *What does your life look like at this very moment? What will life have in store for you?*



In this chapter, we look at discrimination and exclusion from all its systemic angles. We look at the harsh realities of discriminatory, excluding systems and emphasise the need for urgency to act. The good news, however, is that systems are not merely static but are *dynamic*. They change. They can, therefore, be actively changed. Systems influence an individual, but individuals and groups can also contribute to system change. So, the question that we would like to begin to address in this chapter is: what can be done to rewire the inclusive potential of systems? How can you – or your organisation, or peers – locate the leverage point within the system, where you have the power, authority and opportunity to change something in the system?



First, I would like to take you back to the 17-year-old girl that you were asked to think about. A few more details: she is from Lebanon but she is stateless. This shapes her life.

> ***The good news, however, is that systems are not merely static but are dynamic. They change.***

My name is Sara. In 2015, I joined War Child Holland in Lebanon, where I manage and supervise our case management services, which are provided to the most vulnerable, marginalised and at-risk children in the North of Lebanon. Any child at high risk, regardless of nationality, status or other social identity can be identified as requiring help and in need of these services. However, practically, in order to deliver quality work, a caseworker cannot handle more than 25 cases at a time.

My colleagues Hadeya and Iyad, both caseworkers, have identified a very large number of children at high risk of violence, abuse, neglect, and exploitation. On a weekly basis, we discuss new child case plans or follow up on already identified and assessed cases. While some children need access to psychosocial help or access to health services, others require even more complicated interventions.

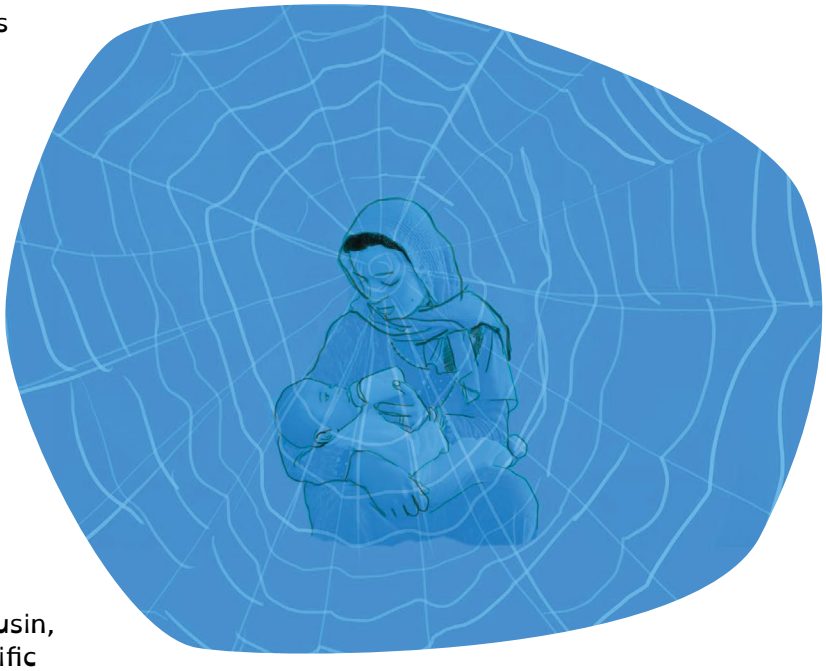
I invite you to read Fatima's story and follow her journey through the challenges she faces from discriminatory systems, and the impact that these have on her and her baby.

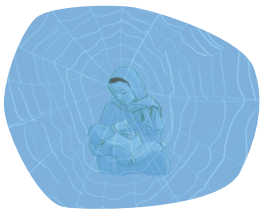
Fatima, unregistered and invisible

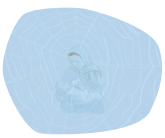
I would like you to meet Fatima (we have changed her name to protect her identity). She is a 17-year-old Lebanese girl who lives with her family and siblings in a tent in an open field north of Lebanon and was married to her cousin at the age of 16. She and her family have no identification papers: the family has not registered her birth or that of her siblings, nor her parent's marriage. Fatima's mother is the only one in possession of identification papers, which she cannot use to register any of her children due to the nature of the registration system. This only allows the father to make such a request for registration, prior to the child reaching the age of 18. After which she must file a lawsuit to prove that her *father* was Lebanese. The law doesn't allow the mother to register children at birth and doesn't penalise fathers who fail to register their children. Non-registered children do not officially exist, which implies that the state can withdraw from its responsibility as primary duty-bearers for the rights of children.

Fatima's father has left the family, so she remains stateless. After Fatima's husband, her first-cousin, decided to leave her, giving no specific reason for doing so, she returned to live with her family. We have not been able to reach him – and so he is not able to register the baby that she is currently expecting. Thus, continues the cycle of exclusion.

While Hadeya was telling me about Fatima's case – though I hate to use this word, it is necessary that ethical and professional boundaries to be respected – the unfairness of her treatment struck me. How is it possible that some children exist physically – I see them right in front of me – but not in the eyes of the law, not on paper? You can acknowledge their existence only once you get to meet them face-to-face, randomly and by chance. How many more such children are there out there?







How is it possible that some children exist physically – I see them right in front of me – but not in the eyes of the law, not on paper?

Fatima: caught in invisible systems

"We realise the importance of our voices only when we are silenced."

– Malala Yousafzai

As a child protection professional, I am constantly reminded both of the immediate threats and the long-term negative impact when children are excluded. Exclusion results in anxiety, sadness, and a feeling of guilt and emptiness that can lead to withdrawal and self-exclusion, with stress-related consequences that greatly harm healthy development. As such children transition into adults, the effects are passed on from generation to generation, with entire communities ending up being excluded.

In many traditional societies children are perceived as passive recipients and the personal property of adults. Being a child often already equates to exclusion. In adding levels of concern to their identity, the child becomes merely a "case" – a child with disability, a child displaced, a child with mental illness, a child with unaccepted gender identity, a child with . . . Such characterisations help us to perceive them negatively, adding further layers of exclusion.

For me, a child is a child. However, in my role in managing our work with such children, I also refer to their identity in such ways, categorising and labelling them in terms of their challenges in order to ease analysis. But do children with disabilities all experience and perceive exclusion similarly? Can inclusion be dealt with by category? "Do this and an excluded child with a disability will be included?" I believe not. More than any other label that the outside world stamps on you for easy reference, exclusion is about how you feel and about the rights you are able to enjoy.

You can learn more about the process of self-exclusion in Chapter 5, specifically in Ed's story.

> ***Being a child often already equates to exclusion.***

Missing out on necessary care and support

The case of Fatima keeps me thinking. Not only is she suffering from severe mental disorders but so is her younger sister as well. Their living conditions are extremely poor, with no access to clean water and nutrition. Clearly the case has to be dealt with in a different way because of its complexity. Hadeya and I identify services which Fatima could be referred to. We take her to a doctor to check the health of her unborn baby, we provide some basic items to protect her from the cold. I follow up with Hadeya on a regular basis, and when Fatima delivers her baby, a girl, we provide her with milk and other items that could be helpful to her wellbeing. However, Fatima refuses to see or care for her baby. She is diagnosed with postnatal depression and does not want to have anything to do with the child.

Engaging actors

We agree that the case is getting complicated – how many cases are we actually dealing with in the same family? We have Fatima, her sister, and now Fatima's daughter. How is it possible to deal with the three children separately? Thinking the situation of this family through, Hadeya and I admit to ourselves that we cannot handle this alone. Much more help is needed than we can provide as case workers. We need to call others, check out the situation more thoroughly, bring people together to discuss the issues, and problem solve. We need more heads to do the thinking and more service capacity. These girls all have a right to access quality services. It is our duty to make them visible and bring light to their existence. They have the right to be included, no matter what.

The baby is cared for by her grandmother, Fatima's mother. It is clear to us that Fatima and her sister need to get psychological help. The family and the sisters agree with this assessment and provide informed consent. MCI (Mercy Corps International) asks them to come to their clinic. They refuse: they want the psychologist to come to their tent as they do not feel comfortable going there alone. IMC's policy is that clients should commit to visit the clinic. This means that Fatima doesn't get the support she requires.

We need the Ministry of Social Affairs (MoSA) to intervene – after all, they are part of the Lebanese governmental system that has the responsibility for facilitating the care of its citizens. Though Hadeya has tried to engage with the system, no social worker has taken up the responsibility to assess her family's situation.

With the Syria crisis now entering its fifth year, the increase in refugee children in Lebanon has had a substantial impact on overall service availability. The UNHCR (United Nations High Commissioner for Refugees) has the mandate and responsibility for refugees, and to ensure that children are able to access the services required to meet their needs. The government of Lebanon has ultimate responsibility for Lebanese children, but facing additional pressures from the refugee influx, even with the best of will, it does not have enough resources to reach its most vulnerable population. Palestinians have a long history of displacement in Lebanon: they are served by UNRWA (United Nations Relief and Works Agency for Palestine Refugees in the Near East), that is if they carry a Palestinian refugee ID card.

Who is there for Fatima and her family?

Case conference to map services

We feel helpless. We realise we forgot to consider so many excluding factors that impede improvement, including that the girls are labelled as 'gypsy' – yet another excluding identity. We decide to call for an urgent case conference: this is an inter-agency meeting held for complex cases and includes representatives from UNHCR, MoSA, UNICEF, IMC and other organisations: the stakeholders and institutions that have it within their mandate and responsibility to act. The purpose of a case conference is to review a particular child and their family's case plan, to explore inter-agency service options, and to reach a decision in the best interest of the child (in this case, the children). Often, both the child and their family participates in such case conferences, where appropriate, and their opinions and input should always be sought in order to feed the decisions that are made.

The process is slow. UNHCR refers to MoSA. MoSA tells us that they cannot provide support, as they do not have registration documents. So, where is the accountability? Why are these criteria allowed to be the cause of continued exclusion, of the refusal to grant rights? Who has the power to decide on these criteria – and with that, the power to make changes?

My frustration increases by the day, and I decide to contact the UNHCR again. The protection officer responds positively, and provides advice on how to move the situation forward, although not understanding that these children are not refugees, so do not fall within their mandate. We do appreciate the effort though, so we send them anonymised information related to the girl. We make sure they know that this responsibility lays in the MoSA, as stateless children within the country.

But we still don't make headway.

One case in a complex system

While focusing on providing our service and adhering to the case plan, I realised that I was missing the bigger picture. In the chaos of a humanitarian crisis, work gets lost in running from one emergency to another. These children have been living in Lebanon for years, long before the Syria crisis. They have never been included because of their illegal status, and no one reached out to them. They are not aware that they have been excluded and thus not aware of potential self-exclusion. I wonder how having a 'gypsy' identity can lead to non-realisation of the right to survival and development, let alone participation, as well as to discrimination and exclusion. But I see this happening in front of me.

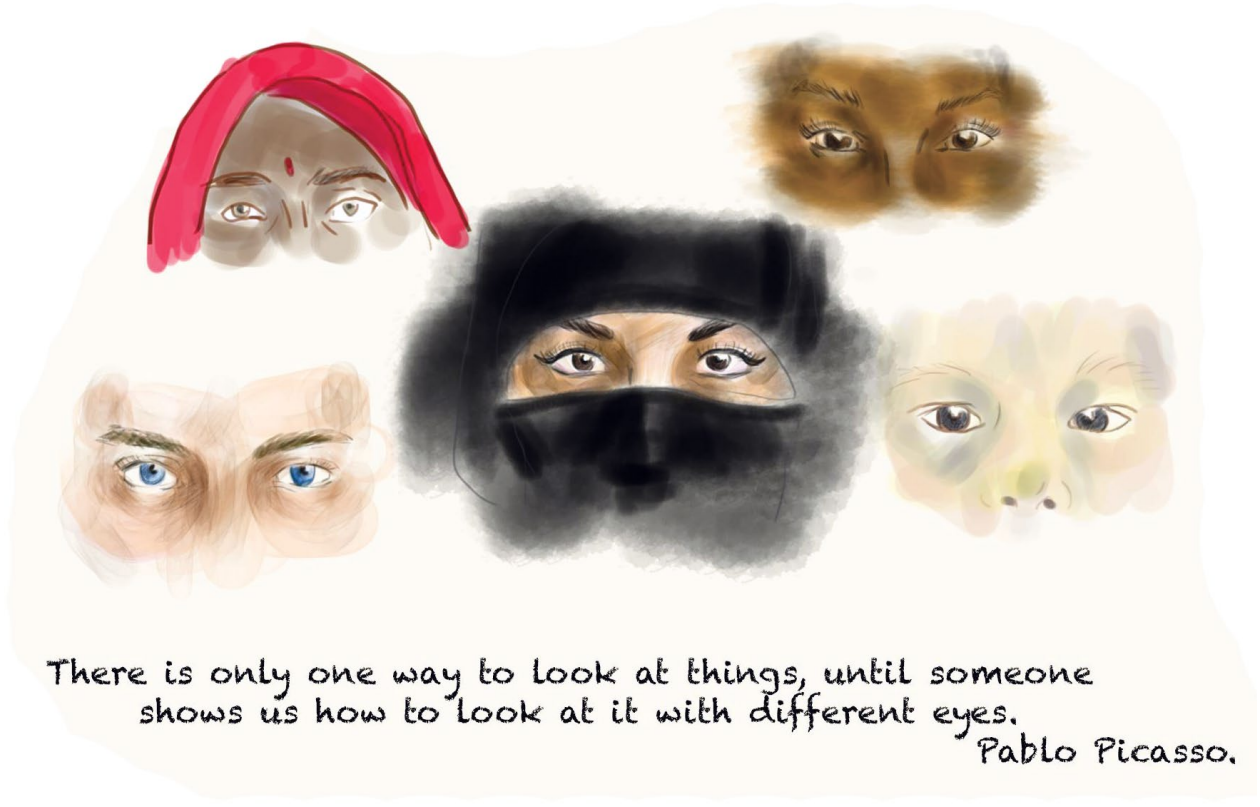
Exclusion can be long-term. It can last for years and be transmitted from generation to generation, consciously or unwittingly. The daughter of Fatima will remain stateless as well, unless the father registers her. Or until the government changes the law. For now, I realise I haven't done enough, only bringing the case to the attention of those who should be bound by responsibility. But what more can we do? What if we first take a step back and explore the different mechanisms of exclusion to increase our broader understanding and learning? What if we start by listing all the almost infinite possibilities and perhaps unconventional forms that exclusion shapes itself, and then identify the possibilities – because they do exist, they must – for being inclusive?

Through our work in case management, we experience the reality of those that are excluded. We seek to address, with other parties, the child protection system in Lebanon at a higher level, as well as in the other countries in which we work. While we are adamant in focusing support on the individuals and families that fall between the cracks, such discrimination needs to be addressed at all the various levels of the system, not just at the level of the excluded. We require leadership to address these leakages in the system and to apply rigorous change: for Fatima, for her daughter, for all the others that currently share the same fate, as well as those to come.

"There is only one way to look at things, until someone shows us how to look at it with different eyes."

– Pablo Picasso.

We see in the course of work that the macro-systems in Lebanon (a state which is neither signatory to the 1954 Convention on the Status of Stateless Persons nor the 1961 Convention on the Reduction of Statelessness) have a direct effect on the statelessness individuals and their families. Unfortunately, Fatima, her sister and her daughter share their fate with many other children in Lebanon and across the world. A recent report indicates nearly 230 million children lack official birth registration documentation (UNICEF, 2004). This has many consequences: without a birth certificate, you are excluded from government services, such as education and health, will encounter difficulties in obtaining official employment, and cannot count on proper treatment before the law. In short, this leaves you dependent on the goodwill of others, as well as your own, and your family's, determination to get out of this situation.



> *power dynamics play a very important role: who is in charge, who influences the outcomes, and who bears the brunt of their decisions?*

In this case, a specific challenge is presented by the current Lebanese law: while fathers can register their children, the law only allows a Lebanese woman to pass on her nationality to her children in exceptional circumstances. The provisions for naturalisation are highly politicised and at the discretion of the Lebanese state. Safeguards against statelessness at birth are interpreted very narrowly by the courts, while seeking court redress costs a substantial amount of money, which is difficult for stateless people to earn when they have no official employment. The problems with the registration law do not stand alone; various personal status laws in Lebanon have one aspect in common: their discriminatory impact upon women.

The story of Fatima shows that many actors directly influence her situation. Who should take up responsibility for the situation of Fatima and her family? They live in the margins of a society that doesn't officially acknowledge them and that places barriers in their way at every step. Even when support is provided, the systematic intrusion of discriminatory measures targeted against them and those like them makes escaping their marginalised position extremely challenging. Even when psychological support was finally made available, it proved too difficult for Fatima to locate the courage required to attend the clinic. Service availability, if existent, is not sufficient in itself: increased accessibility is required to strengthen utilisation. In this case this requires, amongst other things, tackling the systemic discrimination in the legislative system.

Embedded within all this, is that power dynamics play a very important role: who is in charge, who influences the outcomes, and who bears the brunt of their decisions? We – as individuals, as facilitators, as organisations – should look for the leverage to start rewiring this excluding and marginalising system. This raises a key question: what is our role, and what can we do with others to change the situation?

Cumulative Inequality Theory:

the intergenerational element to inequality and the role of systems

The absence of Fatima's father has a major impact on her life and that of her daughter: his absence is the direct cause of their facing the experience of social exclusion. The Lebanese system, especially the legislative framework (along with a number of other areas), firstly impedes their registration and then, with that, blocks their access to social services. This could potentially have a severe impact on their development: not only that of Fatima and her daughter but, possibly, for the generations to come.

In recent years, Ferraro and colleagues have developed what they term the Cumulative Inequality Theory (CIT). This builds upon the Cumulative Advantage/ Disadvantage framework (CAD), which assumes that events early in life contribute to the future of an individual, be it positively or negatively, as well as the Life Course Perspective, which is a theoretical framework that focuses on understanding social factors that influence an individual's life from birth to death. A specific paper written from the life course perspective by Gee et al. (May 2012) indicates that racism can indeed have specific outcomes on health inequalities.

Ferraro and colleagues developed the CIT for a number of reasons, one being that CIT places more emphasis than other approaches on the intergenerational transmission of inequality, a process that we can see in the case of Fatima and her daughter. Furthermore, Ferraro and colleagues argue that while advantage and disadvantage often attach solely to individuals, CIT builds upon the maxim that "social systems generate inequality, which is manifested over the life course via demographic and developmental processes."

This is a powerful theory with important implications. It could be read as saying that systems ensure that "the rich get richer and the poor get poorer." At the same time, the structural and systemic element of CIT is counterbalanced by an underlying belief that there are ways to adjust and overcome the manifestations of early inequalities. They believe this is possible through human agency and resource mobilisation.

CIT underlines the importance of breaking through the impact of systems that are inherently undermining of an individual's chances, and that prevent them from lifting themselves and their families out of social exclusion and poverty.

How power dynamics play out within the system

You may not always be conscious of this, but you are yourself living in a world where many systems contribute to and influence the way you live. Each and every individual on this planet is placed within a socio-ecological system. You might find yourself at the centre of an effectively functioning constellation of systems that enables you to enjoy your rights and that supports you in your endeavours and development: a system that acts as an inclusive one, at least for you, so to speak. But, equally, you might find yourself in a system that puts you at the margins of society, throwing obstacles in your way. Think about where you find yourself for a moment – and maybe even get a pen or pencil and start to visualise this. Which systems make up your constellation and which ones influence you most? Which ones support you? And which ones hamper you and hold you back?

What does your picture look like? Take a few of the systems that really work in your favour and think about why those systems function for you as they do – where does the power lie? Then ask yourself the question whether they are doing the same for individuals with different identities. Can the system which proves so supportive for you, actually be an obstacle to others?

> ***Can the system which proves so supportive for you actually be an obstacle to others?***

To get you started: in your school or workplace, you may notice that peers with specific identities always get the numbing chores. They may not be invited to nice school or work events. And maybe, thinking a bit harder, you may come to realise that certain profiles (identities) are not even present in the school or workplace, maybe not because of these people's competences and qualities but because their surname or appearance suggests that this person is in some way "different" to the acceptable profile. They are left outside the current order of "the way things are done" and so do not therefore even make it through the front door.

Who is invited or not to a job interview is just one example of how power is ingrained in the institution and can lead to discrimination and exclusion. The story of Fatima shows similarly that the government is in a position to simply disregard her and her needs, as well as the many others like her. Perhaps she can be ignored because she doesn't know her rights, doesn't speak up and lives somewhere remote, "out of sight." We've learned that physical spaces can, over time, solidify systems and processes into exclusion. We all know that during the Apartheid era in South Africa there were whites-only clubs, buses, jobs, suburbs. Similarly, in parts of the United States, as recently as the 1960s, the black population was excluded from many public spaces: for example, black people were only allowed to sit at the back of the bus when travelling on public transport until the 1950s. Similarly, in the period leading up to World War II, there was much discrimination against Jewish people: entire businesses and other public spheres in Germany were closed to Jews, while less overt but nevertheless pervasive discrimination was evident throughout much of Europe. Today, in the Palestinian Territory, Palestinians face severe restrictions due to the policies implemented by Israel.

Not all such exclusion is the direct result of explicit policy. Across western Europe, "white flight" has led to a high concentration of recent migrants in certain areas of major cities. This results in large numbers of schools attended largely by "black" pupils while other schools, often in neighbouring areas, remain largely "white." In Amsterdam in the Netherlands, for example, the division between so-called "black" schools and "white" schools is clear. The automatic assumption made by many is that the "white schools" provide better education, which means that many parents wish to send their children to these schools. In 2015, two "black" schools in a multi-ethnic part of Amsterdam started a campaign to attract more white pupils to their schools using the slogan, "Is this white enough for you?"

Schools are interesting places to explore inclusion and exclusion (see also Chapter 5). In Italy, in October 2016, parents rallied to prevent two refugee children from using the bathrooms in a Catholic school, citing that they were afraid of their children contracting African diseases. The nuns who run the school, challenged the parents desire to exclude them, saying, "The children are all the same for us. In the many years of work here in Cagliari, we have never sent anyone away. This story has hurt us. We are concerned about it, as racism is like a contagious virus and we will do everything to ensure pupils are never infected." Fear drove the parents to try and proactively exclude two children from the school system, while the nun's humanity, values, their respect for human rights – and, possibly, the rules of school – led them to oppose the wishes of the parents and include the refugee children.

Discrimination and exclusion is engrained into systems at each and every level and these perpetuate and strengthen one another. To paraphrase Pescosolido et al. (2008) on the complexity of stigma: "Stigma is woven into systems that are interrelated and heterogeneous and that run from the individual to the macro level. Norms are integrated into each cell of society and if you deviate from that norm, even if only by association, you are likely to experience prejudice and discrimination."

Discrimination and exclusion is engrained into systems at each and every level and these perpetuate and strengthen one another.

When we look again at the previously mentioned example of bus segregation in the 1950s in the U.S., this was a systematic, deliberate societal form of discrimination. The public – both black and white – in general accepted, or didn't actually defy, this institutionalised segregation that ran, as Pescosolido describes, right from the individual through the entire national system. This changed only once various people stood up against it (or rather, remained seated!). Rosa Parks, on the 1st December 1955, refused to give up her seat for a white passenger when the driver told her to do so. Rosa was seated in the middle section of the bus, where black passengers were allowed to sit, but the white passenger was left without one, since the whites-only section in the front of the bus was full. In the past, black passengers had simply yielded when told to do so. Rosa's defiant action in refusing to move became a major symbol in the Civil Rights Movement against racial segregation.

Change happens when the excluded refuse to remain complicit with their exclusion. Shamsin, a development worker from Bangladesh, told us of her experience of working with Sabrina and her son Imran. The boy was born with a physical disability, seen as a stigma that would automatically have put his development "in the back seat." But Shamsin did not accept this discrimination and took steps with others to start a movement to make better services available to children with disabilities. The movement focused on actions both at the family level and at the institution level.

The inclusion revolution starts at home

"The true focus of revolutionary change is never merely the oppressive situations which we seek to escape, but that piece of the oppressor which is planted deep within each of us, and which knows only the oppressors' tactics, the oppressors' relationships."

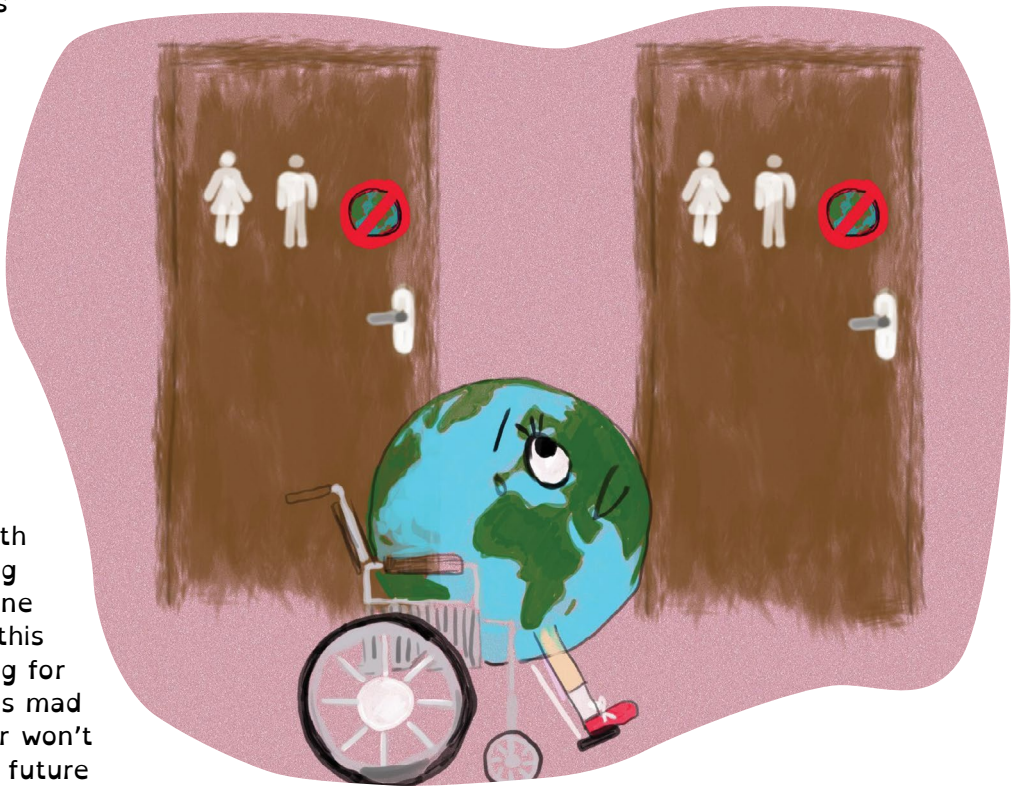
– Audre Lorde

My name is Shamsin. When I first met Imran's mother Sabrina, she had the look of a helpless destitute. Her husband and her in-laws had asked her to leave the family home, taking her "mad" son with her. Her son, Imran, was then five-years-old and unable to stand on his own feet. His eyes looked in different directions and saliva flowed constantly from the sides of his mouth. However, Sabrina loved her son: she was prepared to go out onto the streets with Imran in her arms to beg if need be. "I have no one but a mad little boy in this world: now I have to beg for a living," she said. "He is mad and even his own father won't accept him, what other future do I have than to beg?"

I suggested she take him to a doctor. She responded, "I have no money: it is no use, he will never be normal." I told her I could take her somewhere where she could get treatment for free: The Centre for Rehabilitation of the Paralyzed (CRP). She shrugged, saying, "Well, I have nowhere else to go."

After being diagnosed with Cerebral Palsy, Imran began to receive physiotherapy and psychotherapy. Within a year of receiving therapy, he is now able to walk and run, he has focused vision and doesn't salivate all the time. Above all, his mother recognises that he has potential. She has hope for the future, for herself and Imran. Imran's mother, who could only think of begging, now thinks of sending him to school and of finding work herself. She has reasons to fight for his life and her own.

Imran's father, who had shunned his wife for having given birth to a child he perceived to be "mad," has started taking an interest in his son and his health. He went to talk to the physiotherapist at CRP himself. Though he had earlier disowned his son, he now sees Imran's emerging capacities and he now wants to be a part of his future too.



Changing Institutions

"A social movement that only moves people is merely a revolt. A movement that changes both people and institutions is a revolution."

– Martin Luther King Jr.

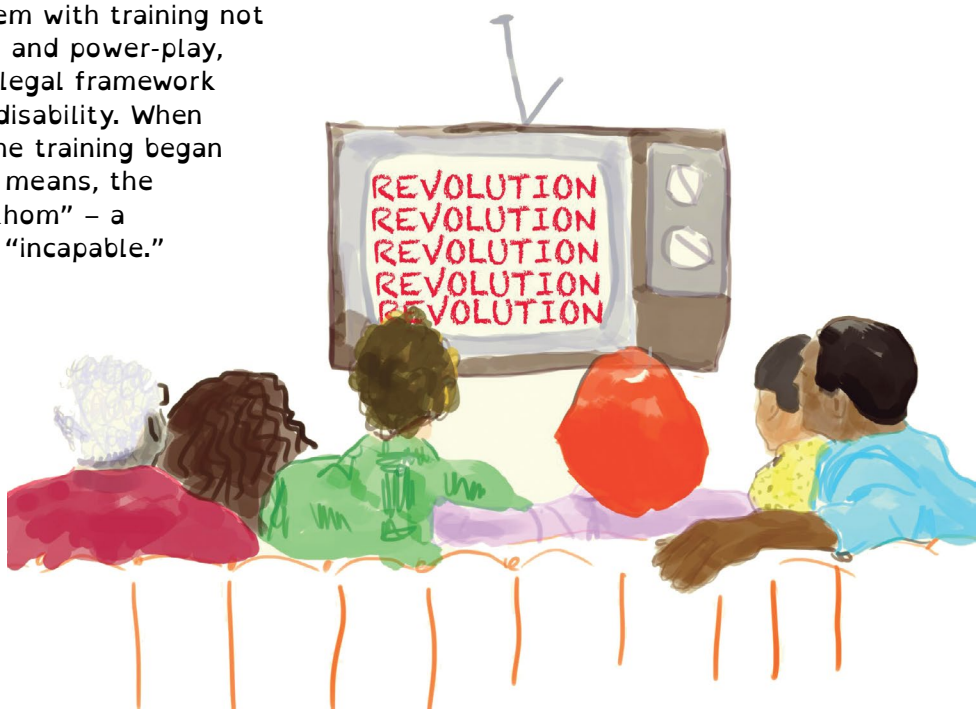
In order to find schools that were both prepared to enrol Imran and were suited to his needs, we reached out to the Disabled People's Organisations (DPOs). The director of one such DPO observed, "But he doesn't have a psychosocial disability." He took out a copy of the law and read out loud: "Psychosocial disability is schizophrenia, depression and bipolar disorders." This organisation, that exists to empower and strengthen the position of disabled people in society, was excluding a boy with a physical impairment! They were, in effect, labelling his condition as being not worthy of help. This is when the realisation hit us that institutional changes were needed across the board.

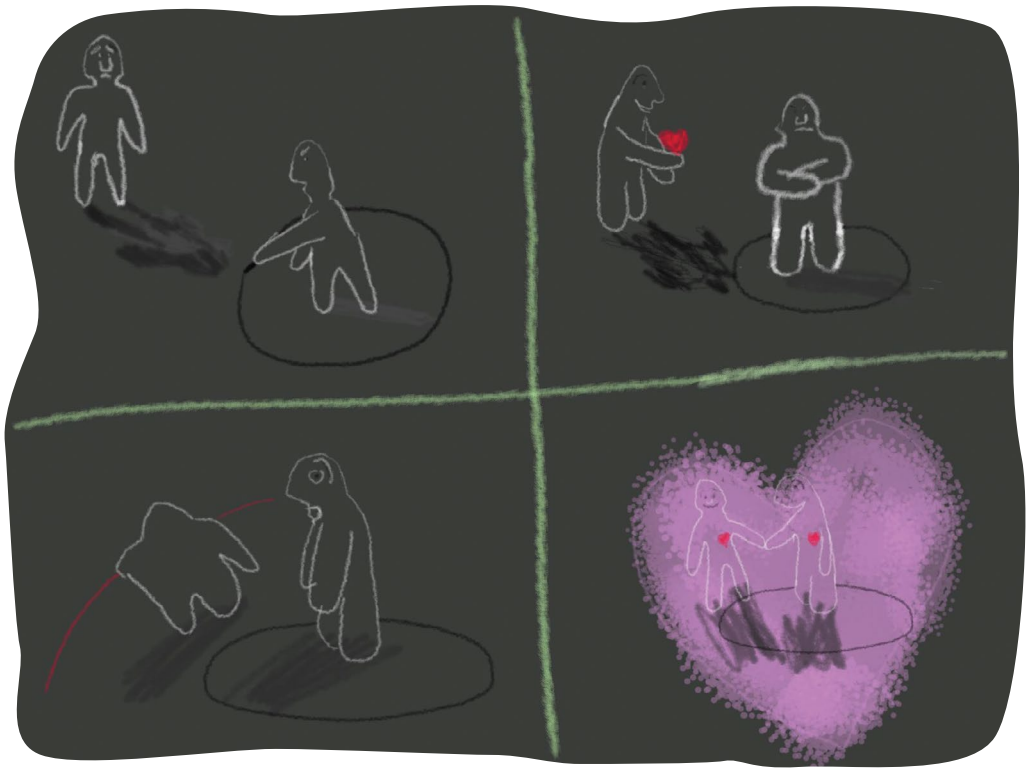
My colleagues and I wished to promote a social definition of disability. When society fails to accommodate people who have a certain condition, it is the society that is disabled. We needed to start a revolution that would question the medical definition of disability and promote a social definition that was inclusive of all "conditions." To bring about lasting institutional change, attitudinal changes were first necessary.

We brought together a group of youth volunteers, providing them with training not just on counselling skills and power-play, but also on the existing legal framework related to psychosocial disability. When we asked them before the training began what the word disability means, the usual response was "okkhom" – a Bangla word that means "incapable." By the end of the training, with every case of disability, they were asking, "How do we change the environment? How can we accommodate the people with (dis) ability so they can meaningfully participate?"

The youth volunteers were sent to four top universities across Bangladesh. In each they presented disability as an attribute of society and not as an attribute of the person. They explained that the focus on psychosocial disabilities, as opposed to "mental illness," acknowledges and addresses pervasive stereotypes, attitudes, and barriers faced by people suffering from mental health issues, learning and developmental disabilities, or conditions such as epilepsy and cerebral palsy. The volunteers trained students and teachers of social work, public health, and development studies. This is the start of creating a cadre of social workers who have the sense and understanding that a society that fails to accommodate people with certain kinds of health conditions is in fact the disabling one. With this movement we are marching forward, towards institutional change and inclusion.

When we asked them before the training began what the word disability means, the usual response was "okkhom" – a Bangla word that means "incapable."





Coming back full circle to the community

He drew a circle that shut me out –
Heretic, a rebel, a thing to flout.
But Love and I had the wit to win:
We drew a circle that took him in!

– Edwin Markham

The Centre for Rehabilitation of the Paralysed where Imran was taken for diagnosis works as a community-based organisation, with social linkages to the society around it. Located in the outskirts of Dhaka, it is a haven providing well-being and an ambience unlike any other health institute. When you enter you may be greeted by Prodip, a young man with cerebral palsy. He sits in a conventional wheelchair and communicates through an iPad while showing you around. Imran and his mother stayed for two weeks. Not only did Imran receive treatment, Sabrina left empowered and independent as well: she was taught how to provide therapy and accommodate his condition.

The centre is the first in Bangladesh to educate and train occupational therapists: the only registered health and social care profession to address both mental and social conditions. Occupational therapists play a crucial role in the social integration of people with mental health conditions and disabilities. As yet, it is a profession that is not fully recognised by many in Bangladesh.

Developing such inclusive institutions and institutional capacity will feed and educate our society. Creating a more inclusive society needs to start in our schools. By improving our school system, by making it less about getting good grades and more about learning and living, we can change our currently unhealthy, competitive, educational system from one that actually teaches exclusion to one that has the right kind of values to ensure inclusivity in our homes, institutions and communities.

Lasting change requires both the power to act and a revolution in how society acts.

Questioning the norms

Shamsin's story touches a sore spot: our own prejudices. These are powerful, yet often hidden from us as they seem so normal and are supported by society. Exclusionary practices are mired in our social structures through divisive concepts embedded in norms around family, class, religion and ideology, in our institutions, laws, systems, daily life. Finding ways to bring these things to the surface and to break the prejudices, while developing an understanding of the importance of inclusion, is critical to developing young men and women who will one day be the custodians of our future and the guardians of inclusive values.

Only when a society is able to see the *capacity* of people *instead of their disabilities*, can it truly flourish. Imran's parents were "handicapped" because they didn't look beyond Imran's impairment and related disabilities. We resort to exclusion when we lack understanding of the variety of human conditions, characteristics and identities because they don't fit into our existing ideas or the structures of society. To challenge this requires contradicting the current ideology.

As in almost every human situation, when we are faced with a challenging position, it is all too easy to fight or take flight. We can fight people with disability, calling them a burden and a liability and implicitly or explicitly constructing barriers that exclude them. We can flee, by not living with them or marrying them, or by ostracising them and excluding them from mainstream spheres of work, education, recreation and politics. But we do not need to do either: we can also open up to new possibilities and embrace them.

Our real work is to question existing norms and to break the present cycle of exclusion. We need to challenge the foundation of a system that is geared towards supporting only the able-bodied and able-minded. We need to see the tip of the iceberg for what it really is and to ask ourselves what lies beneath its surface? We also need to focus on the empowerment of people with impairments and disabilities. This requires attitudinal changes and structural changes. Lasting change requires both the power to act and a revolution in how society acts.

It is not enough to merely disrupt the existing structures in our society. We need to analyse and transform the parts of it that are excluding people. To achieve this, we have to deal with the oppressor within ourselves to make way for co-existence. Institutions such as employers and schools should not be threatened nor attacked for not being inclusive of people with (psychosocial) disability: we need to help them to want to become fit for all.

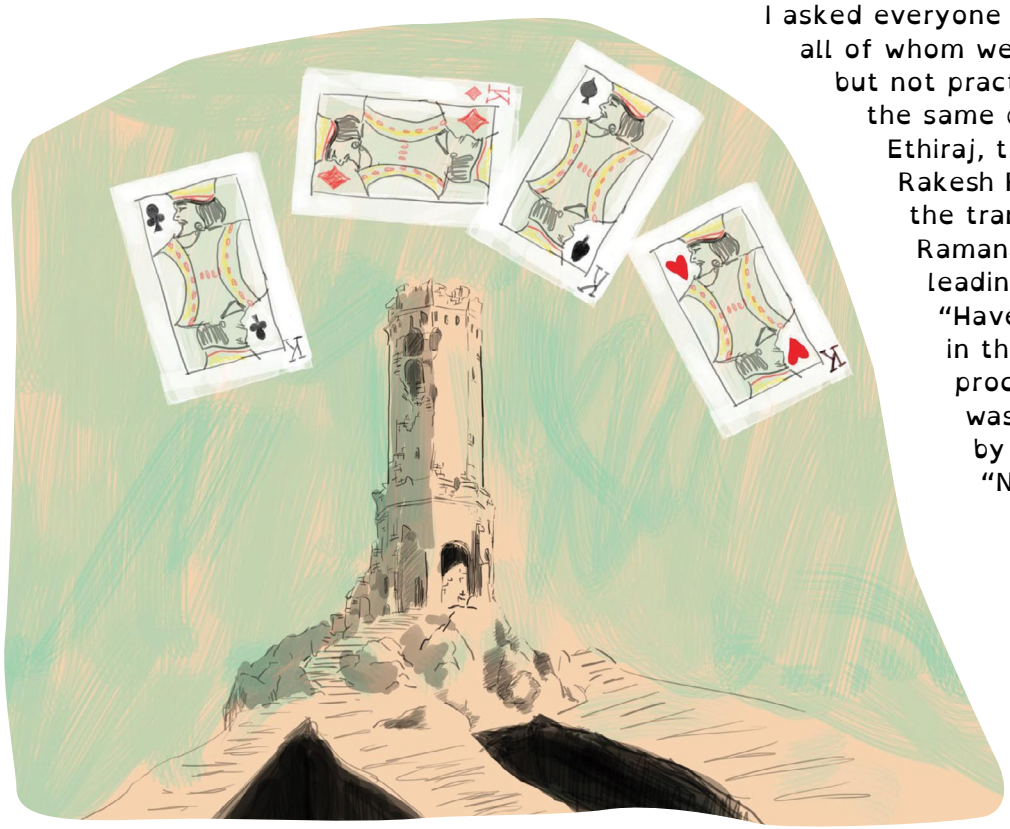
Having now read to this point in the chapter, I would like you to go back to the visual you drafted at the start of this chapter, the one with the systems that surround, cover and influence you, both positively and negatively. Are there opportunities for you to stand up, like Rosa Parks did? What can you do to start an inclusion revolution, as Shamsin is doing in taking responsibility for helping change excluding practices and beliefs?

Let us now focus on Biraj, who is also striving to create inclusive change.

Searching for a way into the tower of power

Biraj works on international development and is a media watcher. Here she describes her steps to influence the process of India's contribution to the development of the Sustainable Development Goals. Her story illustrates the bold, yet constructive criticism that is required to challenge exclusion.

> *Are there opportunities for you to stand up, like Rosa Parks did?*



Asking the bold question

"So, Dr Nanda, have you been invited for the indicators' consultation?" I asked. The question was abrupt and on air on my fortnightly podcast, "Global Summits: where are we going?" Dr. A.R. Nanda, a policy maker, was a panellist on my show in an episode on data and sustainable development. The Government of India had just started a process for setting the indicators for the Sustainable Development Goals. These indicators are the metrics through which our shared destinies, our common futures will be tracked for the next 15 years.

The question was met by a long pause. I believe in the power of awkward conversations but would give my life to avoid one – and here I had just triggered an awkward conversation, on air! On radio broadcasts, silences can be awkward. Dr. Nanda said hesitantly, "No I have not been invited. But I am part of the civil society consultation."

Dr. Nanda was a natural choice, if there was one. So, if he had not been invited, was this an accident, or was this omission by design? The activist, the civil society member in me, who was part of the intense process of developing the Sustainable Development Goals, took over: one awkward question led to another. I asked everyone else on the panel, all of whom were iconic experts but not practising academics, the same question: Govindraj Ethiraj, the data journalist, Rakesh Reddy Dubuddu, the transparency activist, Ramanan Laxmi Narayan, leading health economist. "Have you been included in the indicators process?" The answer was a predictable but, by now, angering: "No!"

Rakesh quoted Einstein wryly, "Not everything that counts can be counted, and not everything that can be counted counts" and then added, "what kind of measurement of farmers' distress, police brutality, women's lack of safety, will we track with a bunch of ivory tower economists setting the agenda?" So, I did what is considered a complete no-go for journalists. I made a public appeal to the person co-leading the indicators exercise in India: "Sachin, you have to come on my show. I think you are a friend. If you have not reached out till now, then please do so immediately. My current panellists are the best names you will get on data and indicators, people who are constantly creating new meanings from numbers and new sources to tell us the nature of reality. The exercise will be diminished if you exclude them. In fact, include data journalists, activists and development practitioners and watch the magic!" My closing words to that episode were, "See that the indicators speak to our living realities."

Acting beyond expectation

After saying goodbye to my studio guests, I took the bus home. I continued to feel that my stomach was tied in knots. Suddenly the enormity of what I had done dawned on me. I had made a public appeal on air to the Director General of the think-tank of the Ministry of External Affairs, who was co-leading India's official efforts for finalising the indicators for Sustainable Development Goals. And I don't even have my own show! What was I thinking? How could I be so cocky, and that too on air? I was sure Sachin Chaturvedi will not take it kindly. Senior, established journalists don't do it, so who was I, a mere media watcher, to do so? I blamed my civil society affiliations for this adventurism.

Being determined

Nonetheless, despite my misgivings, since I'd started this, I would continue: I wrote an email to Sachin with the link of the show and the contacts for the panellists, in case he wished to include them for the indicators' exercise. After all, India had to act fast: the national governments had exactly three months in which to finalise the indicators and to send them to the United Nations. In September, the indicators would be put to the vote. From then on, the way our development is to be measured would then be sealed for the next 15 years. We needed to influence this conceptual exercise to make it reflect our reality.

> *I had made a public appeal on air to the Director General of the think-tank of the Ministry of External Affairs*

I decided to also write to the NITI Ayog, the Planning Commission, as the main lead of the official effort in India, with the link to the show and a request for a meeting. No response at all. This was not surprising, considering NITI Ayog was led by economists, most of whom thought civil society, activists and journalists were an irritating and irrelevant bunch. I reckoned this door was not opening anytime soon. But what about the other door on which I had knocked I – and quite loudly? Over a week had passed and Sachin was silent. One week became two . . . this felt like a really long pause. My activism had given way to despondency. I was starting to regret my actions and I was convinced this was the perfect lesson why people like me needed to know their place. Chutzpah (flagrant boldness) in such cases wasn't good.

A phone call that kick-started change

Two weeks after the broadcast, Sachin called me. I was sure Sachin had called to give me a piece of his mind, to tell me that my public appeal was wrong on so many levels. With mixed feelings, I picked up his call. Instead, I received a very warm and effusive hello. His exact words were, "Biraj, thanks for sending the show's link. Sorry it took me time to get back to you. I wanted to hear and read all of it first. Why don't you draw up a list of practitioners, journalists and activists who you feel should be part of the indicators' exercise? We will open it to them and even more in case they have suggestions too."

The door was suddenly wide open! And so, over the next three months, some of the most inclusive, intense and participatory consultations kicked off. The Ministry of External Affairs' think-tank, RIS, became home territory for the disempowered of India (the rural poor, the working class, the farmers, nurses, the primary school teachers, as well as the activists working amongst them). Everyday people leading their everyday lives were informing the statistical process. Thanks to those everyday realities, some of the indicators we listed were:

"The door was suddenly wide open!

1. Incidence of police brutality, as an indicator of how well the institutions of justice were functioning.
2. Redemption of agricultural insurance by farmers, as an indicator of food security and the security of the farmers' safety net.
3. Number of days of waged work, as an indicator of social protection delivery.
4. Number of public funded crèches and access to the same by vulnerable children and their mothers, as an indicator of women's empowerment and child nutrition.

I believe that none of these indicators would ever have come about if it had been left to academic economists and statisticians alone. In making that on-air appeal, I had played a role, locating the key; but it was Sachin Chaturvedi, the Director General of RIS, who allowed the door to be opened. He has set in place an institutional practice that will last the lifetime of the SDGs and beyond.

Ingredients to kick-start rewiring

Open any newspaper and you will read a myriad of examples of how one group or another has fallen through the cracks in the system. Exclusion is, as we've seen in Fatima's story, a perpetuating cycle and can continue and worsen from generation to generation. This cycle needs to be broken. The authors of this chapter's stories were able to recognise what was happening and decided to act to change this. We have distilled a few of the ingredients that can be helpful in creating windows of opportunity to make changes in complex, excluding systems.

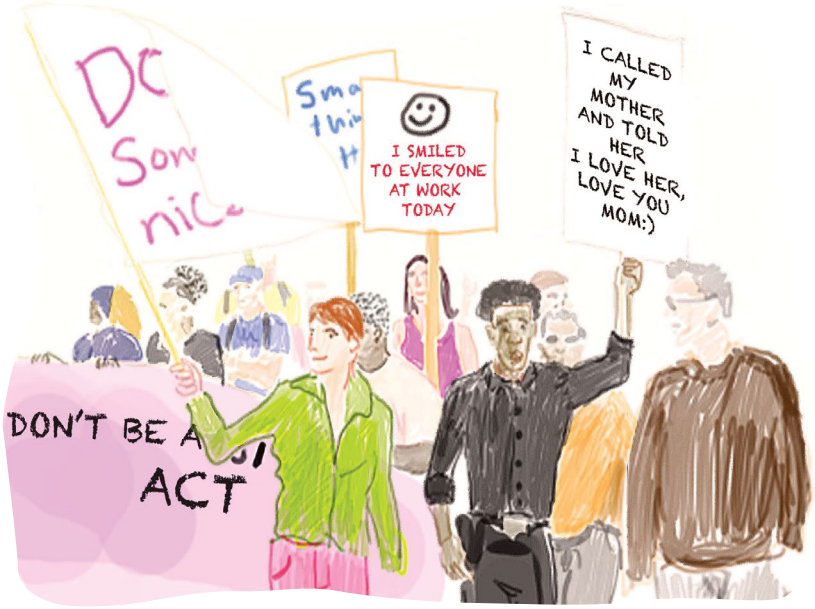
The myriad systems that make up a society have their own sets of rules, codes, regulations, handbooks and secret language. They have formed and shaped our *own beliefs, prejudices, thoughts, assumptions* – ideas that, if they are not challenged, are all too easily held up as being unquestionably true. If we are to have the power to act to be inclusive, we need to *be clear about how the system excludes, stay critical, and stay open.* We need to do this in order both to see what's beyond this normalised vision and to understand what's going on at the various levels of society.

We can use our experience, our knowledge, our humanity to find ways to navigate the myriad systems and to change how they operate.

It is crucial to understand the way exclusion is organised and perpetuated in society, in its institutions and in its communities. This includes identifying the values and attitudes that reinforce exclusion, as well as the underlying ideology that underpins it. Understanding these things will help you to identify where you can find the power to act and how to address the elements that reinforce discrimination and exclusion. Though the systems are complex, the actions we need to take can be simple.

Hope, belief, courage and persistence are necessary for becoming a catalyst for change. Sara, Biraj and Shamsin, along with many others, recognise the unfairness of the present systems, seeing their negative impact on individuals. This motivates them, so that they don't tire of seeking to address the exclusion, identifying persons and entities responsible, and asking for changes in approach and actions that reduce exclusion. Sometimes a relatively small act – such as asking a question on a radio show – can prove critical for increasing inclusion. One person can make a difference. Biraj was able to use the radio show – something not open to all – but Biraj emphasises that critical actions can be taken by anyone at any age, by the ones being excluded – think of Rosa Parks – or by the ones critical of it.

> ***Though the systems are complex, the actions we need to take can be simple.***



Systems change often needs to be facilitated by people taking action *from inside the excluding institutions*. Sara's story, in her quest for a specific person within the relevant Ministry to take responsibility for Fatima's case, shows how such people are not always easy to locate. But contrary to what Biraj feared, Professor Sachin Chaturvedi was not put off by her open and blunt approach on air. He welcomed her thoughts and her message. Those acting as catalysts, who aim to change the system, need to keep in mind that such holders of power may have an open mind regarding suggestions for change, even welcoming such, but sometimes require input from the outside in order to act. Before writing off power holders as excluding in their intention, it is first crucial to *understand their position* in relation to the excluding situation, even when the exclusion and discrimination is happening within the institutions they are in charge of. Taking such an open attitude can lead to surprising opportunities, sometimes even turning such people into protagonists or allies for change.

It is frequently the case that people have a tendency to desire control and to seek out the familiar, as if we are afraid of or unsettled by difference and by change. Just watch when you are next in a two-day meeting: on the second day, the majority of people will sit in exactly the same chair as they did on the first day. This tendency is our way of keeping things stable in an ever-changing world. Because systems are made by people, they behave in much the same way as we do, seeking out continuity and resisting change. This resistance to change means it might take a long time to achieve systemic change. Be persistent, as you are likely to be in for the long haul, and be strategic in which actions you commit to, as you cannot tackle all elements of the system at once. Identify the best way to influence the desired outcome, identify allies, and use this information to shape a strategy that will enable you to move forward.

Sadly, it is often the case that *those who experience discrimination and exclusion do the very same things themselves*. In Shamsin's story, people with disability shut out Imran for not having a disability that fitted their guidebook. Discrimination results from the misuse of power. It would be interesting to *shift the paradigm of power to something more positive and to use power to create cohesion* instead of division, to push open doors instead of creating more walls and barriers that keep people in, out, or down.

Because systems are made by people, they behave in much the same way as we do, seeking out continuity and resisting change.

Education can be used to empower individuals, strengthening their confidence, and helping them to develop an understanding of their rights and responsibilities. It can also provide people with a stronger voice, enabling them to hold power-holders to account (you can read more about this in the next chapter of this book). This can be important in changing attitudes. While many countries have laws and provisions that theoretically support equality, their proper implementation cannot be achieved if the values and norms in society are not aligned with the laws. Sometimes what is needed is a push to align the attitudes with the objectives of the law, sometimes the rules themselves need changing.

Don't be a bystander – act!

Though it is not an easy task, system change is possible. We need to learn to act together to achieve change. We need to stop being bystanders: on the occasion when no one acts in an emergency, this is often because everyone is assuming that someone better able than they are will do so. The good news is that when one person acts, others will often follow.

It is our responsibility to do something about stigmatisation, discrimination, and exclusion. We are part of the system that perpetuates these things. The first step is to be critical about what is considered "normal" in our society to then take the next step towards changing discriminatory rules and regulations.

So . . . going back to the visual you made at the beginning of this chapter: are there unfair rules and regulations in the system you have identified? Could you potentially do something about these? Experiment. First make a small change. However small the change, it might have a huge impact for someone. Remember, sometimes all it takes is a bit of chutzpah.

> *The good news is that when one person acts, others will often follow.*

Multiple layers of exclusion

The Sustainable Development Goals have made inclusion a development goal, calling for building more "inclusive institutions at all levels." The goal recognises that institutions, societal norms, and laws all currently exclude in some way or another and that all individuals and groups need to be integrated into society in order to participate in it.

There are several, interconnected reasons why certain people or groups are excluded:

- They are suffering from poverty, unemployment or related disadvantage
- They are deprived of their full rights as citizens
- They have limited or no social ties

Several related concepts help explain the experience and process of exclusion:

- **Identity** – Can I or my group identify with the aims and processes of the wider society?
- **Humanity** – Am I able to live a full and productive life?
- **Values** – Does society enable me and my group to realise our rights as citizens?
- **Personal** experience – Do I and my group see life as positive, feel supported, and feel part of a community and society that sustains our wellbeing?

Why is it that some people and groups do not have a positive answer to these questions? Three themes run through exclusion.

1. The first is that exclusion emerges in the context of unfair distribution of material resources. Poverty is not solely an absolute state but can be understood relative to income, wealth and status in society. What is considered just and fair becomes a yardstick for exclusion, and this obviously varies across societies.

2. The second theme is related to the beliefs in society about the excluded groups: the situation they are in is somehow of their own making, their attitudes and behaviour being unacceptable, or they are, for some reason, simply unable to participate fully in society.
3. The third theme often associated with exclusion is citizenship. Here, inclusion involves participation and involvement of citizens in the affairs of their community or country. Excluded groups who are not granted citizenship and often live their life as "illegal aliens." Diversity can also throw up disadvantage: disability and gender identity can become barriers to inclusion not just due to social stigma (as in the second theme) but because the law provides neither protection nor rights. Another dimension of citizenship is that not everyone has the capacity to be an active citizen or to act upon their needs and rights. Though they might have rights, disadvantaged people often cannot fulfil their potential.

The Sustainable Development Goals draw attention to structural, moral and legal sources of exclusion. What this means for practice:

- We need to look at the individual as well as the system – to take action that is rooted in exclusion, driven by those excluded, and built from the ground up.
- Create shared societal values – challenge values that exclude, while engaging with the wider society to build new, shared values.
- Recognise and address systemic and structural inadequacies.

The Identity Game

Here is an exercise that can help people to think about how intersecting identities affect an individual.

Resources:

- One prepared statement: this is used to define the task in this exercise and should be about being able to do or achieve something within a certain group. The statement should be as specific as possible, e.g., I can go wherever I like, now, in this community.
- A number of cards or papers, each of which bears a specific identity, e.g., different possibilities of gender, age, ethnicity, married status, nationality, (dis)ability, socioeconomic status, sexual orientation, etc. (the identities that matter within the local context).

Method:

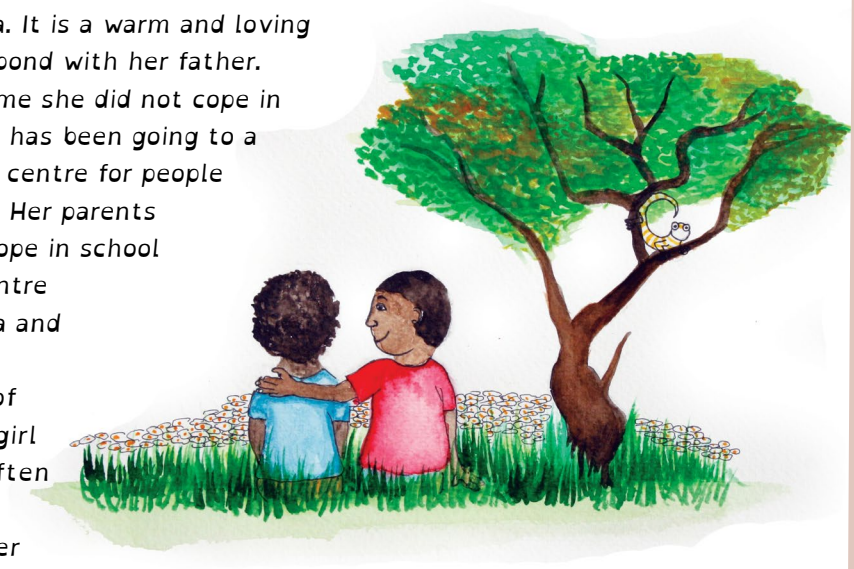
1. Explain to the participants that at the moment they have no identity: no gender, age, background, socioeconomic or marital status, ethnicity or nationality: nothing. They start with a blank slate.
2. Place two notices, one at each end of the room – one says "fully agree," the other says "totally disagree." A line is formed between these two points.
3. Share the prepared statement with the participants. Make sure that everybody understands the statement and make adjustments if necessary.
4. Tell the participants that, on the basis of the identity card they receive, they can move to a point on the line that indicates that they fully agree or totally disagree with that statement, or can stand at any point in between, depending on how much they are in agreement.
5. Each person is given one identity. They then move to where they feel they should stand on the line. Remind them that they only have that identity, nothing else. When the participants have found their spot, ask them about their identity and why they are standing where they are. Do others agree with their choice?
6. Ask them to take a second identity. Remind them they only have these two combined identities, no more. Tell them they can now move the position on the line if they so wish, based on the two identities. Who has moved and who has not? Why?
7. Continue to hand out identity cards and note the changes in position that occur each time.
8. After the last identity card is given out, ask participants to think about one identity they would like to change so that they can move more towards "fully agree." Which identities are mentioned most? Why?
9. Group reflection on the exercise: how did they feel about their identities? What did they notice? What can they take away from their experience of this exercise for their work and daily life?

PERSONAL STORY 5

Children with disabilities are children

Marieke shares stories from Ethiopia

Deceived by a friend



Sara is a teenager who lives with her parents and younger sisters in Addis Ababa. It is a warm and loving family, and Sara has a strong bond with her father. Because she has Down syndrome she did not cope in the regular school system and has been going to a specialised vocational training centre for people with intellectual impairments. Her parents were sad that she could not cope in school but the vocational training centre has brought happiness for Sara and improved her prospects in life.

Sara's mother was aware of her developing from a little girl into a young woman. They often go to church together. She explained to her daughter that she should protect herself from strange men who approach her on the street and not fall for their invitations to share a nice candy or a cup of coffee. Sara's parents live in a middle-class area of the city. They have their own house but there is not a lot of space between the houses, so all the neighbours know each other well. Since her parents have always included Sara in the community's life she is well known in the neighbourhood.

One day, Sara was playing with her childhood friend. He suggested they would go together to a field not too far away. Sara was delighted, since her friend had shown less interest in her than he did in their younger years. In the field, they started to play like they used to. Her friend started to touch her and slowly the touching became more intimate. Sara asked her friend what he was doing. He tried to convince her that this is what friends do when they grow up. Sara was confused. When she asked him to stop, he forced himself on her and raped her.

Sara came home upset and crying. Her parents were immediately alarmed and she explained what happened. While Sara was calmed at home her father went to the neighbours. All were upset. The family of the boy felt that it was not right to go to the police, but the other neighbours supported Sara's father and helped him to report the case of rape. Unfortunately, when the police noticed that Sara had Down syndrome they lost a degree of interest in the case and subsequently failed to advise the family that they should immediately seek a medical report, as this could be important to the success of the case.

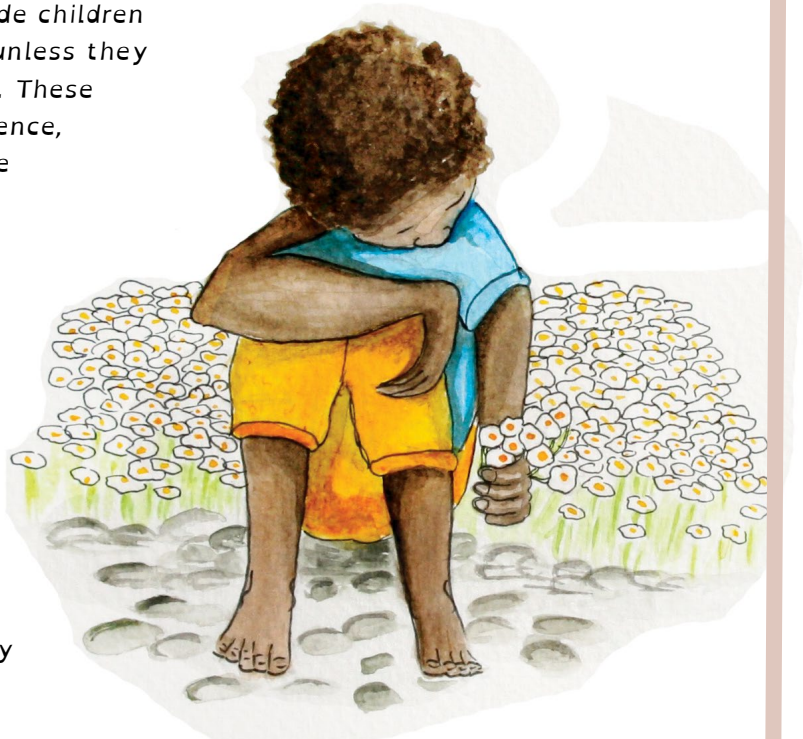
When, after some weeks, the police finally asked the family to produce such a medical report, Sara's body no longer showed signs of her rape and so an important piece of evidence was lost. In consequence, the court case was dismissed and the perpetrator set free.

Sara now counts on the neighbourhood for support and protection. The neighbours told the boy's family that he should be sent away and could not be seen around Sara any longer. She is still going to the vocational training centre and is trying to put this very difficult and hurtful experience behind her.

It became clear to Sara's mother and father that children with disabilities are very vulnerable to violence but that very little is done to protect them from harm. This has set Sara's mother on a journey to discover ways to better protect such children. The following stories come from that journey. To protect the children involved, their names have been changed, as has the place where they live, on occasion. All the stories come from children with disabilities and their families.

In meeting children with disabilities and their families, I soon learnt how isolated they can be. I observed that in most cases children and their families did not manage to make use of either the traditional forms of protection or of the official forms for finding justice in their society. The children were not considered important enough to be protected from violence and their families faced great difficulty in seeking justice for the harm done to children with disabilities. In many cases, their families did not even believe trying to do so would be worthwhile. Some of the children asked me explicitly not to tell their parents about their stories, fearing their parents would take them back home, feeling that was safer, and so they would lose their opportunity for an education that could potentially take them into a workplace. These children considered violence, including rape, to be the price they have had to pay for wanting an education. It was heart-breaking to hear this. The conclusion of the 2006 UN Global study on violence against children is that "no violence to children is acceptable, and all violence is preventable." This should also count for children with a disability, but our experience shows this not to be the case. Organisations that do a lot of good work for the protection of children do not include children with disabilities in their practice, unless they are specifically requested to do so. These children need protection from violence, just as does any other child, maybe even more so than other children. On the other hand, organisations specialised in disabilities feel uncomfortable with the topic of child protection because they lack expertise. As a result, children with disabilities drop off the child protection agenda. The stories of children in Ethiopia show that what children with disabilities most want and need is recognition – to be seen and protected just like any other child.

> ***"children with disabilities drop off the child protection agenda.***



Children at a school for the deaf – excluded from society

I talked to ten deaf children, aged between seven and fourteen, in a school compound of a small school for the deaf. Most of the children are not born in the city where the school is located and live with family members or friends of the family. They are all happy to be in the school and to have friends with whom they can communicate. They feel at home in the school because they all share a common language, something especially important to children who are born deaf and who do not lip read and/or speak. At home, or in their host families, life is different. They feel excluded from family life. No one makes an effort to include them in conversation. Most of them have to undertake many heavy chores after school because the community believes that the loss of hearing makes you physically stronger. The children complain that they have no time for their homework. Their families do not understand that the school they attend really is an actual school supporting academic achievement and so they need to study just like other children. Their families appear to believe that the children's future is in physical labour, so they see no need to give them time to do their homework and pay little attention to their school results.

The children express their need to be respected and included. They want to be treated like other children. When I ask them about going to school, they explained that being amongst other deaf children was extremely important to them. School was the one place where other people understood them, where they felt valued, just like all other children, where they could learn and believe that they have a future. They say that being with their family sounds like a safe solution, but if their family does not support them, it is hard to thrive. One difficulty all the children face is that at home they are not included in conversation. When the family is talking together, nobody is bothered about them or trying to help them understand what the conversation is about. Similarly, no one feels it is necessary to reprimand or guide them or give them things to do, as is the case with other children. While their brothers, sisters, nephews or nieces are told they were should do something, no one considers them. All the children want is to be valued, to matter, to feel their existence is worthwhile.

> ***"they explained that being amongst other deaf children was extremely important to them***

I have seen that when a person with an intellectual disability grows up, people will still think of this person as a child. In the heads of parents such children remain young forever. One thing that does not remain young forever, however, is the body and sexual development. Many parents are shocked and unprepared to find that their intellectually disabled girl starts menstruating: they struggle to teach her what to do to cope. Community Based Rehabilitation projects can help. Through buddy systems of young women, through groups of girls with intellectual disabilities, the girls learn about menstruation, sexuality, desire, and the risks of having sex – including that of sexually transmitted diseases and unwanted pregnancy. The emancipation of persons with intellectual disabilities is still a taboo subject – particularly with regard to their sexuality and decisions about their sexual and reproductive life.

Abel is like a child

When Abel was sent to vocational training he learned how to run a small shop in front of his parents' house. He was proud of his achievement and so was his family. He had become a contributor to the family life, just like his siblings. One day, Abel told his mother: "now you need to find me a wife so I can bring you grandchildren like my brothers and sisters. You have taught me that I can do things and I can be independent. This is what I want to work on next." The family laughed and felt uncomfortable, however they had learned to love Abel and saw there was more and more that he could do, was it also possible for him to have a relationship and raise children?

> ***"was it also possible for him to have a relationship and raise children?***

Marieke reflects

I have seen that in many cases, like the stories I have selected here, society does not recognise children with disability as children. Yet they are actually more vulnerable to violence than children who have no disability. Why can we not see the child as the child it is?

In many countries, social and health services do not have the ability to diagnose and understand disability. This means that many parents will know little if anything about the disability their child is faced with. Though they are well aware that their child is "different" to other children, they do not have a good understanding of the causes of this or what they might do to help their child. Without an understanding of the condition of their child, parents may unknowingly neglect the child's needs – not on purpose, but due to a lack of knowledge and information.

> ***Why can we not see the child as the child it is?***

Being able to access services for children with disabilities is also an issue. Health and other professionals whose job it is to respond to and protect children from violence are part of society and do not necessarily have a thorough understanding about disability and rights. There are endless stories of children with a disability who are denied access to services by the professionals in those services. Like the rest of society, they can feel that these children are less worthy than others.

In some cases, the trauma children face in dealing with the services is almost as large as the abuse they have faced. When professionals deny you access to justice, you feel your pain is not important. This can feel like a repetition of the abuse.

There are children with a disability who grow up to become confident and skilful adults. However, many parents worry overly about their child with a disability, this can result in them being overprotective, leaving the child little room to develop skills and confidence.

I was shocked to learn about the need for a project that works with adolescents with a disability on how to form friendships. The youths in this group had no friends. They had been surrounded constantly by caretakers and so never had a chance to build friendships. How sad it is to have to take a course on something that is such a natural part of life for most people.

I did meet very confident young people with disabilities in Ethiopia. When I asked them where this confidence came from, they said it was due mainly to meeting others with disability, either in school or in an association. For many of them, the turning point was to realise that the violence that happened to them was unacceptable and should never again happen to them, or to any other child.

Simple solutions?

Looking at these sometimes-heart-breaking stories of children's exclusion, isolation and unfulfilled dreams, the solution seems so simple to Marieke:

Start looking at children with disabilities as children
and do not focus on their disability
Encourage them to develop and to find their strength and weaknesses,
as all children have to do as they grow up
And most of all
Look at them as worthwhile, worthy to be part of our society
and to be protected from harm like any other child
Because
No violence to children is acceptable
and all violence to children can be prevented.

CHAPTER 3

Heal the Wings and Learn to Fly

Improving social accountability for better access to services

"We are like birds with clipped feathers, fallen in the field"

– Praveen's story

Disabled women giving birth in government hospitals tell scary stories about how they are laughed at and badly served. LGBTI youth tell of how they are frightened to talk to mainstream doctors about sexually-transmitted infections. People in remote villages complain about the complete lack of services, be this health, water, or transport. How do inclusion practitioners deal with huge demand on the one side and a lack of understanding and limited resources on the other? In this chapter on improving accountability for better services, we explore how marginalised people and government bodies can engage in relationships that improve accessibility.

Accountability is about the formal and/or informal obligation of individuals and organisations to explain what they do and why they do it to the wider public, and to be transparent about what it is they do. It is also about the expectation of account-giving. Accountability is all about relationships: power plays an important part in accountability issues. The idea is that citizens have given "power to" their government to provide services (such as drinking water, education, healthcare, and security) and to protect their rights (such as equality, freedom of religion, and respect for ethnic diversity), so there need to be ways for citizens to check on this and to sanction the government, if need be. When citizens demand accountability they retain "power over" their government. Ideally, government officials don't sit and wait for citizens to request accountability, but actively and publicly explain what they are doing and take responsibility for their choices and actions.

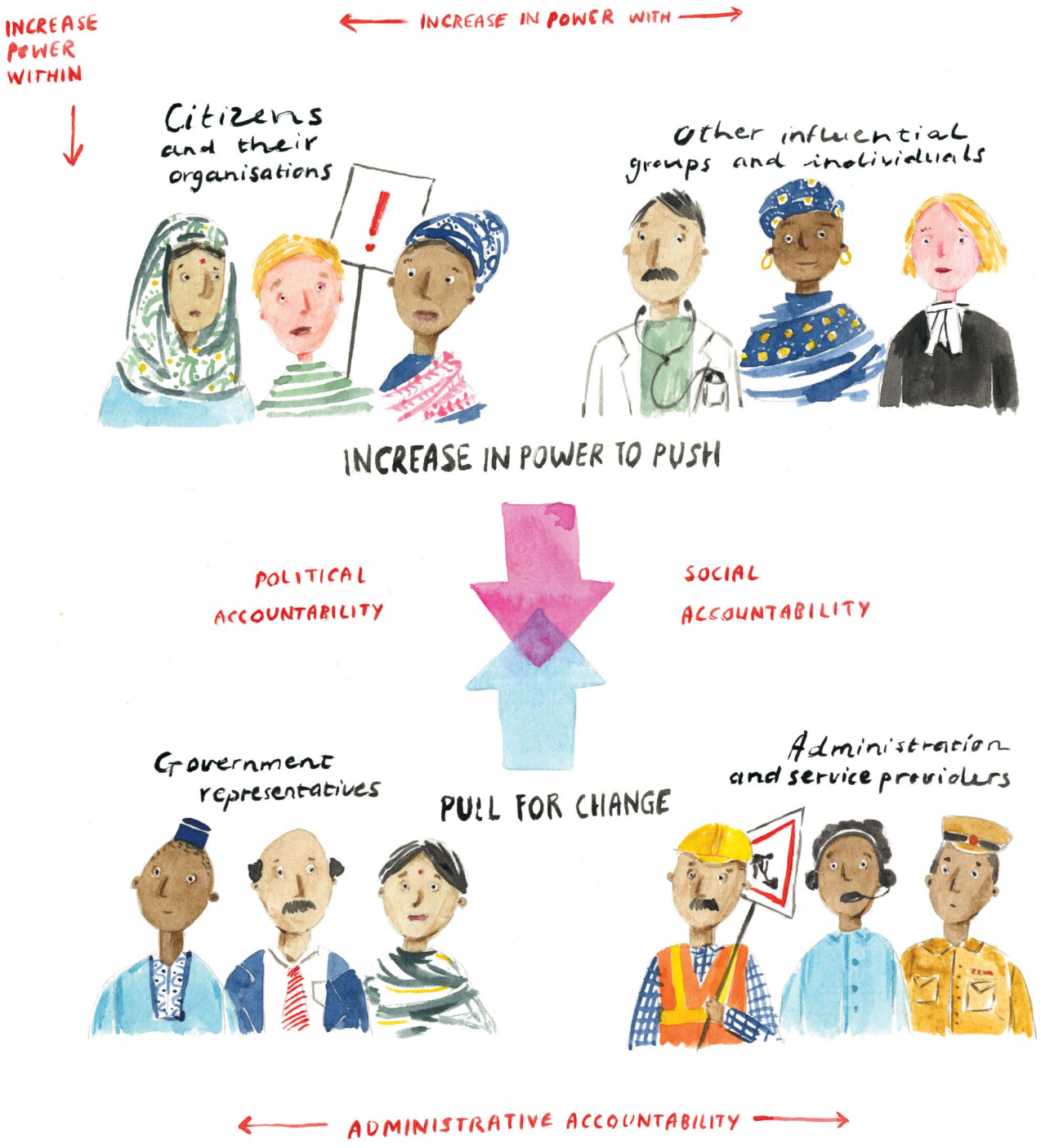
All over the world, people feel that their representatives are not speaking on their behalf and do not deliver on their promises. Many groups in society feel that their views are not taken into account. Vulnerable and discriminated groups, in particular, often lack a say in the governance system. Political accountability is failing, and because government representatives tend to be detached from everyday life, they cannot hold the administration, its services and security providers to account in the way citizens want them to.

In this chapter, three inspiring case studies describe how better social accountability contributed to improved service delivery to marginalised groups in Ethiopia, Madagascar and India.

The three studies are not about the development of new policies or legal frameworks. They are about how accountability was improved within existing policies and legal frameworks by empowering marginalised groups, facilitating dialogue, and creating mutual understanding of each other's needs, possibilities and limitations. Accountability was improved through changes in social relationships. The accountability we touch on in this chapter can best be described, therefore, as "social accountability." Social accountability initiatives aim to achieve more inclusive governance, public services that are accessible to all, and to facilitate development initiatives that "leave no one behind."

In the conclusion to this chapter we will present the main lessons about social accountability as an instrument for improving access of marginalised groups to services.

The illustration below visualises social accountability. The text on the next page explains the illustration in more detail.



Theory:

Governance, Accountability and Inclusion

Are elected representatives of government obliged to ensure that citizens' demands are heard and met? In most countries representatives agree they are. But the next question, then, is: are they accountable to citizens (political accountability) and are they, in turn, holding the administration to account (administrative or horizontal accountability)?

> *Policies and policy practices can be changed by influencing push and pull factors.*

Social Accountability strives to overcome shortfalls and failures in the governance system. It is an active form of citizenship in which people and their diverse groups take responsibility to demand accountability from their government. In social accountability, empowered people organise to be more directly involved in government decision-making and resource allocation processes, and to monitor government services and hold them accountable.

There are many ways in which social accountability can contribute to inclusion. In this chapter, we emphasise two theoretical views on this.

Increase the power within, the power with and the power to

One way is to increase the "*power within*," "*the power with*" and "*the power to*" of marginalised groups. The power within the marginalised groups can be strengthened by making these groups more confident and aware of their potentials to contribute to society. An example of how confidence and influence of such groups can grow in society is provided in Chapter 1 of this guide. This gives such groups more power to pressure for change. Empowered marginalised groups will also be in a better position to engage with other sympathetic groups in society that can support their plight: this increases their "*power with*." The engagement with many groups in society and the empowerment process enables the marginalised groups to increase their power to push for change in policy practices. [For more on these kinds of power, see Chapter 1.]

Increase push and pull factors for change

Policies and policy practices can be changed by influencing push and pull factors. As described above, marginalised groups can increase the push factors to exert pressure on governments to better meet their needs. The chance for change is much higher, however, if the government representatives themselves also start to better understand the needs and desires of marginalised groups and also start pulling for change themselves.

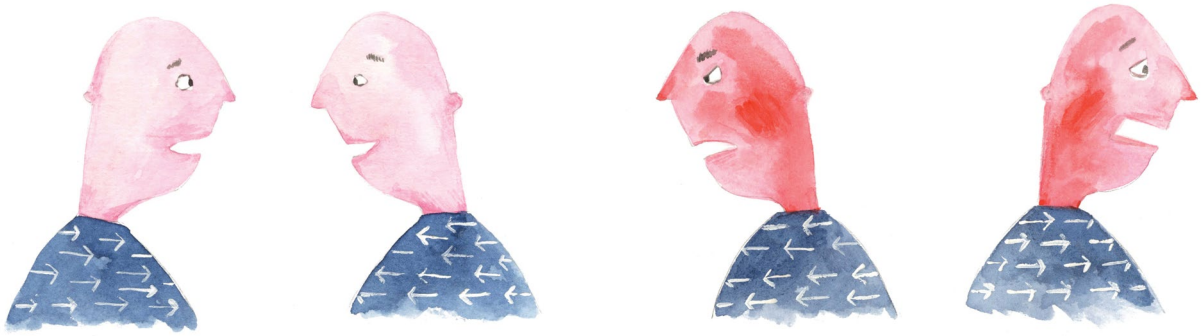
Unlocking the inclusive potential of government policies and services

– by Lucia –

"Systemic change is not about changing the system, it is about incremental change in habits . . . people have got to get to know each other, build friendships and start to appreciate each other as people."

– Peter Senge, author of The Fifth Discipline

It was in February 2013, that I first found myself in front of a group of over 200 people to launch a social accountability programme. Nerves crept in. Were we, as the initiating International Non-Governmental Organisation (INGO), doing the right thing? What were we thinking in bringing together over 100 Ethiopian NGOs with regional and federal government officials at this fragile point at the start of the social accountability programme? Did we really think that we could improve social accountability in almost 25% of the districts across the country? This was Ethiopia, a centrally led state, with decreasing space for civil society.



Fortunately, the ice-breakers did their job, and soon there was animated conversation at the tables. During the coffee break I heard mixed feedback. The NGOs were clearly pleased with their conversations with the officials, who seemed to take a genuine interest in their work. But I also sensed widespread suspicion: "This is Ethiopia, and the only reason we have the social accountability programme is because of the donors."

In my short vote of thanks at the end of the two days, I said, "Please use this programme to demonstrate what can happen if government joins forces with NGOs. While there may be more fundamental issues you would like to work on, consider that a working relationship with your government should be one of them. And please realise that basic services affect the lives of millions of poor and marginalised Ethiopians." I felt a bit like a preacher, and got some harsh feedback about "being in the government camp." Anyway, it was said and done.

Now, almost four years later, it is clear that the social accountability programme has improved public services in all districts, towns and city administrations where it operated, and that this has positively affected the lives of millions of people. At the moment, despite the ongoing state of emergency, the government of Ethiopia is working with development partners, local social accountability experts and local NGOs on the design for a programme that aims to scale-up social accountability.

During the final conference, I was repeatedly asked why we were emphasising the service improvements so much. We should really emphasise the mind shift on both sides: citizens and service providers. Wow! – mind shift – I feel such pride in what this programme seems to have started. Yes, it has achieved much in terms of service improvements, but it has also started something that is going to be so much more valuable if it can keep growing: the capacity, in both citizens and local government, to listen to each other and have a productive dialogue. A mind shift indeed!

The crucial role played by the NGOs in "bridging the gap" between citizens and government should not be underestimated. NGOs have raised awareness about service entitlements. Not only citizens but also many governmental service providers do not necessarily understand what citizens are entitled to, nor what resources and support they are entitled to in order to provide basic services in the best possible way. NGOs have identified vulnerable groups, often together with the social welfare office of the local government, by asking "who is not being served?" They were tasked to always ask about women, youth, the elderly, people with disabilities, people living with HIV/AIDs, and to bring such social groups together in case they were not yet organised. They motivated CBOs to actively engage in the social accountability process, and providers to listen to how citizens experience the services and where their needs are not being addressed. NGOs also prepared citizens and service providers for productive dialogue and facilitated what were often difficult dialogues. They learned along the way how to keep the issues of women and vulnerable groups on the dialogue table, so that conscious decisions are made to support them.

There are many, many stories from the programme about what can happen when people "get to know each other." Here are just two.

The crucial role played by the NGOs in "bridging the gap" between citizens and government should not be underestimated.

The story of Hadisa, a circumcised woman

A pregnant woman, Hadisa, was given the chance to share what she went through when she went to the health centre for delivery, as the government policy decreed. The staff refused to help her. They told her to go to the hospital to deliver. The ambulance was not available, so she spent all her money to travel to the hospital over a bumpy road in the middle of the night. She almost lost her own life and her baby. However, as she vividly tells, "Thanks to Allah, we both survived the ordeal and we are even still strong today."

Hadisa told her horror story in vivid colour to the health workers who had sent her away. In the social accountability dialogue, it became clear that the nurses had not known how to help her because they were not familiar with deliveries of "cut" women. Not knowing what to do, they had turned her away. The health workers felt terrible hearing the story: the health centre decided to take action. Today, they welcome all women. Recently, Hadisa safely delivered a boy at the same health centre. She has now become the biggest advocate in the town for the government's health centre-based deliveries policy.

Hadisa told her horror story in vivid colour to the health workers who had sent her away.

The story of a father who realised there was a state budget for his disabled son

Each district in Ethiopia receives funding for special needs education. In one district, however, this budget was always underspent and reallocated: the district education office said there was no demand for it.

When a social accountability partner started asking around, it turned out that disabilities were a taboo and that children with special needs were kept in the family hut, away from society. An activist father, who did not know about the possibility of his disabled son receiving an education nearby, had been saving money to send his child to a special needs school far away, in the capital. When he learned about the local possibilities, he personally went from door to door to convince families that their differently abled children could have a productive life ahead of them. With the increasing demand, the district opened a special needs wing in one of its schools.

Change happened because the NGOs helped citizens as well as civil servants to listen to each other's experiences, possibilities and limitations. These stories show how more human relationships were built as appreciation gradually developed on both sides. Civil servants have told me that it is as if they are looking into a mirror, and it is not always nice what they see. They feel they can and should do much better. Community leaders have also done some soul searching: they know that they can and should do much more to make sure everyone can be served. When everyone comes together, they can and do find local solutions.

Of course, none of this work came without struggle. How do you get the local government to approve your project when they think it is against the law for NGOs to be involved with governance work? It cannot happen without a high level political support, which we called upon when needed. That is one advantage of a centralised state: when there is commitment, it is pushed down the system. How do you subsequently convince the sector office that your project is not about blaming, but about dialogue? How do you explain that services will improve, although your project doesn't have money for infrastructure nor social development? How do you assure poor people that there will be no repercussions when they speak up? You try and fail, and try again and again, and eventually achieve some small successes.

What we learned as facilitators of the social accountability programme

- Failure leads to deeper understanding. We, the programme staff, learned to be understanding and supportive, and created space for the NGOs to share and learn from each other (not from us, the so-called experts: we had no clue how to do it!). We always brought the government into the room. It was their programme – so what could they do to help overcome the hurdles? When small successes emerged, we let those speak who went through the change: citizens who overcame their fear of speaking up, the service providers who overcame their fear of being blamed. We gave everyone involved a variety of platforms (local, national, virtual) to be heard and be recognised. We didn't focus much on the big challenges, although they were heard, but on the small changes: has anyone been able to make a step forward? How?

- There was always something to celebrate along the way. Even the repair of a water tap in a school, after five years' of its not working, is a sign that social accountability is, in the end, going to make government care and work better for all. The tap's repair may seem a small thing, but it is big matter for all those children who can now drink water at their school because they asked to do so.

> *When small successes emerged, we let those speak who went through the change*

- When excluded groups get a chance to be heard and are treated as equally deserving of opportunity, we saw that society and its government can find ways to cater to their needs. When excluded groups sat at the table, they showed themselves perfectly capable of presenting their special needs and balancing this with the wider needs of society.

- We also saw it was unhelpful to blame government for not delivering to excluded groups. Local governments have many competing interests to take into account, with very limited resources. NGOs can help them to study inclusive development objectives and to reflect upon what they can do to achieve these within the limited means available. This dialogue, and subsequent reflection on the ways forward, has multiple benefits: priorities are carefully negotiated, so that the local government can become more responsive.

At first, it was hard for us, the NGO facilitators, to make headway because social stigma, the attitudes of citizens towards the government and the government's attitude towards NGOs were all deeply entrenched. Yet we stuck with it and trusted the process: this worked towards an open dialogue.

The experience shows that all people, including those in local and regional governments, can live up to their potential to doing the right thing. The main role of the facilitator is to enable social groups to be heard at the table where government budgets are planned and evaluated. As NGOs, we avoided speaking on behalf of vulnerable people because we have seen that their own voices and stories are much more powerful than ours!

Using technology as a tool to make voices of marginalised villagers heard

– by Praveen –

> *As the government is at a distance, the villagers were not able to complain about their situation to any authority.*

In April 2013, I travelled to the district of Kalahandi in Odisha, a remote area of India. I visited the villages there to talk to the villagers about the challenges they face. Godapokri village is one of these villages, far from the main road, where the basic healthcare centre (Anganwadi) is situated. The women there told me there were 150 households with around 500 people, the majority of which are from Kond tribes (a tribal group in Odisha state). The primary healthcare centre was three kilometres away, at the panchayat Urladhani. The stream which flows between the road and the village fills up during the rainy season, cutting off the village from the road, as people cannot cross the torrent. The women told me they had no electricity in the village and there is no mobile phone network. This leaves them and their children at risk. As the government is at a distance, the villagers were not able to complain about their situation to any authority.

My meeting was with the self-help group women that is supported by the NGO Seba Jagat. Their leader is Rajkumari Mjhi, a strong woman, who some two-years previously had become the leader of the group as a result of her conviction and passion for changing the fate of the women in her village. The self-help group operated through a thrift and savings activity. The members were happy to meet once in a fortnight in order to save Rs.5 or Rs.10 and to discuss village issues.

I asked them what they did for drinking water. They replied that there were only two hand pumps in the village, both not functional. They had submitted an application for their repair at the panchayat office but to no avail. I asked them how long it was since they had submitted the application. The answer was over a year ago, and still there was no action. They had to go to the stream to fetch water, which meant that they had to walk two-and-a-half kilometres to get a pot of water.

Another issue was that the Auxiliary Nurse Midwife who should visit the village every fortnight doesn't come regularly. Pushpa Maji, a housewife and a mother of three, shared with me that she had missed out on antenatal care during her pregnancy and that she was not aware of the importance of immunisations. She told me she had lost her first child at birth: it was a home delivery. "This is a critical issue in my community." Her tears streamed down her face as she spoke. As dusk descended, we could hear the noises of the sheep and goats passing by. I asked the self-help group members what other challenging issues they encountered. Rajkumari answered, "There is no paid work for us and we do not have much to do. Our children do not study as they cannot access schooling beyond primary level. We live in darkness. The government does not listen to us." She ended with words that kept resonating in my head: "We are like birds with clipped feathers, fallen in the field."

I asked the women how the situation could be improved. The women did not see real options. "We can go to the block headquarters, which is 20 kilometres away. The next option is to go to the district administration office in Bawanipatna, and that is 80 kilometres away from here." Pondering this, they added, "Each time we go there, we forego our work, our daily labour. We end up spending most of our savings without anything in return. It's a tedious process and it feels like hitting our heads against the wall."

> ***We live in darkness. The government does not listen to us.***

As I walked back to my room that evening I wondered what could make the government more responsive to the women of this isolated community. How could they air their grievances and get a response from the government?

The next day we had meetings with the district collector of Kalahandi, Mr. Bijay Ketan Upadhyay, I.A.S. I shared with him how technology was helping to support local governments to fulfil their duties in other districts. I described how service delivery in Koraput district had been strengthened, since citizens could directly demand and track their service entitlements under national and state government programmes with the help of an internet-based SMS platform, "Samadhan" (Samadhan means resolution). At first, the district collector was reluctant to engage, but as I kept on sharing some of the success stories and explained the process step by step, I noticed him getting more and more interested and drawn into the possibilities. I was pleasantly surprised at his curiosity and positive reaction, which I had not expected, since the Samadhan system promotes transparency, accountability and citizen participation. I was happy to be proved wrong: the collector asked my organisation, VSO India, to develop the technology platform and to also train the district administration staff in its use as quickly as possible. He asked us to be ready for the launch of the system within three months.

Short description of the steps of the Samadhan system

Step 1

Citizens file a complaint by sending a simple text message to a helpline number.

Step 2

The message is registered and a reference number is sent to the complainant.

Step 3

The relevant line department is linked to the complaint and action is taken.

Step 4

The complainant receives a message telling how the problem has been handled by the line department.

Exactly three years later, in May 2016, I visited Kalahandi district again. Already over 3,000 complaints had been received through the Samadhan system and many women and children had benefited from the increased responsiveness.

One of those to benefit is Seema, who was 32-years-old and living in Durladhani, a village with a predominantly tribal population that has a low level of literacy and limited access to services. She told me: "During my pregnancy, I was aware about the various health facilities set up by the government through the community health club in my village promoted by VSO. I registered at the local Anganwadi and visited it regularly, taking the trouble of travelling the three kilometres in pain to Ghodapokhri for all the routine check-ups, as I know that they are important for me and my child. During my pregnancy and after my delivery I was entitled to receive MAMATA (government financial support for pregnant and lactating women). But I did not receive it. Every alternate day I checked with the Anganwadi centre but the Anganwadi worker turned me away saying there was no news. It was like going to the fair price shop (a ration shop that distributes food grains to the poor) and returning without the food grains. I had heard about the Samadhan system through one of the meetings I attended. I filed a grievance on the Samadhan in July 2014 through SMS. In August, I received a response and I also got my MAMATA grant. I was so thrilled that my problem was solved through investing one rupee for the text message!"

> ***I was so thrilled that my problem was solved through investing one rupee for the text message!***

There are many more stories of improved government response due to the introduction of the simple Samadhan system. Yet, what this experience underlines for me is that it was the "small" introduction of simple mobile technology that most improved transparency and encouraged responsiveness: this can make a world of difference to women living in remote villages of India, like the ones that can be found in Odisha.

Using radio as means to create inclusive dialogue in southern Madagascar

– by Yvonne –

In 2010, Madagascar found itself in a political crisis following a coup d'état. With no democratically elected leader in power, the country was in a state of instability with plummeting development indicators. As the crisis advanced, the disenfranchisement of local populations in the country's governance, profoundly lacking even at the best of times, was deepening. The international community shut off funding. In consequence, development projects and local services were struggling to meet local needs.

In the south of the country, the crisis added yet another layer to the existing communication gap between citizens and decision makers. As an NGO, we asked ourselves how we could build on our ten years of successful experience using local media, especially radio, as a tool for development to engage citizens in improving the situation – we wondered how we could promote dialogue that could foster greater social cohesion, more transparent systems for social service provision, and more accountable development action.

This was no small challenge. Communication gaps are prevalent in Malagasy society, especially in the remote southern regions where profound isolation, deep poverty, environmental hardship, drought, and low literacy rates conspire with traditional taboos and belief systems to maintain social hierarchies and exclude many from civic participation, especially women and young people. Additionally, the widespread self-censorship of media in the face of repressive laws and the risk of imprisonment for journalists, demanded courage and creative mechanisms to engage all parties without creating social conflict and media closures.

It was a hopeful sign that we found that many in the villages in which we were working were prepared to discuss their community's problems, and to identify and collectively debate the key issues they were facing. However, they were fearful about identifying themselves publicly on radio on controversial topics for fear of reprisal. To ensure villagers felt safe to engage with leaders, we had to offer a form of immunity. The only way for us to ensure that all ages, educational levels, gender, economic status and abilities could be included in the radio programming was to keep the citizens' voices anonymous.

The question for us was, how do we ensure that local decision makers would agree to participate and respond publicly on the radio to the citizens' questions? We were worried that vested interests and the desire for self-protection might hinder our efforts. However, many local decision makers understood the benefits of using the medium to reach Madagascar's communities, as most of them had participated in our previous radio projects. Most importantly, they trusted the local project director and team because the results of their working together in the past had been both reliable and impactful. A range of decision makers agreed to participate, including regional authorities, ministry representatives, local mayors, service providers, such as the local police, the local energy supplier, and NGOs.

We aimed to circumnavigate the barriers to inclusion by setting up Radio Listening Groups (RLGs).

What are Radio Listening Groups?

Radio Listening Groups (RLGs) provide a safe space to discuss issues. Citizen groups formulate their concerns in the form of a question and then elect someone to record this on their behalf, anonymously. The citizens' question is taken to the office of the relevant government authority, who listens and records a response or commitment to action. The question and answer are edited together as if in a live debate and this is then broadcasted through the local radio station.

We discovered quickly that decision makers would not always provide full answers, or offer all the information or solutions required in one and the same session. In response to this, RLGs were helped to reformulate and pursue new iterations of their question, until they were finally satisfied with the response they had received from the decision makers. We thus created a "spiral of engagement."

The broadcasts delivered both an explicit response from a decision maker and also another unspoken message: that it was acceptable to engage in dialogue with leaders, to ask a decision maker for information, to express your views and opinions, and to hold those with power to account. A monthly radio phone-in programme opened up topics for broader public debate within the wider community: the RLGs' mobile phones helped their communities to participate.

> ***People's questions were now being answered directly on the radio and misunderstandings were being cleared up on the spot.***

These activities offered citizens an unprecedented opportunity to determine the agenda and create spaces for inclusion and democratic public discourse that had hitherto been unavailable. People's questions were now being answered directly on the radio and misunderstandings were being cleared up on the spot.

Citizens in the villages reported unexpected social change as a result of such engagement, including the sharing of financial benefits and support between women in polygamous marriages, more usually the source of jealousy and conflicts: "I chose to share my husband's salary with his second wife, though I did not have to." Parents stopped beating their children. Villagers reported feeling courage: "I am young and I want to progress," as well as a sense of self-respect gained from helping others.

Decision makers also appreciated the benefits of this approach because, once people were clear about how things worked, they accepted their own responsibilities.

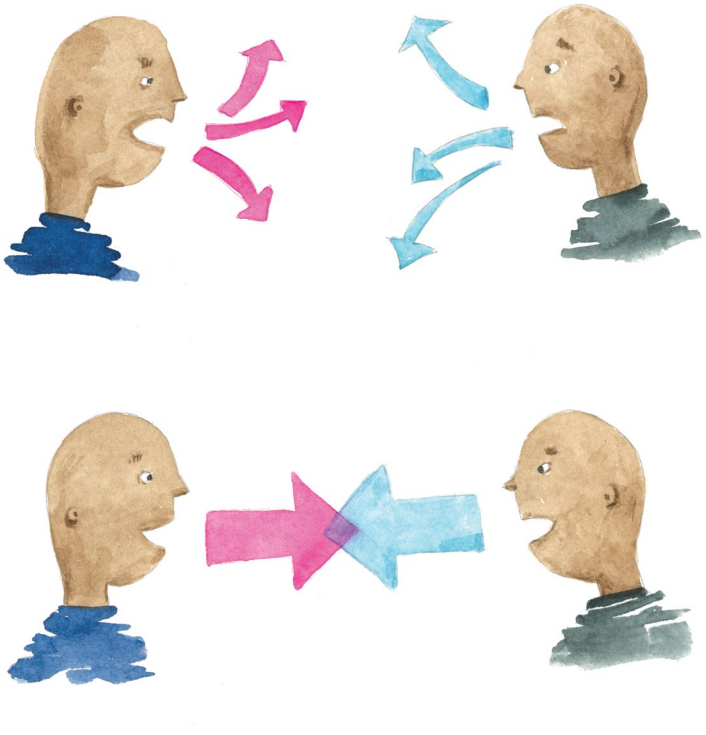
At the same time, many policy makers came to understand that their assumptions about those living in the villages were often wrong. This bottom-up process led to decision makers for the first time comprehending many aspects of the villagers' lives, bridging communication gaps hitherto hidden from them. This changed the ways decision makers and agencies listened to local people who, in turn, were also more confident in speaking up. This experience in Madagascar demonstrates that inclusion is not only about making space for everyone irrespective of gender, age and other social determinants, but is also about building the confidence to occupy that space and to participate in it in meaningful ways. The RLGs are just one example of how a safe space can be created where different voices can meet to discuss important issues.

Concluding remarks on what counts in strengthening accountability

The authors of this chapter all started their stories with a sketch of their reality in which marginalised citizens felt unheard, desperate, even apathetic, and where government departments lacked initiatives and ideas about how to make their government resources and services more accessible. At the start of these programmes, the practitioners were nervous, as they were not following well-laid-out plans: they had to trust the process.

The practitioners assisted the two parties to listen to each other and to create a dialogue to develop solutions, without knowing what the result would be beforehand. During the process set in motion by the practitioners, many of the citizens' incorrect assumptions and lack of knowledge about the workings of the government were cleared up – as well as those of decision makers about citizens. This led to both parties understanding each other better, greatly improving the quality of dialogue. Much to the relief of the practitioners, this better dialogue eventually led to improved accessibility to services.

These stories show that strengthening social accountability requires careful process-holding. This contains the following elements:



1. Process-holding is key in improving social accountability

- Strengthening social accountability is not something that can be forced on people: what is required is to create the circumstances that can enable this to happen. The results may be large or small, as their magnitude and characteristics need to emerge from the process and can't be fully planned for in advance. It is very important to celebrate changes in attitude, be these small or large, as well as to provide role models and the space and time to voice the needs and requirements of marginalised groups.
- By enabling open communication between diverse groups of citizens and policy makers, it is possible to help remove the barriers created by incorrect assumptions about each other's attitudes and requirements, thereby opening up new possibilities.

- Citizens and frontline service providers need to be made aware of existing policies and rules: often they lack the necessary knowledge of these.

- These stories show the power of constructive, appreciative and opportunity-based approaches. It is usually unhelpful to tell governments how deep the gaps are between the needs and the delivery and then blame them for this. Local governments have many competing interests to take into account, and often have only very limited resources. Civil society actors can help them to study inclusive development objectives. By reflecting together on what can be done, surprisingly often, mountains can be moved despite all the hurdles.

2. Technology can be very helpful in improving social accountability

- It helps when the expressed needs of the citizens are channelled to the relevant departments: the use of technology can prove very helpful in this.

- Technology can also be used to overcome the physical distance between policy makers and citizens, especially those living in remote areas.

- Technology can help in creating safe spaces in which citizens can meet, enabling them to remain anonymous.

All these stories illustrate that the attitudes of development practitioners towards government often need to be examined and questioned. If practitioners do not start to expect better from their government, then that government is unlikely to ever live up to its potential for furthering inclusive development.

PERSONAL STORY 6

We are Proud To Be Us Laos

A story from Lao

Let us introduce ourselves

We are four friends living in Vientiane, the capital of the Lao People's Democratic Republic. We would like to share our story with others, as we are eager to connect to more marginalised groups in other societies. We can contact each other and learn from each other. We want you to get to know us, so that we can also get to know you.

We are representatives of the LGBTQI community in the Lao PDR under the movement called "Proud To Be Us Laos." As you will see from this story, we are proud of who we are. When we are together, we have fun and do not feel marginalised. Outside our peer group, however, it is hard for us to express ourselves, especially when we are in an educational or professional environment, where we are forced to be restrained.

> *"You know, very bad words are used for us."*

How we realised we were different

Soupha tells, "At the age of thirteen I realised I felt more attracted to boys than to girls and I hated myself for it. Why was I different? I felt very bad about it. I even hated myself."

Kai is an elegant and slender transgender woman, she gives a friendly laugh and says in her soft, slightly low, charming voice, "At primary school I had male friends and I liked to play with cosmetics. I never felt bad about who I was."

Ilin says, "I started to realise I was different when I was seven years-old. People told me I had girly behaviour. I was curious about other boys." Anan chips in, laughing: "Me too! Curious about other boys!"

Anan explains that though he never felt bad about himself, it was hard to withstand the teasing that went on. "You know, very bad words are used for us. Like 'plastic vagina' or 'iron cock'! I felt as if I was a funny object in the eyes of other people. The harsh words used by peers were hard to bear. But it was also something I got used to. The constant harassment also made me a fighter."

How our parents reacted to us as "women-like creatures"

Soupha: "My father, especially, never made a secret of his dislike for me and feeling of shame. He made fun of me and complained a lot. Why are you like this? This is a sin." Anan agrees, adding, "This is told to all of us: that we are a sin. We are told, 'You are so lucky to be a man! You are the luckiest creatures. You do not have periods, you do not have to bear children. Why do you want to be like a woman, behave like a woman?'"

Ilin: "I was also told I should be a man, that I could even be a male leader. My father felt I was challenging the ancestors. He mentioned ancestors who had even been soldiers and asked me why I shamed them. He said I was an embarrassment and I should act like a man."

The common expression in Lao PDR for being gay is "sia sard kert" which means "useless life." It is not only used for LGBTQI, but also for people who are handicapped. It is a word that tells you: "you have defects!" and it goes to the heart. The word used a great deal in the past was "karteoy," which means "fag."

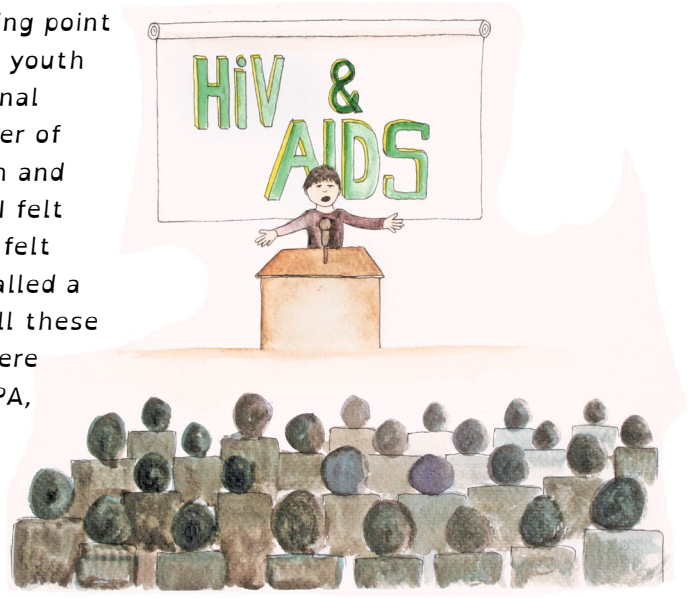
> ***I was this boy who had been called a fag and now I was in the same room as all these high-powered officials.***

Soupha listened silently for a while, then says, "All the time, constantly, my father bashed me with words: 'Don't walk like a girl, don't talk like a girl, don't eat like a girl, don't drink like a girl'."

How we went on with our life

Soupha: "When I finished high school, I obtained a scholarship to study abroad. I was young, and eager to escape. I went to Malaysia, a Muslim country. I tried to hide. No way could I try to change people's minds. Some people loved me, especially the female students. I was cheerful and funny and they appreciated me for that."

Anan: "At age 16 I started to work as a volunteer with a INGO fighting HIV and AIDS. I then saw the real problem. It was HIV and AIDS and it still is HIV and AIDS. I had hundreds of meetings and hundreds of trainings. Then, and this was a real uplift and turning point in my life at age 18, I was appointed as a youth representative to join an important regional conference, together with the Lao Minister of Health in Manila. I represented Lao Youth and I sat in a panel with many high officials. I felt so empowered, and I had so much hope. I felt I made it. I was this boy who had been called a fag and now I was in the same room as all these high-powered officials. So many people were at that conference: foreign experts, UNFPA, Women's Union, to name a few. I did not dare to say anything but I still felt very important. I felt this would be the gateway to getting LGTBQI accepted."



Anan laughs at the memory: "My parents called me and asked why I was going to a conference in Manilla with the minister. I told them I had been doing this volunteering work for a few years on HIV and AIDS among men who have sex with men and with transgender women groups. They had not known about it and they said nothing. But I felt they were proud, even though they could not say so." Anan's face glows and his enthusiasm is compelling.

> ***But I felt they were proud, even though they could not say so.***

Kai shares a memory that still makes her feel sad, saying softly, "You know, in high school I really wanted to be a star and I wanted to make people happy. I was so proud of my sunglasses and while happily talking and joking outside in the playground, my teacher called me, so I came. 'What beautiful sunglasses you have,' he said sympathetically. 'Could I have a look at them?' I gave them to him and he broke them in front of everyone. He ensured he made a show of it. Many people were around. He wanted to make me feel embarrassed. I tried to hold myself up but, you know, the memory still hurts. I could not do anything. But I did curse him."

The meaning of the Proud to be Us movement

Soupha: "A lesbian friend of mine in Melbourne introduced me to her friends and her movement. I accompanied them in demonstrating for same-sex marriage. From that I learnt that: I learned that I do not need to question things on my own but can be stronger by uniting with others. I learned so many things in Melbourne about LGBTQI issues and about how to question those issues in society. I am proud I am now also a member of a movement in Lao PDR. Through this movement, I can apply the lessons I learnt in Melbourne."

Ilin: "My best memory is about the IDAHO day 2016 (the International Day Against Homophobia, transphobia and biphobia, on May 17th). That day, I wore lipstick. I felt freedom to present myself as I was. I felt happy, I felt as myself. I felt we presented ourselves as a specific group. Not a group better or worse than any other group in society, just as a group. We did not present ourselves as victims of HIV and AIDS. We were given the space to show ourselves as people with our own identity."

Kai chips in: "I wore a skirt that day. And I was interviewed by a journalist and appeared on the national news. I was the first transgender woman who appeared on TV in the Lao PDR and we were so excited about this!" Soupha turns to Anan, saying, "I was very impressed when you took me to embassies and introduced me to partners as a team member. And you encouraged us to speak English. Proud To Be Us Laos is our window to more opportunities."

Our Hopes and Dreams

We all share the dream of obtaining legal registration for Proud To Be Us Laos. Once this is obtained, Proud To Be Us Laos can officially cooperate with other CSOs, INGOs, ministries and the government.

We have many dreams, like organising the first gay parade in the Lao PDR, being protected by law, and having the very existence of LGBTQI in the Lao PDR recognised: giving recognition to LGBTQI as a group with its own identity, and not only as a group but one more vulnerable than others to HIV and AIDS, as a group of people who can do so much, who can contribute to national development, as people who matter and who are appreciated for who they are.

Go to https://www.youtube.com/watch?v=GGUiy_Iv3xA to see a video of a shadow play about the life of a transgender person in the Lao PDR.
www.facebook.com/proudtobeuslaos

Walk the talk

Striving for inclusive organisations

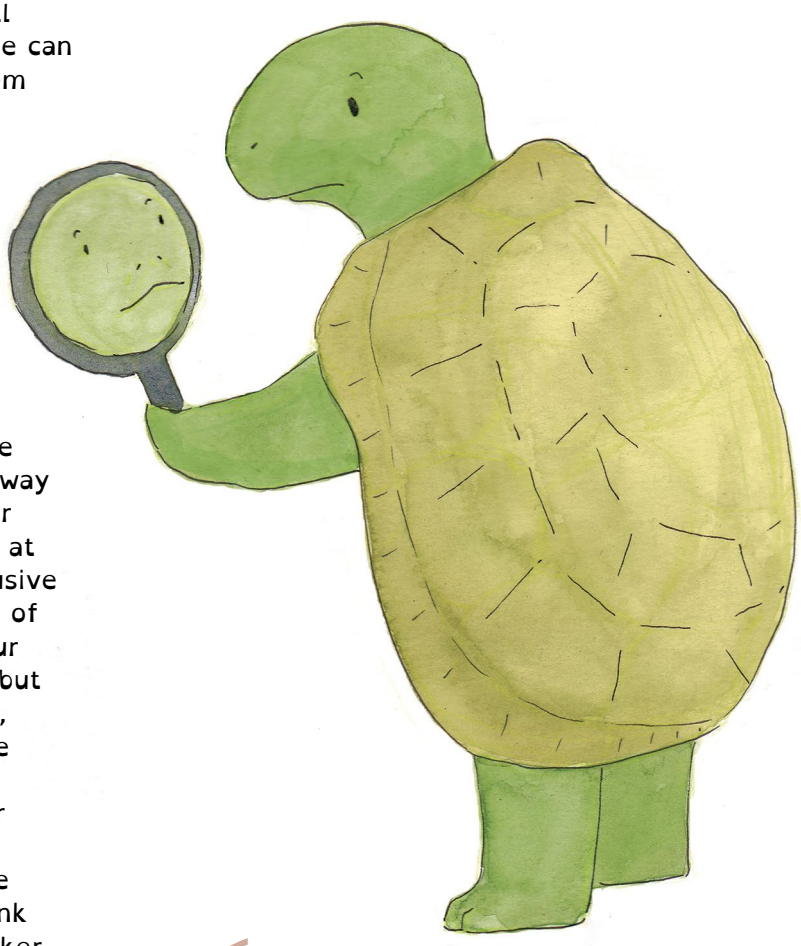
Pay attention! Reading this chapter could be the most important step you will take towards making our world more inclusive. The second most important step will be to act on it.

As development practitioners, we are keen to get out there and change the world. We are at our most motivated when we are working directly with marginalised groups, supporting them to make changes in their lives – or when we are lobbying policymakers to change laws so that all children can go to school or poor people can access a justice system that treats them well. We are busy people and there is much to do.

But we need to take a look at ourselves in the mirror. If we are not mindful, our organisations tend to reflect and perpetuate the practices and attitudes of discrimination that exist in the society in which we operate. It's not just about the type of people we tend to recruit – usually people like ourselves – it's there in the everyday practices and processes, the way we organise the furniture, and claim our expenses. Unless we sit down and look at ourselves and start to unpick the exclusive patterns that are woven into the fabric of our organisations, we will undermine our work in society. Doing so is hard work, but as we discover new colours and shapes, think of how beautiful our new inclusive patterns will be!

Why is it so important to change our organisations? Shouldn't we spend all our energy on working directly with the people who are excluded? Stop and think a moment: would you listen to the smoker who tells you to give up smoking? Would you give a donation to a charity that is housed in a palace and whose staff all drive round in expensive sports cars? When we reach out to people who are marginalised, they look at us and judge us by our actions, not our words. How can we develop relationships of trust if we are reinforcing the very exclusion that we tell we are seeking to overcome?

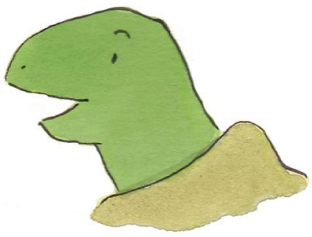
So, what can we do? We can change ourselves.

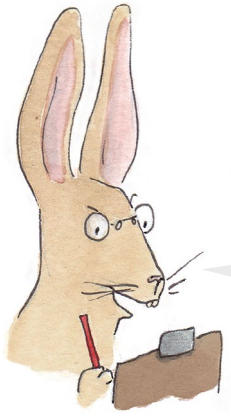


we need to take a look at ourselves in the mirror

"Okay, I accept that I need to change my organisation! Tell me what to do. Give me the tools and I'll do it. Show me what an inclusive recruitment policy looks like and I'll copy it. I don't have much time."

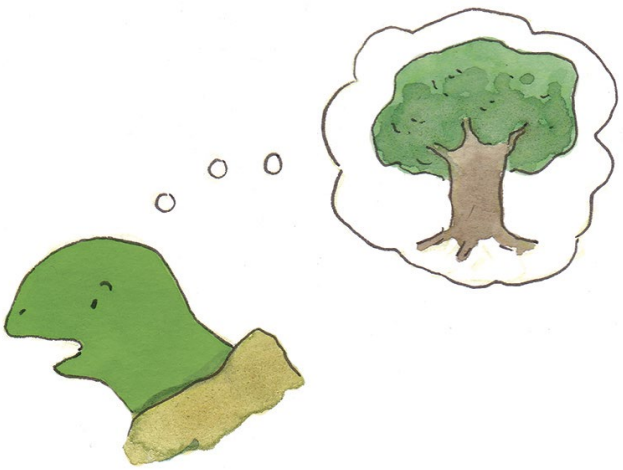
"Well, here's the thing: there are no off-the-shelf tools. There is no single right way. There's no shortcut. It takes longer to unpick a rug than it does to make it – and you can't just unpick it and leave it at that. You need to weave something new."





"Right – Okay, then we'll appoint a team to take care of it. Someone from human resources, someone from finance, maybe a volunteer."

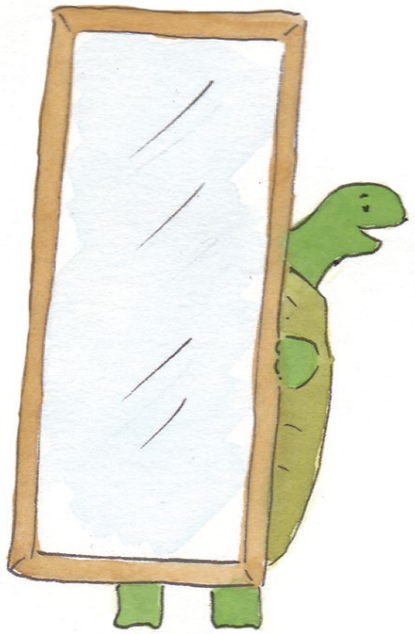
"In order to change an organisation you need to involve everyone who is part of the organisation. You can't delegate fundamental change to one part of it: you all need to be involved. Think of a tree – every part of it is doing the work. The leaves can only be shed at the end of the season and then re-grow at the start of the new if the roots and the trunk are doing their work and are changing and adapting to the seasons."



"It all sounds very difficult. Maybe it's too hard for us. Maybe later – next year – when we've finished this important project . . ."

"No, wait! There's one very simple piece of advice we can offer – and it will help you every step of the way."

"Great! Tell us, what is it?"



"Ask questions: that's all you need to do. Keep asking yourself and others hard questions and listen very carefully to the answers that are given. Then what you will need to do will become clear."

Some useful questions

- What does our society look like? Who are the people living in it?
- Who has power and who has not? How would we like it to be different?
- What does our organisation look like? Who are the people working in it?
- Does our organisation reflect the diversity of our society or only part of it?
- Does it replicate or challenge the power structures that keep some groups marginalised?

"Is that it?"

"Well, there is a tool to help get you started: it's that mirror again. You need to stand in front of it and look at yourself very carefully. How far do your staff, your volunteers, your visitors, or the people you engage with every day, reflect the makeup of the society in which you live? (You may find a census report useful here.) Who is missing? Who are you excluding? Don't analyse yet or ask why – just start making a list. Unless you have already done quite a bit of inclusion work on your own organisation (Well done! Celebrate this, but don't stop now . . .) you will probably find that the list is quite long. Go deeper: within your organisation, whose voices are the least heard? Who makes the decisions and who does not? What is missing from your organisation?"

Next, ask the most important question, the one you will keep coming back to, the one you will always be asking: why?

Why are the missing groups not represented? Why do you never see them in the office? Why are they not involved in decision-making? But don't just ask yourselves, ask others too. Go out and find the people who have been excluded and ask them to give you guidance and ideas (and later to help you implement these).

Listen to their ideas and be prepared to act. Involve them in implementing the changes they suggest. There is nothing more excluding than having your ideas for change rejected and ignored. See yourselves as others see you. Prepare to be shocked and surprised.

Of course, you may already have made good efforts in the right direction. Reflect on these and draw encouragement from what has been achieved.

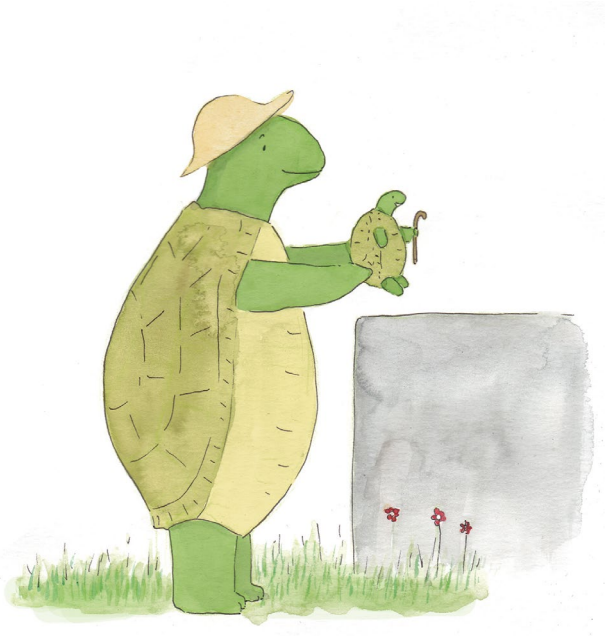
Be self-critical too. Take time to think deeply about this and examine yourselves critically. Don't hurry this process. Be prepared to open long-locked cupboards and see what is there – and what is not.

You may have carefully hidden the gaps, but look behind the screens and see where the empty spaces are. Make the invisible walls that you have built to keep people out visible, so that you can begin to tear them down.

This sounds daunting, I know. Where to even begin!

It's a bit like climbing a mountain – you start by taking it one step at a time.

Be prepared to open long-locked cupboards and see what is there – and what is not.



Man, have you seen this mountain!

Awareness – we have an issue and something needs to be done.

Inclusive development is not about pity. It's about human rights, about giving people an equal opportunity – and sometimes an extra opportunity – to enable them to overcome the extra barriers they face. And providing them with a bit of encouragement, for starters. We all need to recognise that we are currently a long way from providing equal opportunities. When stigmatisation, discrimination and exclusion has been imbedded into society for centuries, inclusion is not going to happen automatically, not even within your own organisation. Often, one needs to be challenged by the dispossessed before one can see the how big this gap truly is.

How to raise awareness

Attitude change is the first step towards commitment to inclusion. So, what can you do to raise awareness within your organisation?

- Begin by inviting people who are interested, because they can help you convince others later. A few is enough.
- Keep it simple. Ask questions to stimulate awareness and conversation. Don't give boring lectures.
- Use informal moments to talk about the issues – this makes it easier to talk freely without people feeling they need to "talk management" or be politically correct.
- Set up meetings set up to discuss inclusion pleasant for those attending – include an interactive exercise and bring a snack to share (see the example at the Save the Children Resource Centre: https://goo.gl/2r4euQ).
- Help people to understand exclusion through exploring their own experiences of it (see the following page).
- Engage people directly affected by exclusionary practices in raising awareness and advocating for their legitimate rights.
- Organise a workshop or training session to sensitise staff members.

"I was giving a training to a partner organisation in Ethiopia, about the importance of disability inclusion. During the coffee break one participant asked me, 'How many people with disabilities do you have on your board?' And I had to confess we didn't have any. Then they asked me, 'How many of your staff members have a disability?' And I had to confess we didn't have any. I didn't feel credible anymore."

– Programme Manager for a disability organisation

"When Shitaye, from the Ethiopian Centre for Disability in Development, came to us to do an intake assessment, the inaccessibility of our office became very clear. She could not enter with her wheelchair, so we had a meeting on our parking lot. This really shocked me."

– Programme Manager, water and sanitation programme

Understanding what exclusion feels like

Sometimes organisations seek to be more inclusive, but they act as if this can be brought about solely through developing new policies. It is a job for Human Resources, not them. All too often, the last time anyone looks at the policy is when it is signed to say that the organisation agrees with it. Inclusion only works if people live it and feel it, if all those involved truly understand it.

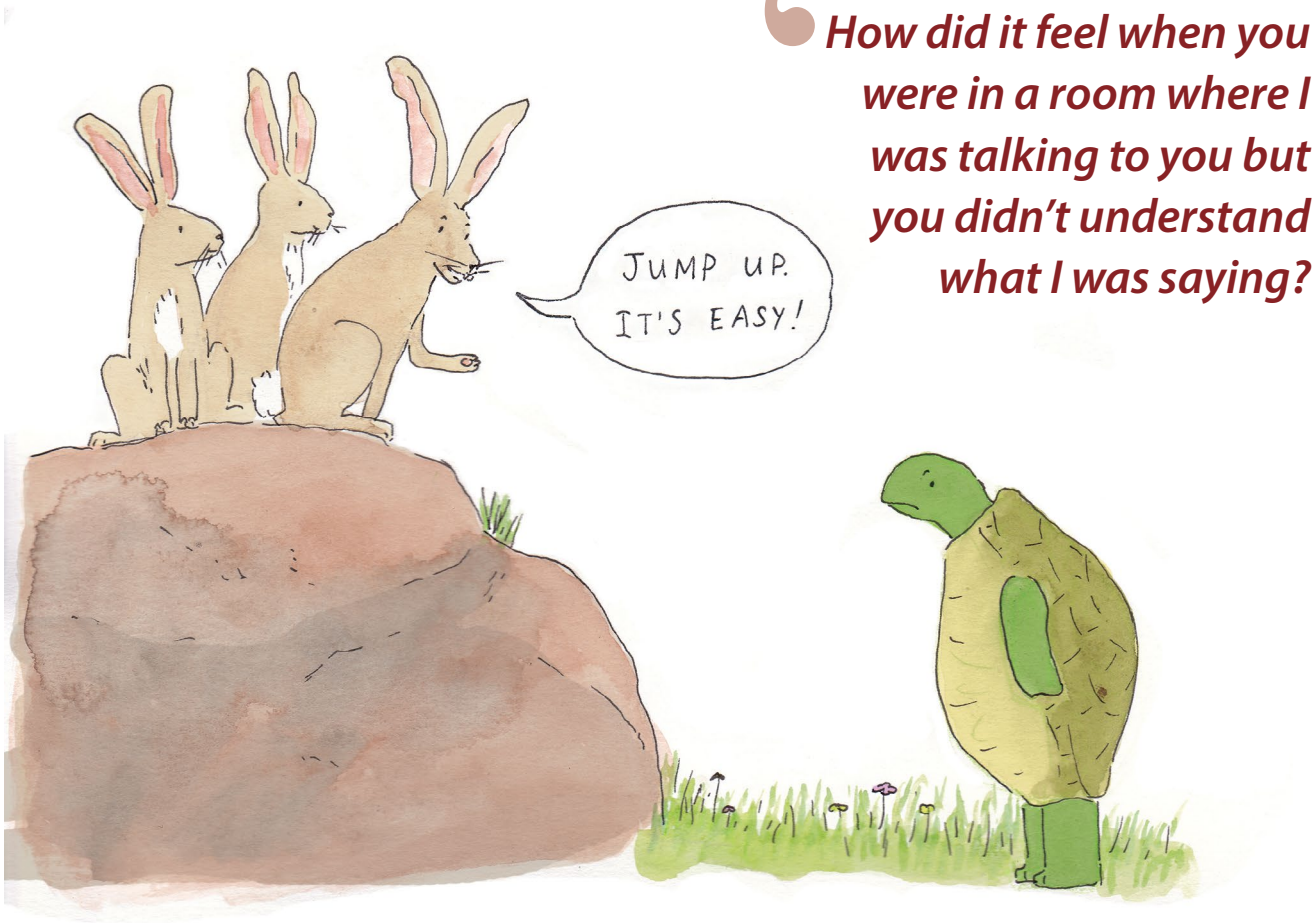
One of the things that can help develop this understanding is to experience what it is like to feel excluded. If we share, even if only for a short time, the feelings of disempowerment, distress and frustration this can deepen our understanding. There are many ways this can be done. Here, we provide examples of what others have done. Feel inspired to adjust these to your own circumstances, or to think of other experiential exercises.

Remembering a time when you have been excluded – Everyone has been excluded at one time or another. Perhaps you were always the last to be chosen for a team in the school sports lesson, or you were not invited to a meeting at work that concerned something that you thought you should have been consulted on. Ask people to work in pairs and to share with each other memories of an occasion when they have been excluded or felt discriminated against. Ask them to describe it in detail – what happened? How did they feel? What did they do? Once back in the larger group, people can share their feelings and how they reacted. This can lead to a discussion of the causes of the discrimination and the feelings of the people who were doing the excluding.

Experiencing exclusion through visualising – This exercise has been used at the start of a two-day workshop for education officials in order to help them learn about inclusive education. In the first session, I asked them to close their eyes and to imagine a child in their family – a son, daughter, brother, sister, nephew, niece or cousin – on their first day at school. I then took them through the activities at the start of the school day – getting them up, making sure they had their breakfast, helping them get washed and dressed, giving them their bag and then walking them to the school gate. I asked them to imagine how they were feeling. I told them there was someone standing at the gate when they got there, a teacher. As they approached the gate, the child was eager to enter. He or she could see lots of children playing in the playground.

> *imagine a child in their family – a son, daughter, brother, sister, nephew, niece or cousin – on their first day at school.*

How did it feel when you were in a room where I was talking to you but you didn't understand what I was saying?



As you approach the gate, the teacher stops both of you: "I'm sorry," she says, "but you can't go in." The child starts to cry, you beg and you plead, but it's no use, the teacher will not let you in. How do you feel?

The education officials shouted out their emotions; some of them were visibly upset. During the break, several of them came up to me to say they had never thought about what it must feel like when your children cannot go to school. The discussion afterwards about the barriers that children face was impassioned and there was a real will to change things.

Participants can share their experiences of this exercise in the group.

Experiencing exclusion physically – Prior to a session on disability that I ran for development workers, I piled chairs and tables in front of the entrance to the door. I made sure there were no signs that a session was going to take place in the room. I stood where I could not be seen from the doorway. The first participant came, looked at the chairs and tables and went away again. The second participant did the same. Two participants came together. They had a discussion about why the entrance was blocked. One of them started to climb over the chairs. When he was in, he saw me and asked me a question but I answered him in a language I knew he didn't know. Other participants began to enter, climbing over and under the furniture. I started the session, again speaking in a language they didn't know. Some participants looked confused, one or two shouted out that they didn't understand.

After some time of this, I asked them, "How did you feel when you got to the door, what did you do and why? How did it feel when you were in a room where I was talking to you but you didn't understand what I was saying?"

Once people have felt (or remembered) what it is like to feel excluded, they can more easily empathise with those who are routinely excluded in society. They have felt the same feelings, if only for a short time. When they discuss how to include people, they are thinking about how to stop them feeling like they felt. This changes their attitude: they now care about making the required changes.

Developing an Exclusive Workshop –

an activity designed to help people think about how we inadvertently exclude people

- Tell the participants that they are going to organise and design a workshop – a very special workshop. We want to make absolutely sure that NO women come. (You can use any group of people who are excluded in your society – if there are enough people, different groups can work on excluding different groups of people – or be really extreme and ask them to exclude as many people as possible!).

  At first, they will be reluctant. If they find the task difficult, you can prompt them by asking questions to make them think about the structure of the workshop:
  - *At what time should the workshop start and finish? Why?*
  - *On what day of the week?*
  - *How will you organise the sessions?*
  - *How will you arrange the chairs?*

- As they get deeper into the task, you can refine the questions: what would be most effective in excluding young women? Older women? Women with young children? And so on . . .

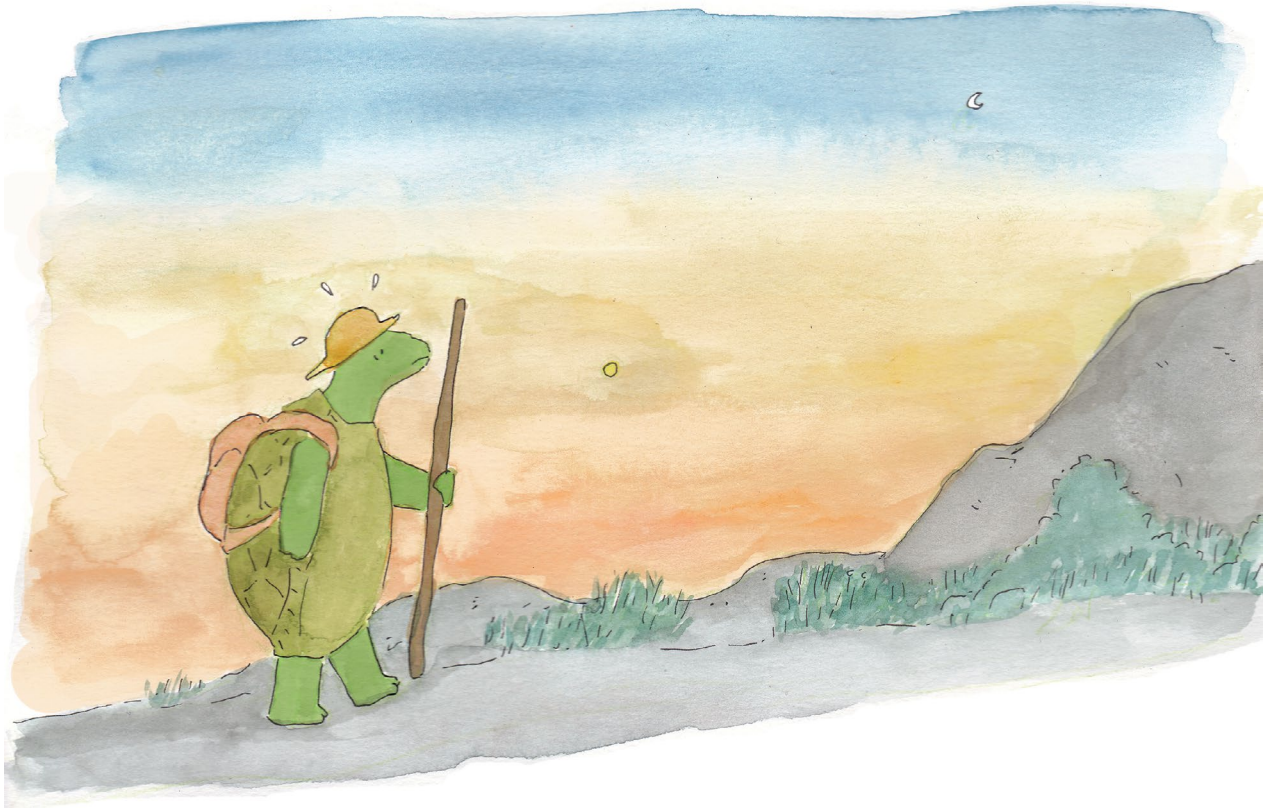
- When they are ready, they can share their arrangements for the workshop on a flipchart labelled "Exclusive" For each point they write on the flipchart, ask them why they have chosen to do that – why would this exclude women?

- Now ask them to say what the opposite of this workshop design would be – what things would make the workshop most inclusive of women. Write these points down on another flipchart labelled "Inclusive".

- On a third flipchart, ask them to write down what they have actually been doing in regard to including women when organising workshops. This should highlight a number of actions, whether intentional or not, that could be improved upon. Usually this reveals some shocks and surprises.

- Finally, on a fourth flipchart, ask them what they can do immediately to make their workshops more inclusive, as well as what they can commit to changing in the longer term.

You can do this activity for any event/process or system – try it yourself – it will help to make you more inclusive in your recruitment, communications, or financial systems.



This mountain needs to be climbed now

Creating the urgency required to make a start.

To change an organisation, from one that is content to do business as usual to one that actively seeks to remove barriers to inclusive participation, does not happen overnight. In fact, this process won't even start unless the entire organisation feels a sense of urgency about the need for change. This requires putting in time and effort to convince everyone in the organisation, from top to bottom, that it is important that we climb this mountain together, and that it should be done now rather than later!

"We wanted to raise awareness in our board about the importance of a rights-based approach towards disability. We asked Yetnebersh Nigussie, who has a visual impairment herself, to host the session. She showed an awareness video and did an interactive exercise. The presentation was a big success; the board members looked really touched. Later on, during the evening, the board members had to decide on our new policy on the rights-based approach and disability mainstreaming. The documents were accepted without any hesitation."

– Programme Manager

The important thing is to surface any doubts or tensions and not to ignore them. Exclusion is about power and resources. People who have more power and resources often don't want to give this up. Often, they have become so used to having power that they either don't see that they have it, or think that the present situation is "normal", so that any reduction in their power is a denial of their rights. To install accessible toilets might not seem to be controversial in itself, but if this means diverting money from someone's budget, or taking their space, then they might well feel aggrieved.

That is why it is so important to live by the organisation's values. If people see something is values-driven and they agree with it and want to live by those values, they are much more likely to give up power and resources gracefully. If changes are imposed upon them, even in the name of those values, there is likely to be resentment. Involving people and letting them decide what fits in with their values may take a little longer, but the outcome is much more likely to be accepted, even embraced.

A question to donors and NGOs

"Are you supporting and participating in the lives, processes and initiatives of the excluded, or must they participate in your procedures and projects?"

There is a tendency for external development initiatives to create their own change processes and projects and to impose these on the excluded. The danger in this is that these imposed solutions might not fit with the culture of the participating stakeholders or "beneficiaries." This resulting discomfort from this lack of fit might well deepen their sense of exclusion and undermine their sense of ownership, thus negating the very purpose of the work.

In 2016, FrameWorks Institute carried out research on how best to communicate about and frame Human Rights issues in order to be most effective as an advocate. Some of their recommendations include:

- **Contextualise numbers:** Often, we use numbers and statistics to make our case, such as "one in seven persons have a disability," thereby asserting that this issue deserves our attention because the affected population is so large. Facts without context, however, do not help people understand how to interpret the data. Place data within a frame, a visualisation that demonstrates what meaning the numbers have. For example: "Only 10% of children go to school. This is like having a classroom with 30 seats, but only three students."

- **Avoid crisis language:** Crisis language emphasises the great urgency of the problem. However, framing issues in this way can lead people to conclude that the problem is too overwhelming to resolve. It is better to combine urgency with efficacy: "The problem is real, but solutions exist."

- **Provide explanations rather than descriptions:** Often, we list and describe the issues that marginalised groups face, rather than explaining how the problems arise. Explaining how and why the problems happen, helps people understand why the given solution is going to solve the problem.

Getting commitment from the management, specifically, as well as from the organisation in general, can be a tough job. There are many excuses for not being inclusive – and these excuses need to be tackled one by one.

Some of the most common excuses we have met, and their rebuttals, include:

It's not in our mandate

Actually, if you are a development organisation, it most likely is. If you want to tackle poverty, you can't do that *without reaching the poorest and most marginalised groups*. Moreover, inclusion is a human right. If your goal is to tackle youth unemployment for instance, then keep in mind that youth are not a single homogenous mass: some are female, some disabled, some gay and some from indigenous groupings, or any combination of these. They might all be unemployed but face differing challenges. Again, if you're an entrepreneurial organisation, think of all the potential talent you are unnecessarily eliminating from your recruitment process.

It's not cost effective

As development organisations, we seldom have unlimited funds and don't want to commit to unnecessary expense. Organisations often fear the extra costs committing to a new programme can entail. However, being inclusive is often actually *more* cost effective than not being inclusive. Take, for example, the cost of special schools for children with disabilities. Although these provide facilities very important for some children, particularly those with severe disability, many others, who currently attend such schools could, given only slight and relatively inexpensive adaptations, attend regular schools. Research done by Morgon Banks and Polack (2014) shows that it costs society more to maintain people as unemployed, compared to the cost of including them in retraining and job-preparation programmes.

It's not efficient

This is just another way of saying that such programmes cost time and money. They do, but only once. Meeting the needs of *everyone* once and for all, rather than the needs of only some, can prove very efficient. Having to organise a taxi every time you go to work, because the trains aren't wheelchair friendly, is decidedly inefficient! Setting up a separate schooling programme because indigenous children aren't welcome in public schools, is costly as well as inefficient.

We don't have the time

This is true: none of us do, not to do everything we wish to. There is too much to do and so many issues to deal with. But if inclusion is in your mandate and mission (see the first point, since it most likely is), then any time spent on inclusion is time well spent on achieving your organisation's goals. In addition, small changes in the way you work don't need to cost much time.

So now we no longer have excuses as to why we continue to be exclusive . . . let's begin!

Start by tackling the easy slope

Go for quick results in small, bite-sized steps.

Quick wins can motivate people to keep going. Don't start with the hardest, largest part. Start with something simple, mark it up as a success, and keep going from there, inspired and encouraged by what you have achieved. Start with a small pilot project, for example, where you actively try to include marginalised groups. Use this experience to convince management and colleagues that inclusion really is viable.

"One of the first things we wanted to do was find a new office. We drew up a list of criteria for the perfect office. We knew that it would be very hard to find a building that met all the criteria. In Kathmandu, people build high to make the most of the limited space and, because of frequent power cuts, lifts are not very practical. None of the places we found were on a single floor and none of them had a lift. How were we going to make sure that people with disabilities felt welcome?

"We asked one of our partners, an organisation of people with disabilities, to come and look at the office and give us some advice. They suggested we work to make the ground floor fully accessible for those with mobility challenges. We built a ramp to one of the entrances and widened the door of the toilet so that a wheelchair could get in. The governance team, who worked most directly with our disability partners, had their office on the ground floor. We also made sure there was one meeting room there. We invited our partners to use our meeting rooms when we weren't using them.

"It wasn't perfect, but the organisation of people with disabilities could see that we were making an effort to include them. And regularly having people with disabilities in the building made us more aware of their abilities as well as their needs. They weren't just people we were supporting 'out there,' they were part of our organisation."

– VSO Nepal

Quick wins can motivate people to keep going.

"In the beginning, the disability issue was not a priority of VSO Nepal. Their policies were not disability friendly. The VSO Nepal office was not accessible for persons with disabilities. When we started to work with VSO Nepal on their governance programme, they sensitised themselves. They made the office accessible, at least the ground floor. VSO staff took sign language classes and had an internship for persons with disabilities. They encouraged and gave support to their partner organisations to address disability issues in their organisations and programmes."

– Shudarson Subedi,
disability activist and President of the Nepal Disability Network

For more quick wins, work on embedding inclusion in the things you are going to do anyway. If you are planning to rewrite the HR policy, see if you can incorporate a statement on diversity within it. If you are planning a stakeholders meeting, pick a location that is accessible and easy to reach, rather than the usual hotel. When writing the budget for next year's project, put aside a small amount of money that can be used to pay for such things as a babysitter that might enable mothers to attend your activities, or a sign language translator to enable deaf people to participate. In your daily work, remain focused on where you can readily make a small difference.

Mr. Bekele, a health worker in rural Ethiopia, was carrying out consultations during an outreach for eye care services. During the consultations with male patients, he asked about their wives and families. Surprisingly, a lot of them have wives with eye conditions. Mr. Bekele insisted that they bring their wives with them during their next visit. To make sure, he scheduled appointments with them in the morning because he knew that the women have household responsibilities in the afternoon. Because of this, Ms. Fanta, who otherwise would have stayed at home, was brought into the clinic and had her cataract removed.

Sometimes you will take a wrong turn . . . and that's OK

You will make mistakes. It won't be pretty: but you can't compromise and leave stuff out.

There are quick wins, there are successes – and there will be failures. You can't learn to play guitar if you are afraid of hitting the wrong note now and then.

The thing with inclusion is that there are no set of rules yet on how to do it correctly. There are tips and tricks and lessons learned and guidelines, and there is this Barefoot Guide. But there are no guarantees that if you follow certain steps, you will become inclusive of all the people you need to be inclusive of, nor that you can do so without any problems.

"I regularly give trainings, and try to ensure that all participants are able to attend and participate equally. One time, I had a list of participants quite a while beforehand, and I knew that none of them used a wheelchair, so I skimped and rented a location which did not have an accessible toilet. Two days before the training, a last-minute participant – a wheelchair user – signed up for the training. I felt so embarrassed to have to tell her that the training location was not accessible for her. After that experience, I decided to never ever compromise on accessibility!"

– Programme Coordinator

"During our last bi-annual conference, one of our colleagues was left out of the activities during quite a few of the sessions. He is blind, and the facilitator had been using very visual exercises. We're an organisation for persons with disabilities – we should know better!"

Tackling thorny issues and horned dilemmas

The journey to achieving inclusion isn't easy, nor is inclusion a soft and woolly thing. It is a journey full of sharp corners and wrong turns. How can we include everyone when many of their needs are so different and often conflicting? How do we reconcile the needs of widely differing groups? Whose needs should be prioritised? And what happens when being inclusive to one person has unintended consequences for others?

"We were delighted when we recruited Raj as Education Programme Manager. He was a Dalit, from a caste of musicians, who were sometimes discriminated against by other Dalits. He was also the director of one of our partner Dalit organisations. If he left them, it would leave a gap. It was hard to find Dalits who had the education and experience to run an organisation. Our partners often complained how international organisations were always poaching their staff, offering them much higher salaries. Had we been inclusive only to deprive a marginalised group of one of their leaders?

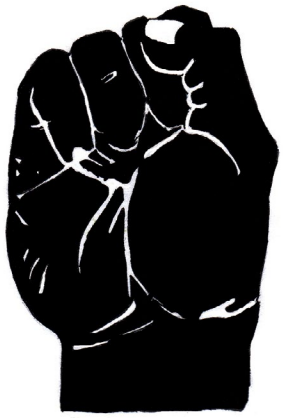
"We decided to talk to the board of the organisation. We asked them how they felt and how we could help so that the organisation did not suffer as a result of Raj leaving. Their initial response surprised us. They were delighted that a Dalit would be in a senior position in an international organisation, especially in education. He would be working closely with the government and they felt it would help to change attitudes and give them a stronger voice. However, yes, it would be difficult to replace him and whoever they appointed would need some support at first.

"We agreed to be flexible about when Raj would leave, allowing them to get someone else in place. We also gave him time to work with the new person until they were ready to manage alone. We had an international volunteer working for the organisation who also provided extra support. The transition was able to happen smoothly, though it was challenging for Raj to take on a new position while he still had some responsibilities with his former organisation."

Raj's experience: "It was not easy for me to leave my organisation as there were a lot of sentiments attached and also I was in the leadership position. With heavy heart and mind, I shared the news of my selection by VSO with the board members. It would really be difficult for the organisation to find a replacement who understand the issues and could lead the organisation. However, board members of JUP considered this news as an opportunity for the entire community of Dalits to influence an international organisation to have more focus on supporting marginalised communities, and also influencing government policies. The board members were open looking at how VSO could support a smooth transition. Even after joining VSO, I was seconded to my organisation for a week to support the organisation and also our VSO volunteer supported and mentored my replacement."

"Our organisation, wanting to become more inclusive for persons with disabilities, developed a Diversity Personnel Policy and developed a norm for 10% of staff members with a disability. In a first attempt to reach the norm, the organisation advertised for a 'Programme Coordinator with a Disability'. We were subsequently reprimanded by the Dutch Bureau against Discrimination, stating that this form of recruitment was discrimination of persons without a disability and, therefore, not in line with the Law on Equal Treatment. We did learn from that, and now have several staff members with a disability, hired through fair and honest recruitment processes."

One's intentions are important. People usually recognise when you are trying to be helpful and fair, even if you get it wrong. This is not always the case, of course: people with disabilities rightly get angry when people ask their carer questions about them instead of asking them directly. Often independence is a hard-won achievement, something that those with disabilities are rightly proud of. However, how this shapes what is required varies. I have asked people with disabilities in countries where the infrastructure is particularly disabling if they mind when people just help them up the stairs or across a road without asking if they require the help: mostly they say they don't mind because it at least shows that people recognise their situation and are willing to do something to help. Of course, it is way better to ask the person concerned whether they want help or not, but we shouldn't beat ourselves up too much if we get it wrong. Just say sorry, and ask how you can do better next time.

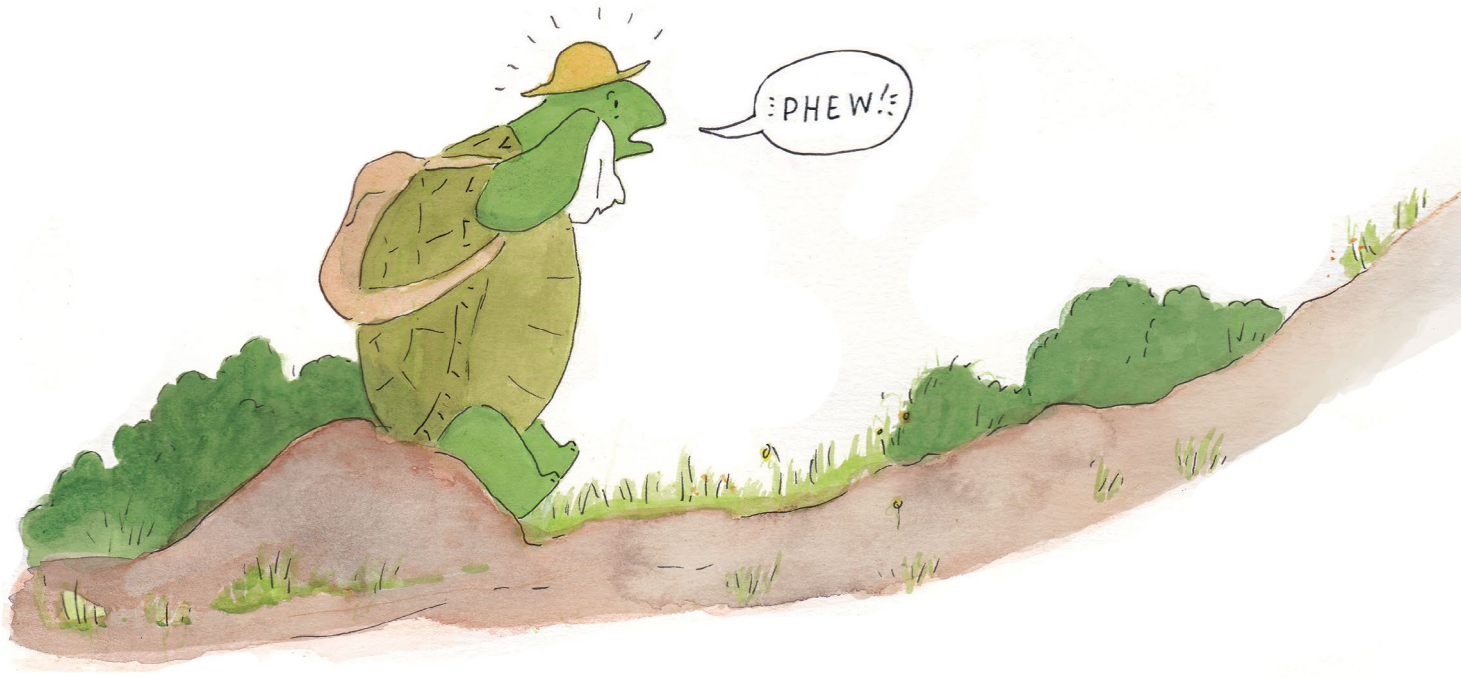


When is exclusion inclusive?

Sometimes, in order to lay foundations for inclusion, it's ok to work exclusively with the excluded! This is often the case when the objective is to strengthen the position of excluded and to augment their power. For example, if women are organising themselves to participate equally in village governance, they will first probably need to meet separately, without the men, to first gain the strength required to prepare themselves for this. Although men are excluded from these preparations, they are not excluded from the decision-making.

In South Africa in the late 1960s, the Black Consciousness Movement, led by Steve Biko, recognised that the "non-racial" organisation of students, called the National Union of South African Students, was dominated by confident and well-resourced white students. Even though they were well-meaning, this was inappropriate. Seeing how this "inclusive" organisation was actually excluding black students, Steve Biko launched the South African Students Organisation, which only admitted black students. Through such organisations, black people were able to find and strengthen their own voice and build solidarity, before eventually liberating themselves and paving the way for a more inclusive society. The white student organisation was not excluded from a role: it found an effective place in the struggle by conscientising white people about the evils of Apartheid.

"in order to lay foundations for inclusion, it's ok to work exclusively with the excluded!



This is going to take a while

Change takes time: it's a process.

"Inclusion is a process which needs to be seen as a never-ending search to find better ways of responding to student diversity. It is about learning how to live with difference and learning how to learn from difference. In this way, differences come to be seen more positively as a stimulus for fostering learning among children and adults."

– UNESCO, Policy Guide on Inclusion and Equity in Education, 2016

Never-ending! That sounds a bit daunting, especially in this results-oriented age of plans, targets, and deadlines. How can it just go on and on? But think about it for a moment: we don't set deadlines to living our values or working towards a better society. We know that these are lifetime tasks. There will be some successes to celebrate along the way, but there will also be setbacks, times when we make mistakes. People need encouragement to learn from these, without this, the task can seem rather daunting: it is all too easy to fall back into the old ways of working.

It can take a long time for organisations to be fully willing and able to commit to inclusion and the active removal of barriers for all marginalised groups. In the Netherlands, for example, the Law for Equal Pay for men and women was signed in 1975. In 2013 – 38 years' later – women still earn 18.5% less than men. This doesn't mean that the law has had no effect, however: the progress to equality is slower than many would want, but it is there.

Changing an organisation takes time. To sustain change over the long haul requires the task to be given sufficient priority, and this demands ongoing commitment from management and staff. The secret is to make thinking inclusively second nature, so that one is constantly thinking about how to include people more fully. We need to always be on the lookout for ways that we might be excluding people. This requires understanding what barriers exist in policies, activities, and buildings. It also requires identifying the mindset that can prevent people from participating fully.

There are a number of simple questions we can ask ourselves to help ensure we stay on the right track.

Who might we be excluding? Ask this question every time you are organising an activity. If you have identified groups of people that you know are often excluded, it might help just to go through the list and think of ways you can make sure you are enabling them to be included.

Are we involving marginalised people in planning and implementation? If we intentionally involve previously excluded peoples in planning activities, and in developing new practices and policies, then they will feel included right from the beginning. They will help us to recognise when we might unintentionally be excluding people. Involving them might lead to the processes take a little longer than usual, especially at first, and we may be challenged by what we hear but, in the end, their involvement will lead to more inclusive activities and practices. This will help us to make better decisions about inclusion.

Are we showing others how the organisation is changing? Agree on some changes that everyone wants to see and how you will know when they have happened. Set goals: these can include such things as changes in the composition of the staff, or in the people who get involved in your activities. Counting and measuring impact can be useful in understanding and communicating success, so long as this does not lead to an over-focus on targets to the exclusion of the real purpose of the change.

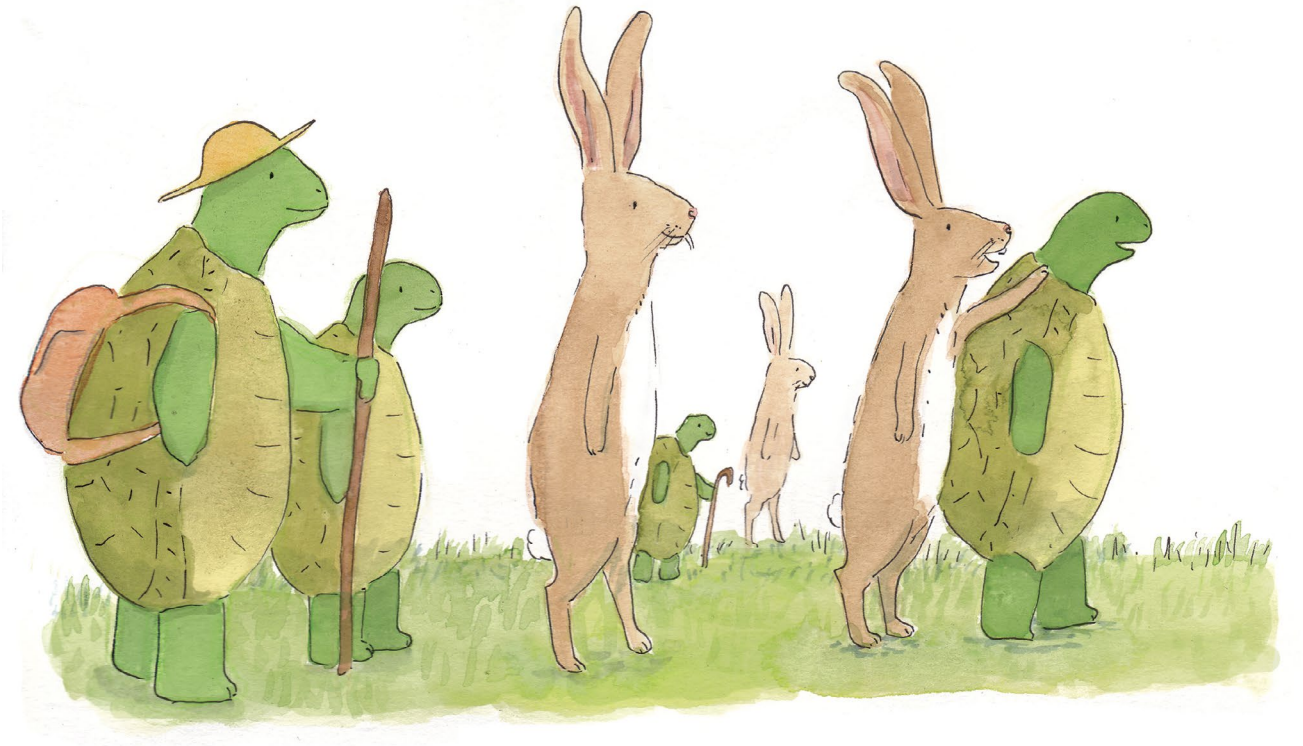
You can also choose more unusual and less serious ways of recognising that you are changing.

It's important that as many people in the organisation as possible are involved in agreeing what these targets should be.

You can also choose more unusual and less serious ways of recognising that you are changing. Choose something that resonates with your team or organisation – maybe an increase in the diversity of music that people are listening to, or how many different types of food people bring to the team lunch, or changes in the style of meetings, or which days are given as holidays in the office. Just asking the question, "what has changed?" time and again will increase people's awareness that there are differences and the organisation is truly becoming more inclusive.

The journey continues

Becoming a truly inclusive organisation can be a long journey, and you may encounter setbacks and take wrong turnings along the way. We have been working on inclusion for quite a number of years now and, to be honest, we still don't know the best way to achieve it – but the journey itself is so exciting! Take it one step at a time, and choose your battles carefully so that you are not overwhelmed. Try out a new approach, learn from this, and move on to the next. Finding the right path to inclusion will take time, so don't expect to become "an inclusive organisation" overnight, but if you keep making frequent, small changes, you might come pretty darn close!



PERSONAL STORY 7

The shadows that broke the silence

How young people in Vietnam were able to break through an unspoken problem

– by Tung –

Le Thi Ho: "My parents didn't support me to go to school. 'Going to school for what?' they thought. Everyone has dreams, but I didn't dare to dream big, so I just waited till the day I got married." I met Le Thi Ho more than a year ago. Then she believed that girls should get married at around 18 and take up a new life in their husband's home. Like other girls in the village, she took this for granted. But Le had her own dream of becoming a teacher in her community. She had hobbies too, like dancing hip-hop and singing rap songs. Getting married too early would defeat her dream and her hobbies. In this community, most young people faced the same cultural barriers.

This social problem has also resulted in health problems for young people. Since early marriage is encouraged, young people commonly start dating and having sex from around the age of 15, but do not know how to protect themselves using contraceptives. As a result, they are at a high risk of getting sexually transmitted diseases and becoming pregnant.

Huong Hoa district, Quang Tri province, Vietnam has a total population of nearly 80,000 of which above 50% are people from the ethnic minority groups Pacoh and Bru Van Kieu. They have no written language and have limited access to educational information and quality health services. A baseline survey done with young people in this area in 2013 revealed that 56% of young people under 16 had already experienced sex, 78% didn't know how to protect themselves from STDs, 14% of teen-girls got unexpected pregnancy, and 97% showed they had little to no knowledge of contraception.

(MCNV research report, 2015)

MCNV has been working in Huong Hoa district for many years, but we were shocked by our findings there. What was stopping young people speaking about their problems? What actions could we take that would be culturally appropriate? These were difficult questions to answer as we were working with members of ethnic minority groups who were totally different to us in terms of their language, culture, lifestyle, education, level of socio-economic development, and social environment.

We started by meeting with young people to understand them better and to establish what it might take to break their silence. Through our government and Youth Union contacts we met forty young people through a series of "co-creation workshops" on sexual reproductive health (SRH). Throughout, the young people were timid and shy and didn't care to say what they thought. So, instead of discussing their problems directly, we let them share, in small groups, true stories of the consequences of practicing unsafe sex at a young age.

This story-based approach proved to be powerful, building trust between us, and making it less difficult to discuss such tricky issues. It did not change the fact that they remained shy and that many lacked even basic knowledge about SRH.

In order to develop appropriate ways of tackling these issues, we shared our knowledge and experience and then encouraged them to identify ways they could contribute to addressing the problems. They decided that they would tell the stories they had shared with us by performing plays at social events, using these as food for thought. This would enable the audience to interact, learn and discuss the issues with each other. Since the young people had never performed plays before, we decided to involve village health workers (VHWs) in this project.

Village Health Workers (VHWs) are local community volunteers who receive special training in community health, providing their villages with an essential link to commune health stations. This includes giving health educational communication at the grassroots level. With the support of MCNV, they have for many years learnt and successfully applied many creative methods for behaviour change communication, such as drama, shadow drama, participatory video, photo-voice performance, and puppet shows.

The VHWs joined the co-creation workshops and worked easily with the young people. Since they came from the same villages as the young people, they often knew each other quite well socially. Together, they started developing storyboards based on the stories shared in the co-creation workshops. These became the basis for a series of plays. They then decided they were ready to perform these plays in their community. This was easier said than done, however. The young people quickly found that they didn't feel at all comfortable on stage, appearing in front of a crowd of people who knew them. The show was cancelled.

We brought them back for a workshop to reflect on their experience. They shared their feelings of disappointment and discouragement. After much discussion, someone suggested using shadow drama. This would enable them to tell the same stories, but would enable them to do so without having to show their faces, as they would be performing behind a curtain. The MCNV staff and the VHWs helped them with this new drama technique.

The VHWs also helped them to try puppet shows. Both the puppetry and shadow drama not only allowed them to hide their faces but gave them more diverse and vivid ways to tell their stories. The original plays were not wasted, however: these they performed at the workshop, taking photos of the performance. The photos were then transformed into animated clips that were shared on social media.

> **The monkey, a character who could appear in the puppet shows, was selected to give this advice.**

Someone came up with another idea: "Let's create a character, a hero who can protect teen girls from being victims of unsafe sex and who can remind boys to 'protect' their girlfriends . . . delivering correct information about SRH to people." The monkey, a character who could appear in the puppet shows, was selected to give this advice. He would also appear at the end of the plays to make fun and deliver key messages, as well as in the animated clips shown on social media.

It was wonderful when the shadow and puppet plays were performed in the community. The audiences were so impressed and felt involved in the stories. The VHWs played their part by showing up after each play and interacting with the audience about what had happened in the stories. This motivated the young people to become more active. They started forming interest groups, enjoying their hobbies together, like hip-hop dancing and rap music. MCNV staff helped them connect with a hip-hop group, who came to Huong Hoa to teach them to dance. They have continued learning hip-hop from YouTube, often gathering after school, some even composing and singing their own songs about friendship and love, without forgetting to include educational messages about SRH.

Once a month they organise a hip-hop and rap exchange night that includes the participation of hip-hoppers from different villages, who come to perform and compete. The exchange nights are not only a rendezvous in which the young people can perform hip-hop and rap but are also occasions on which they can present shadow drama, puppet plays, and animated video clips.

Significant changes

Le is now an active member of her hip-hop group and still performs the shadow plays. She is proud to be making a contribution to bringing about positive change in her community. Along with the other young people she feels empowered and motivated to do more. "SRH is not the only problem in the community. There are many other problems, for example, alcohol and drug abuse among young men. We are also thinking about using shadow drama to communicate with people about those problems."

> ***She no longer takes it for granted that she is going to get married at 18.***

Le has not previously felt so valued or been so motivated. Shadow drama has helped her get out of the shadow. She has decided to finish high school and take a college entrance exam next summer, holding onto her dream, determined to make it happen. She no longer takes it for granted that she is going to get married at 18.

CHAPTER 5

Walking Alongside

Supporting people to dare to change

"It is not just how good the idea is, or how well it is packaged, it is also about those who are saying it, and how much they live it?"

– Ravi Gelati,
Changing the Way We Change the World video

How do you facilitate processes that seek to be more inclusive?

Excluded people express the desire to belong. In fact, everyone wants to feel they belong: to be me, just the way I am, but at the same time wanting to feel part of "us." What is it that turns isolation, discrimination, marginalisation into belonging?

In this chapter, we will look at stories of practitioners that have facilitated inclusion, where people could regain the sense of belonging. This practice of accompanying fundamental change in individuals, organisations, communities and society runs through most of the chapters: we can all be facilitators of inclusion. Here we tease out what facilitation means: the frameworks and practices we can use to make sense of exclusion, to envision a more inclusive society, and to work towards it – together.

This final chapter studies a diverse set of inclusive practitioners: Ed, Victoria, Anouk and Jürgen.

Teacher Ed writes, "Many of my students felt they belonged to a kind of 'them,' branded as misfits and failures. My quiet being with their painful memories made them less afraid." His most profound learning is that, "*Hope does not emerge in effortless, colourful Hollywood moments* – it comes from a profound and costly process of change."

Victoria, an artist, and her collaborator Woods, a businessman, started working together in 1993. New people arrive and others leave, but Victoria and Woods' leadership fuels energy and spreads commitment time and again, so that *everyone takes responsibility for the inclusion process*. Everyone is an active change agent in the life of a person with intellectual disability.

Anouk is self-employed. She shares a practical example with us of how people with intellectual disabilities can be supported through a process of co-creating a more meaningful life, including their role in the family and society.

Jürgen is an agricultural development specialist who grew up on a farm where his father never tolerated anyone looking down on someone else. This is possibly where Jürgen developed the ability to *relate to everyone as they are*, which is one of the most basic capacities we need to cultivate as facilitators of inclusive development processes.

While these practitioners describe a number of different practices, they all bring "presence" to their work. Their stories illustrate what it means to "be the change."

Reconnecting to hope

– by Ed –

As I walk towards my classroom, some of my less positive memories crave my attention. I know my classroom will be overfull, with too many adolescents present. A large number of students had to switch to my class during the middle of the term because of their rapidly mounting behavioural problems. The thing they cling to – the only positive thing, in their mind – is that once they successfully complete this "transition programme" they will be allowed to return to a "normal" class again.

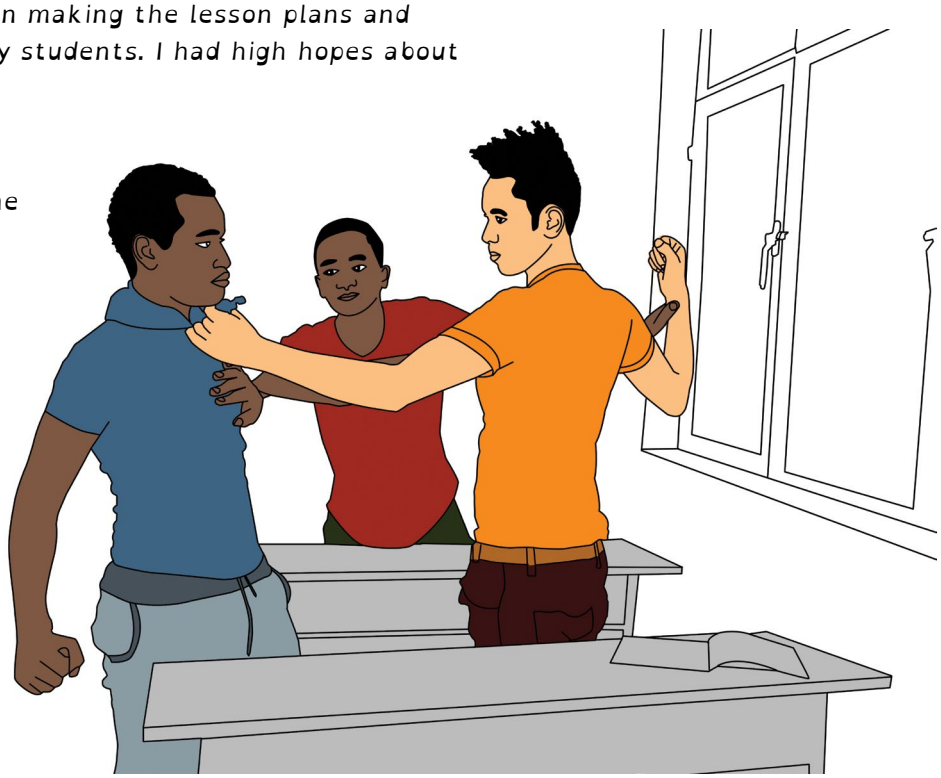
Halfway through this lesson only a few students are participating. The more introvert ones try hard to remain invisible, while the more extrovert students make trouble. School policy dictates losing the inactive and the troublemakers, suggesting a fast track that leads to expulsion, but I am hoping to entice their cooperation and involvement. I've learned from my mistakes and I now have an inkling of how to achieve. Surviving here has depended upon finding solutions to new and unexpected problems.

I started this job feeling "streetwise," full of energy and courage. I knew I would meet violence and opposition. I was used to dealing with violence in institutional settings, where my colleagues and I were expecting it and were trained to deal with violent behaviour. I felt prepared and able to work here: I would use everything I had learned previously. I would build an environment with the appropriate level of challenge for my students: giving them a chance to show themselves and grow as students. I thought I knew how to do this.

But I was used to dealing with adults who at least paid lip service to being in my class. The situation here was different. Some adolescents made no secret of the fact that they were here to avoid being cut off from social benefits. Others told me they were here against their will, or due to a fault in the system. No one wanted to be here. This created, what was for me, a new and stressful type of opposition that I needed to learn to deal with.

> ***No one wanted to be here.***

I thought I had succeeded in making the lesson plans and environment fit for most of my students. I had high hopes about the effects of the programme I had designed. After a while several groups began to show some difference, it was not the positive overall result that I had hoped for. Looking at the students as a whole, I could see they usually showed one of three types of reaction: yes, I can (students responding well and engaging); sadly, no (students failing to engage or attend); and the undecided (not engaging but present, barely hanging on, with bad results overall).



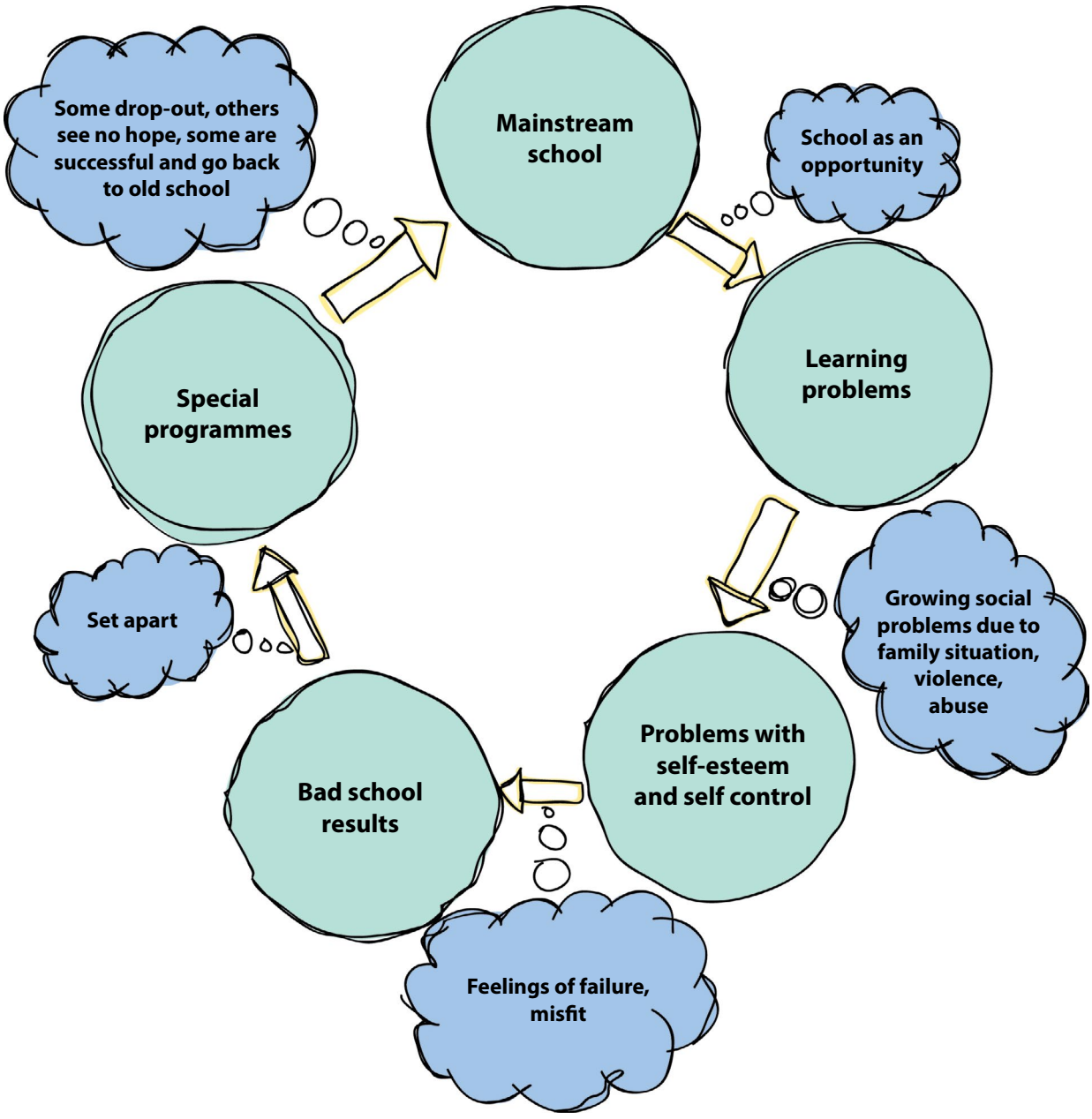
This third group puzzled me most: what was holding them back, and what was keeping them here?

I had completely used up my usual bag of teacher tools and tricks. This left me asking, how would I cope with this challenge: by starting to remove these inactive and troublesome students as school policy dictated? I wasn't yet ready for that. But nothing I did changed the situation for this third group, which made up the majority of the class. I had to find out more about them.

> ***what was holding them back, and what was keeping them here?***

I organised moments outside the classroom to talk to these students, giving me a chance to learn more about their background and the educational programmes they had previously participated in. I started to understand the chain of events that lay behind their present situation. I discovered that what seemed to hold them back was a change that had taken place to their self-image.

Typical chain of events that my students come into:



My students had been assigned to my classes through such a chain of events. Their previous misbehaviour was taken as proof of their incorrigibility. Their failure visible for all to see.

They faced social stigma in not living up to their parents' hopes. Though school can be a motivating force for the child who does "well enough," it can easily demotivate the child who fails to meet the expectations of others. Social stigma weighs heavily. Many of my students felt they belonged to this outsider group, branded as misfits and failures.

> ***it can easily demotivate the child who fails to meet the expectations of others.***

And then there is the challenge of coping as a 15 or 16-year-old. Adolescence is a challenge for a large number of young people. Those in my class appeared to have adopted one of two strategies: to hide in plain sight (the inactive), or to become outwardly tough (the troublesome). Both having lost contact with their desire to achieve or to belong to "us." Most of all, it was their loss of hope and self-confidence that struck me.

So, what held them back? – The conviction that they were basically unfit to succeed. What kept them here? – Perhaps a lingering remnant of hope, still flickering deep within, regardless of their disappointments. There were many things that I needed to achieve if these students were to grow. The question I asked myself was, how could I help them become active once more and in contact with their real "self" and their surroundings?

I am glad I didn't quit

Although there had been moments that I had seriously considered leaving my position, I realised that I had slowly begun to learn to cope with the challenges I faced – ones that I had once thought too heavy for me. I now felt better equipped and stronger than I had been at the start of year one. That was a good feeling. Based on my experience from my first year, I now started holding talks with the new students early in the year, trying to pick out those who had most trouble connecting. Even though I now recognised the underlying dynamics, this sometimes did not make these talks any easier.

Angry Sara

After a good start, Sara fell back into anger, distancing herself from the class. So, I scheduled another talk with her. She told me that she would rather "just get a job." She admitted that her prospects were bleak for getting work that would provide sufficient earnings to support her, but she imagined something good would happen if only she would be allowed to leave school.

I tell her that I believe she can succeed at school and that she can make the required changes, even if these might only be small changes at first. She explodes: "You do not listen AT ALL!!!" The conversation ended with me repeating what had become demands upon her, with her repeating her objections. I was not being effective.

The point of no return

I have come to recognise situations like the one with Sara as the "halfway point." Students are able to look at what has really happened, what they actually did. As long as you keep it fair and factual it seems doable. But move towards what students should do next, what they could do differently to benefit their situation, or talk about hope and my beliefs about how they can change, this can create a violent reaction in which they seek to switch the conversation to any other topic. Faced with this challenge, the students get angry, try to blame others, or talk about ways to escape the school situation they are in.

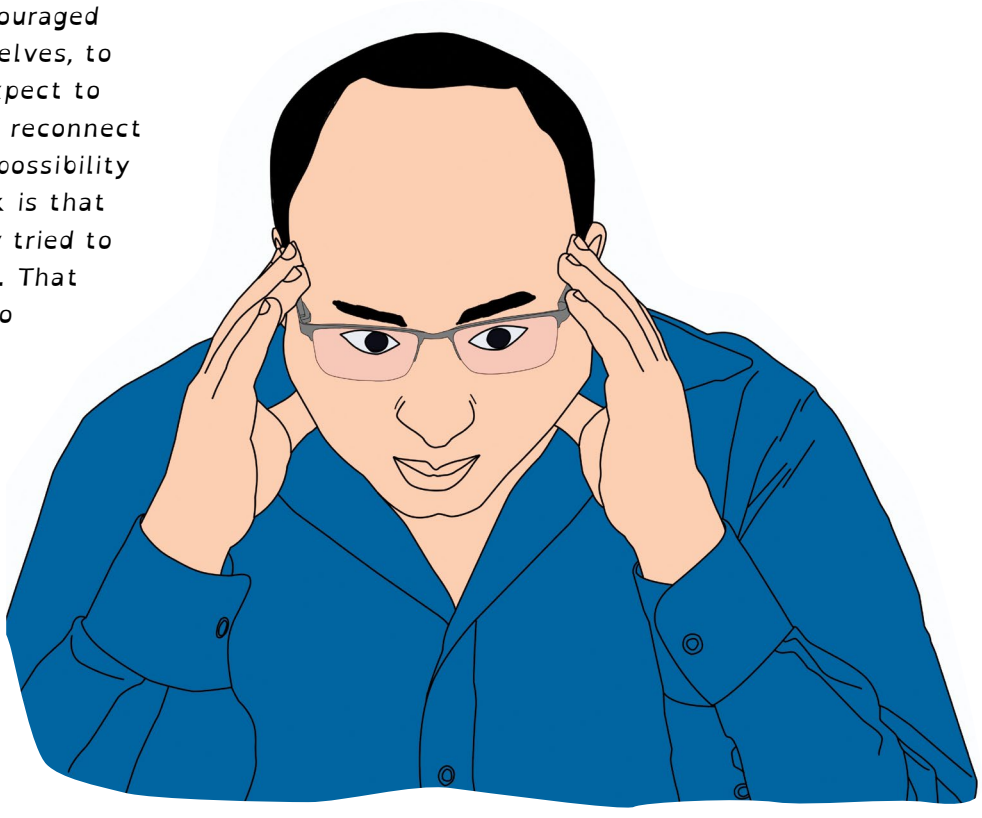
Experience showed that I was not able to end such conversations well, and the practical results were mixed at best. I plodded on. Time showed that the reason for their "flighting" also held the seeds of the solution.

As life challenges us severely, our emotions and reactions seem almost too heavy to bear. When one reaches this point, where "things are just too much," the instinctive (and mostly unconscious) process of disconnecting starts. Bit by bit, one disconnects from parts of one's own experience. Many of the students "still hanging on" had shut away their feelings of hurt and disappointment. They took on the outward attitude of being tough and cunning, apparently not caring any more. The result was isolation.

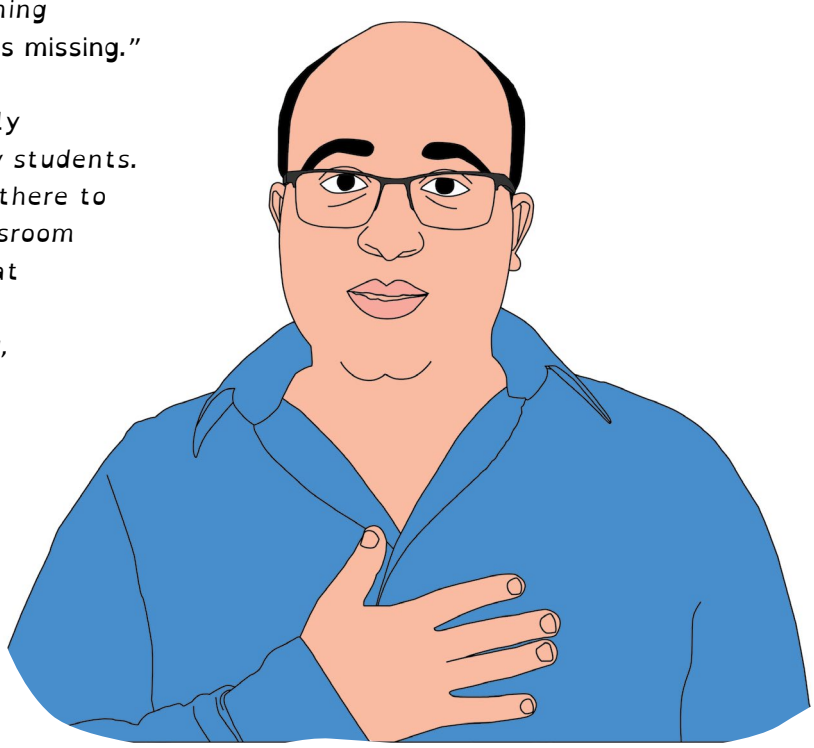
The point of return

Why was it so hard for students to reject their isolation? After all, what was waiting for my students was the real chance of success. Admittedly, re-engaging would be challenging and stressful for them, but surely, they could recognise that this would also open up new possibilities? I came to see that the costs of their "reconnecting" are directly linked to the reasons for their self-isolation. When I encouraged students to say to themselves, to feel, "I really hope and expect to succeed," this attempt to reconnect brings into view the real possibility of "failing again." The risk is that all the hurt and loss they tried to shut away will come back. That is, unless they escape into blame, anger or fantasy. This conundrum leads them into a kind of stalemate. To them, their self-isolation is in some sense the better option.

> ***Why was it so hard for students to reject their isolation?***



Something was missing – and it turned out to be me!



Me!? This still seems a frightening sentence for me to write: "I was missing." I will hasten to explain.

As a teacher, I have a strictly functional relationship with my students. I am there to keep order. I am there to structure information, the classroom situation and their time, so that they can learn. I am there to correct things if they go wrong, to clarify choices, and to act upon those choices and their consequences. In short, "I provide the appropriate environment for learning." As a mentor, my role in "correcting" things means that I must ensure I engage with the students, inviting the isolated student who has "disconnected" (parts of) herself to reconnect and start meaningful work again. This requires my presence. Someone like Sara cannot possibly be alone when she makes the choice to face her sense of hurt and loss and to reconnect, rejecting her isolation. What is required by her is not me, personally, so much as my presence as another human being. It is the quality of that presence that matters most.

The quality of presence – One should be aware, when entering into a conversation about personal strengths and reconnecting to hope, of the potential for a moment of re-emergence of past harm. That moment signals the actual point of return, or reconnection, so to speak. When this happens when I am present, I am there as someone who can acknowledge what is true: acknowledging the emotions and being witness to all the emerging images and thoughts, whatever their content. There is no place for judgement. Any kind of "comfort" that might be offered at this moment is only likely to hinder the process: it is unlikely to be seen as adequate to the task. Maybe later on, one could invite the person to re-examine her experiences to see whether or not she still thinks her judgement of these to be completely true. But this is not appropriate at the moment of re-emergence from isolation.

I learned not to label things in connection to the school situation of the student, nor to spell out consequences, but only to acknowledge what is true. True to her sense of what are the facts (even though I might later try to help see the bigger picture, including facts that she might not previously be aware of) but also "true" in the sense that these are her personal reactions to her emerging images and memories: they are just as they are.

More "handling" than "coping" – for me, and the student, the work involved is not so much "coping" with these memories, in the sense of achieving decisive results or a change in the nature or meaning of what is seen. The work is staying in contact, "handling" them, in the sense (metaphorically) of touching upon these thoughts, feeling their "weight," hearing what they have to say, and then letting them rest as they are, so we can visit them again another time – but with somewhat less fear than the first time.

I was previously unaware that this essential condition of "not being alone" at exactly this moment was what I had not provided the student. I was too busy wanting to change things, to influence, wanting so hard "to be effective." There was no peace and quiet in my presence: I did not first let it be, allowing the other person to reconnect and to give time to get acquainted with what had been lost. Actually, the very act of my very trying to be effective had blocked their process.

Effects – as small as this change had seemed, I soon noticed fewer conversations "blowing up." And if they did, I knew the way back, so that we could "land" together, back in what was present and here. I learned, against all apparent logic, that this quiet "being with" their more painful memories, without "working on them" made my students less and less afraid of confronting what they had shut away from. This way, they could begin to get past their point of return.

Sara, again

Sara (at last) sat down after nervously pacing up and down. I have taken her out of the classroom for a few minutes. Sitting next to each other, for a moment we just look outside at the rooftops. It's a sunny day. She sighs. "Feeling better now?" I ask. "Suppose so . . ."

> ***Actually, the very act of my very trying to be effective had blocked their process.***

What have we learned so far about facilitating inclusion?

Enabling environment and quality presence

Ed's story describes his attempts to support students in a remedial schooling programme in the Netherlands. Initially, he focused on providing the right kind of school environment. He thought that this would of itself enable his students to start using their skills and energy. As it turned out, he was wrong. At the point of failing, he discovered that an essential kind of support was missing in his approach: a quality presence at the "points of return," when the pain of students' experience of exclusion could be held and could "just be."

We believe that the combination of these two kinds of support, "the enabling environment" and "the quality presence," which Ed discovered the hard way, has broader application. Some pointers:

Modelling a reflective culture – 'seeing yourself'

Starting alone? You can be a force for making a culture in and around you that helps you to be present. There is something very basic, even simple in the act of being present. The paradox is that simplicity is sometimes hard to attain. It helps to learn to stay quietly present with all that lives inside you. And it helps to seek out others who are likewise willing to learn to integrate this reflective culture into the way they work. Lastly, care must be given to develop safe ways of expressing identity if you are working in a society with different and maybe conflicting cultures, beliefs and religions.

"You can be a force for making a culture in and around you that helps you to be present.

- **Internally, view yourself with kindness** – It does not help to be harshly critical and judgmental towards what you discover in yourself. The absence of self-recrimination will enable you to look longer and see clearer what lives inside of you. Tolerate mistakes if you discover them: do not make more of these than you need do.

- **View and react to others with kindness** – It works equally well for others. But you can only hope to do this sincerely if you have learned to be kind to yourself first. So, the first skill, of being kind to yourself, is a prerequisite.

- **Try to see as clearly as possible what is there** – Be clear in your inner observations and feelings. Stay patient with yourself and try to understand why you are the way you are, why you do what you do. Postpone making a verdict and keep looking: a quick and harsh judgement is often a way to avoid seeing what is actually happening within.

- **Try to "handle" rather than "cope with" your more difficult issues** – At first, let your own painful issues be, just as they are, without the reflex to immediately "fix" them. Take time to get acquainted. First-hand experience will show you how your fear subsides with every repeated encounter. Having become more at ease with yourself makes room for new ways to see and deal with what is difficult.

- **Set goals realistically** – You might make real discoveries about things you aspire to become or to do differently. Still, if you have a big distance to cross, small steps will take you there.

- **Release tensions where possible** – The more you feel oppressed by a situation, the less strength you will have to deal with it. Try anything that can relax you: beauty, music, cooking your favourite food, being in organised surroundings (even one organised corner if that is all you can manage), enjoying the tranquillity of a favourite place in which to just sit, whatever it is that helps increase your wellbeing: small things can all add up to help release tension. Relaxing in this way might seem trivial in the light of all you are facing, but it can often prove crucial for survival because it directly lessens the impact of the burden you feel resulting from your experiences.

Modelling a reflective culture – 'seeing others'

Reconnecting to one's own hopes and personal strengths is also strongly connected to (re)discovering a more true identity in others too.

The group you work with might be in a minority position, or connect to an identity that is not accepted within the surrounding society: in such circumstances, the exploration of this identity can prove powerful for all concerned.

- **Organise safe opportunities for expression** – This involves enabling everyone to express themselves by speaking about their (more) true identity. Be aware that many situations are often not free and safe for certain individuals or groups. Give thought to setting up conditions and occasions for meetings that might, at least initially, be less public, so that people can safely learn again to express themselves freely. Be discrete.

- **Be clear about wise boundaries to behaviour and initiatives** – This involves expressing yourself through your behaviour, showing the person you aspire to be. Think about what amount of freedom you have and the ways of expression that will not immediately endanger you and your group. Though there may be inevitable tensions with the surrounding community, you can choose the best alternatives.

Why all this complication, when hope seems such a basic and simple force? Why would you give precious time to this exacting inner work and preparation? The lesson for Ed has been that practical hope when it is most needed often does not emerge in effortless and colourful "Hollywood moments". Real hope is part of a profound and costly process of change that will require your "presence" in order to achieve it.

In all states

Understanding self-isolation

You have probably heard people say, "They are difficult, they just don't want to participate," when they refer to excluded groups. Perhaps you have also wondered at times, do they really want to change?

The following schematic explains different states of being. A chain of events that is too hard can lead to self-isolation, to a state where people no longer can engage, because they have somehow lost themselves. Some situations are too difficult or painful, for too long: however hard you try, you cannot cope. This can lead to (unconscious) self-isolation – you dare not be, or see, you. You have reached a point of no return, unable to engage with the possibilities and risks.

The practitioners' work is being there, touching upon the thoughts that emerge, feeling their "weight," hearing them and then letting them rest as they are, so that we can visit them again another time, but now with somewhat less fear.

	DIFFERENT STATES OF BEING					SELF-ISOLATION
	TOO LIGHT	RELAXING	MANAGEABLE	STRESSFUL	TOO HARD	
The nature of the situation:	No meaningful challenge, repetitive activities	At rest, at play	A known challenge, I can handle it with my present skills	An unknown challenge, but I can adapt my skills	The challenge cannot be overcome, despite all my skills and resourcefulness	Hesitant to engage, shielding myself from contact with people and reality
How I deal with it:	Bored, killing time, what I do makes no difference	Recovering energy	Getting things done, sometimes in the "flow" of activity	Struggling, but still achieving (overall) success	Gradually giving up, not achieving and eventually failing	Merely reacting, no drive to achieve
How I feel:	I shrink, feel useless and bad about myself	I feel ok	I feel good about myself, confidence increasing	I feel stressed, but still confident	I feel depressed, hurt, unfit and afraid	Outside: angry and strong Inside: lost all hope

Strength in diversity

People with intellectual disabilities in the workplace and in wider society

Ed's story has given insights into the meaning of reflective practice. He has shown how this practice can help you stay connected to hope while finding new ways forward, often a tough task in the many difficult situations faced by those who are marginalised and discriminated against.

Our next story delves into inclusion in the workplace. Carolina tells us about an unlikely alliance between two people that has held strong for over twenty years, and that has added value to the lives of many persons with intellectual disabilities, their work colleagues, the company they work for, and the society they are both part of. At the heart of this story is a long-term commitment to the task, combined with a practical approach to working with companies.

Co-creating: dancing, acting and the fast-food business

– by Carolina –

I am driven by words: I love to write, I am committed to sharing stories, I am devoted to art, I love colours and shapes. I am honoured to be a facilitator in the Victoria–Woods collaboration, thrilled to be part of the DISCAR-McDonald's working teams and grateful for the opportunity to write about inclusion of people with intellectual disabilities within the workforce and in the workplace. I believe that any time, everywhere, each of us can have an impact: take a look at these two ordinary people that have shaped extraordinary social impact. I invite you to take a look and to find the inspiration to co-create in collaboration with others. It is possible, it is simple, it is worthwhile: good things can and will happen.

> ***I believe that any time, everywhere, each of us can have an impact***

Five bags – five jobs

Here we are, seated in a huge training room in one of the best-known companies on the planet: we are at Arcos Dorados, the McDonald's HQ in Chile! Through every window the Andes Mountains protect us and honour this blessed moment with their majestic snow peaks.

Anxious glimpses, firm hands, nervous sips of aerated soft drinks. The five have come a long way. They desire this moment and breathe triumphantly. They have been patiently growing towards this, with support from occupational professionals because of their intellectual disability. There is a world outside, the adult world. We are adults and we are heading for that world together.

Five bags have their names written in strong red ink: José, Mayckol, Felipe, Guillermo, and Andrés. Inside each bag rests a new uniform and a job contract that is ready to receive their signature. Those signatures have been rehearsed over and over again.

- Andrés is spotless: light blue shirt and striped tie. I am trying to guess if they are his, or if somebody has lent him the attire for the occasion.
- José has never met any member of his family. He has been living in an orphanage since the day he was born and now, aged 26, the Chilean state determines that he must earn his own living. This job means the world to José.
- No one can understand Guillermo when he talks, but his smiles tell it all.
- Mayckol, such a lovely guy, just like his name, is sitting in the very centre of the room. His eyes are dancing, embodying his energy.
- Felipe finds it hard to write, and takes a long time to sign his contract. We all cheer each at every one of his traces.

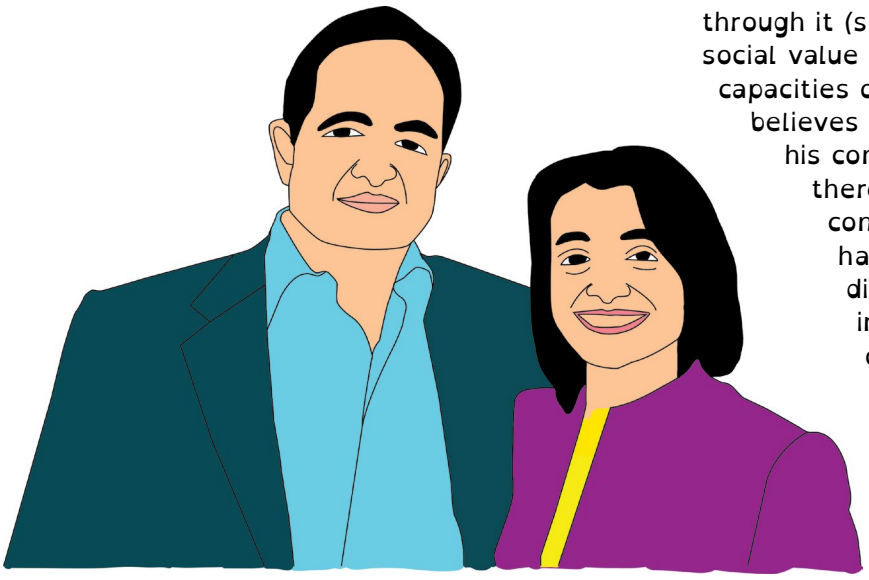
This is life: intellectual disability and opportunities brought together. Simple, real simple. Like five loaves of bread and thousands of fish. Abundance . . .

"Anxious glimpses, firm hands, nervous sips of aerated soft drinks.

"Believe" is the most significant word that comes to mind when I reflect upon the alliance that I came to know ten years ago. How could two people, so very different and from even more diverse situations, get to know each other and give birth to an alliance that has been growing steadily for the last two decades?

Meet Mrs Victoria Shocrón from Argentina. She has always loved dancing and acting, and was a leading actress in musicals and a TV-show in the eighties. During a family holiday, Victoria invited an isolated little boy to play with her son. She discovers that the boy has difficulties in communicating with them. He only joins in playing when Victoria starts singing and drumming on sand buckets. She is moved to see her son and the little boy with intellectual disability play together and share the rest of the summer with each other. This ignites a spark in her to share her art with such vulnerable people.

Her dream comes true when DISCAR is born, the Centre for Arts for People with Intellectual Disabilities. It offers them theatre, music, art, and bodily expression workshops. After two years of experience and observation, Victoria realises that much more could be done. She sets her energies to develop a programme to include her students in the workforce.



She knocks on the door of the world's largest McDonald's franchisee, Arcos Dorados.

She knocks on the door of the world's largest McDonald's franchisee, Arcos Dorados. It has close to 2,000 restaurants in 20 countries and employs more than 90,000 people in Latin America and the Caribbean, with revenues of approximately US $ 3.8 billion in 2012. Arcos Dorados began trading on the NYSE in April 2011.

Meet the owner of that door: Mr. Woods Station, a U.S citizen born in Medellin, Colombia. Woods is the chief executive officer, chairman of the board, and controlling shareholder of Arcos Dorados.

Victoria: *Can you give jobs to our young people and adults with intellectual disabilities?*

Woods: *Yes, but you tell me how to do it!*

This marked the beginning of a social employment model that had an impact far beyond the people with intellectual disabilities who have found employment through it (see the box on page 119 on social value added). Victoria believes in the capacities of these people, and Woods believes in her capacity to guide him and his company in this adventure. But there is more. Woods' motivation comes from his own experience of having a brother with intellectual disability. His brother thrives in life, when given the right opportunities. He works and lives on his own. This is what triggered Woods' reply to Victoria's question.

Since 1993, they have been working together professionally, with energy and a great sense of humour. It is this remarkable sense of humour that helps make things go smoothly, since the realities they work with – disability, lack of opportunities, poverty – are hard.

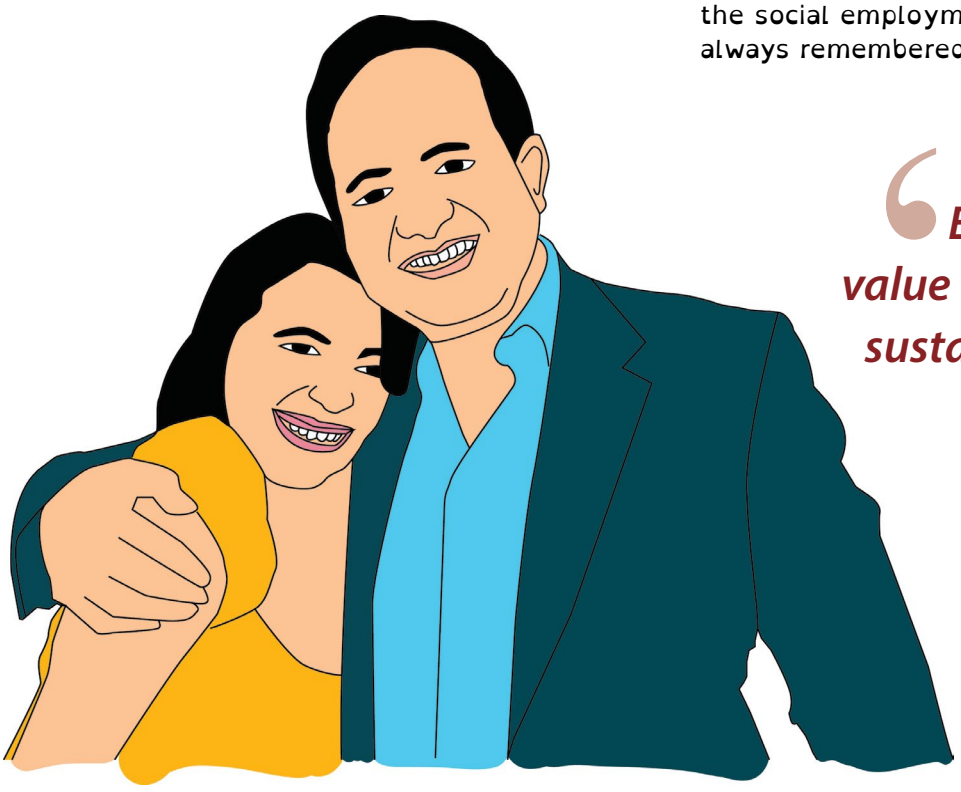
The programme that supports the employment of people with intellectual disabilities systematically tackles their inclusion in the workforce. It allows businesses to be part of the change and offers them an opportunity to help their communities, whilst improving their own working environment. The organisations benefit by hiring human resource professionals with expertise in disabilities and social inclusion. Each employee is assigned a professional who assures adequate and sustainable inclusion throughout their employment. Mr. Pedro Heredia (now 54) was the first employee with intellectual disability to work at McDonalds. After 20 uninterrupted years at work, Pedro will soon be retiring. The DISCAR professionals are giving support to Pedro, his family and his peers at work to thrive in his transition from being an active to a retired worker.

At the start of their programme, as leaders in their organisations, Victoria and Woods both gathered their teams and began to discuss the inclusion project.

In DISCAR-MacDonald's, Woods entrusted the whole programme to his Human Resources Department, a successful decision that is celebrated today. Human Resources are responsible in the company for hosting the social employment programme. This means that the inclusion of a person with intellectual disability is part of regular employment procedures, with support provided by DISCAR professionals.

Under the motto, "we need to take care of the company," Victoria and her professional team began with the design of the model, its various implementation steps, and the most important step: the follow up. The focus of the programme was on the needs and rights of persons with disability. It may seem obvious, but you might be surprised to learn how many social programmes often forget to put the beneficiaries centre stage – needless to say, their mission is seldom achieved.

Since the start in 1993, the teams in both organisations have changed. New people arrived, others left. But their leaders' commitment fuels energy and spreads the same commitment again and again, so that everyone takes responsibility for the inclusion process. Everyone is an active change agent in the life of a person with intellectual disability who is to be included in the workplace. Each person adds value to successful and sustainable inclusion. The invitation to all employees to keep the social employment programme alive is always remembered and celebrated.



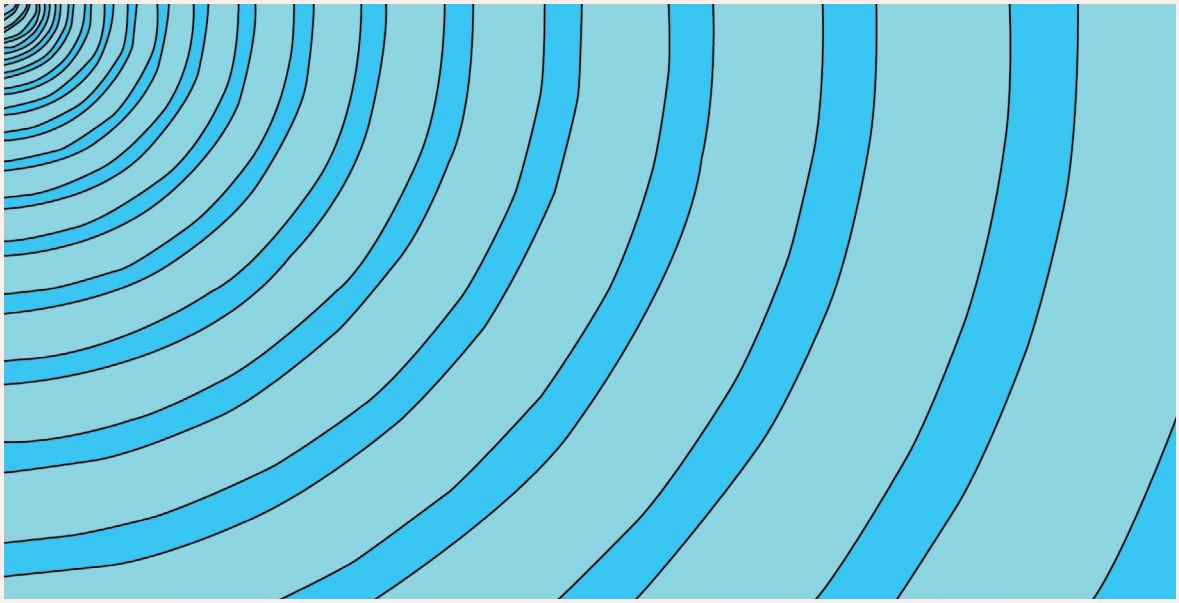
"Each person adds value to successful and sustainable inclusion.

Inclusion adds social value

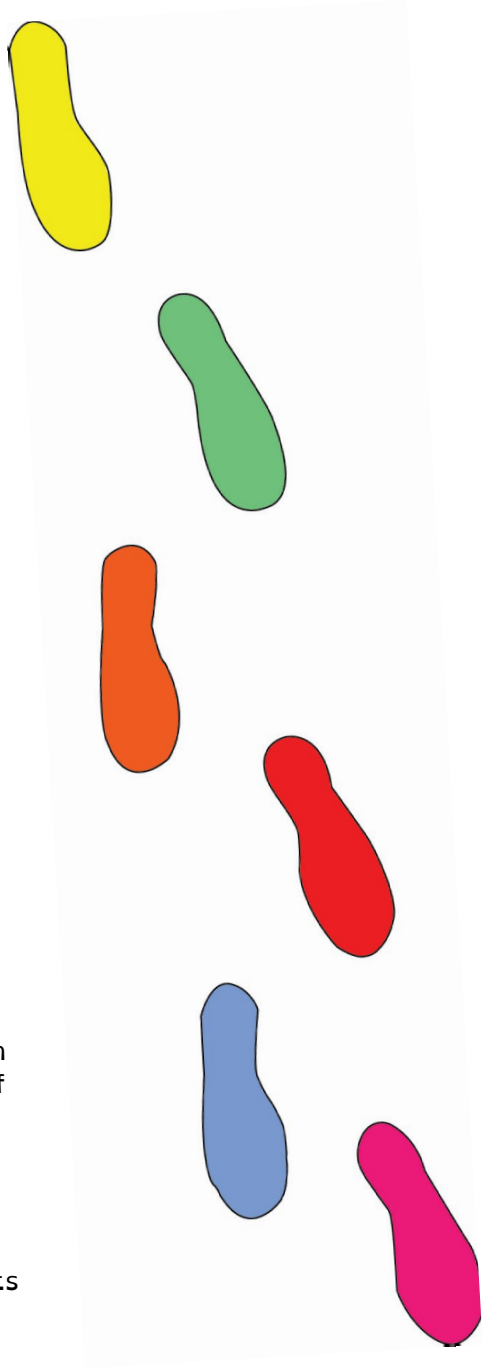
The employment of people with intellectual disabilities has had a tangible impact beyond the individuals involved, namely for their colleagues at work, the company, and the wider community. Inclusion creates ripples of change – you can see other examples of this in Chapters 3 and 4. The table below shows how we may understand these ripples from the value added in employing persons with intellectual disabilities.

Value added

Person with Intellectual Disability (PwID)	Colleagues	Company	Society
Social and work inclusion	Being a change-maker	Support from social inclusion specialists	Awareness about PwID and their contribution to society
Trained to be employed	Feeling good about positively affecting the life of a PwID	Collaboration with civil society	Positive impact through inclusion of PwID
On-the-job training and support	Fears, prejudice and indifference decreased	Reduced turnover in positions that are now taken by PwID	Research on the evolution of disability in society
Enhanced commitment to work	PwID bring joy to the workplace and make you re-value your own job	Positive impact on the whole value chain	PwID taken up in public policies
Autonomy and respected citizens	Virtues developed like patience & acceptance of the other	Diversity as a value	Participation of all
Dignity – rights and obligations adhered to	Open mind and heart through diversity	Good will – "mouth-to-mouth" advertising	A path to inclusive living and working



How does the inclusive employment model work in practice?



In 2010, after 20 years of including people with intellectual disabilities in the workplace, Arcos Dorados took this model to its other Latin American markets. The DISCAR inclusion professionals describe their five-step approach to accompaniment of a company as follows:

- **Step 1: Contact the company** – We work with each young person with intellectual disability on their responsibilities, presence, habits and the virtues of work beyond their specific job. We support them to prepare for a position in the company. They have proven to be very reliable and loyal, and have brought staff turnover down.
- **Step 2: Survey jobs** – We identify tasks that could be undertaken by people with intellectual disabilities, and develop a mutual understanding of the best position within a team.
- **Step 3: Evaluate and select applicants** – We identify people that will be a good fit with the company, the position and the team they will become part of.
- **Step 4: Train the company** – We make adaptations together, making the best of the work environment.
- **Step 5: Monitor systematically** – We continue to work with the employee and the company throughout the duration of employment, throughout their career.

FUNDACIÓN DISCAR 25 años trabajando por la inclusión

DISCAR encourages all companies to use its social employment model – see more at http://www.fundaciondiscar.org.ar/

Victoria and Woods have a personal drive to wholeheartedly engage with their work on inclusion, which Caroline summarised in the inspiring word cloud below. What drives you?

Realising a meaningful future

Co-creating an inclusive process

The following story reinforces Victoria and Woods' approach. It is a practical example of how people with intellectual disabilities can be supported through a process of co-creating a more meaningful life and role in the family and society.

The story of Fynn

– by Anouk –

In 2011, I was self-employed and collaborating with Perspectief, a centre for know-how on inclusion and self-determination. The organisation wanted to shift from evaluation research in social services to working directly towards an inclusive society.

> ***Most of his days are spent sleeping in his bed box at home or at the day-care centre.***

The Dutch alliance for support organisations (that is, social services) had discovered that clients only saw an average of five people a year from outside the support organisation. Perspectief was asked to change this in co-creation with clients, their families, and five support organisations. The clients were in the lead. The purpose of the programme was to support the clients and to give shape to their lives, according to their interests and talents. The support organisations would learn to work in a client-centred way.

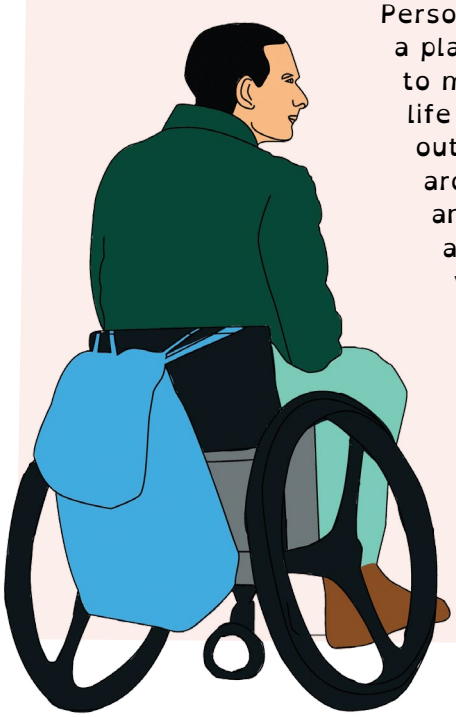
Four months later, in November, we sat down with Fynn. He sat in his chair, his mother next to him. Today, she was his "putting-into-words-person." She knows more about him than anyone else. Fynn is 51-years-old. He loves to feel the wind in his hair when he goes out for a short walk in the street. There isn't much happening in his life. Most of his days are spent sleeping in his bed box at home or at the day-care centre. When his father heard about the idea of Fynn joining the project he was enthusiastic, because "there's never anything going on for Fynn."

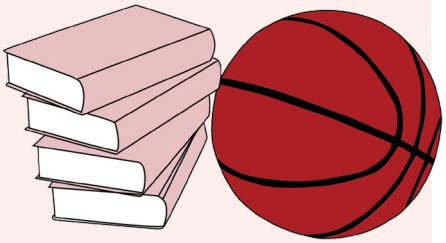
Together, we talked with Fynn about his future, his parents and sister, support assistants, and a board member of the support organisation. We used two imaginative approaches to help Fynn envisage his life: social role valorisation and personal futures planning (see boxes). We talked about his life until now, about his interests and talents, and about the roles he would like to fulfil in society. Together we made a plan for action. A graphic facilitator recorded everything in images.

Social Role Valorisation

Social role valorisation is a comprehensive theory about the cultural dynamics of inclusion and exclusion. The extent to which people experience inclusion or exclusion in their lives is related to the roles they fulfil in society. Examples of roles are sportsman, literature lover, friend, colleague, coach, painter, musician, and gardener. By fulfilling socially valued roles, according to your interests and talents, you can live your life to its fullest. You can use the insights of social role valorisation for building neighbourhood initiatives that contribute to an inclusive society.

Personal Futures Planning

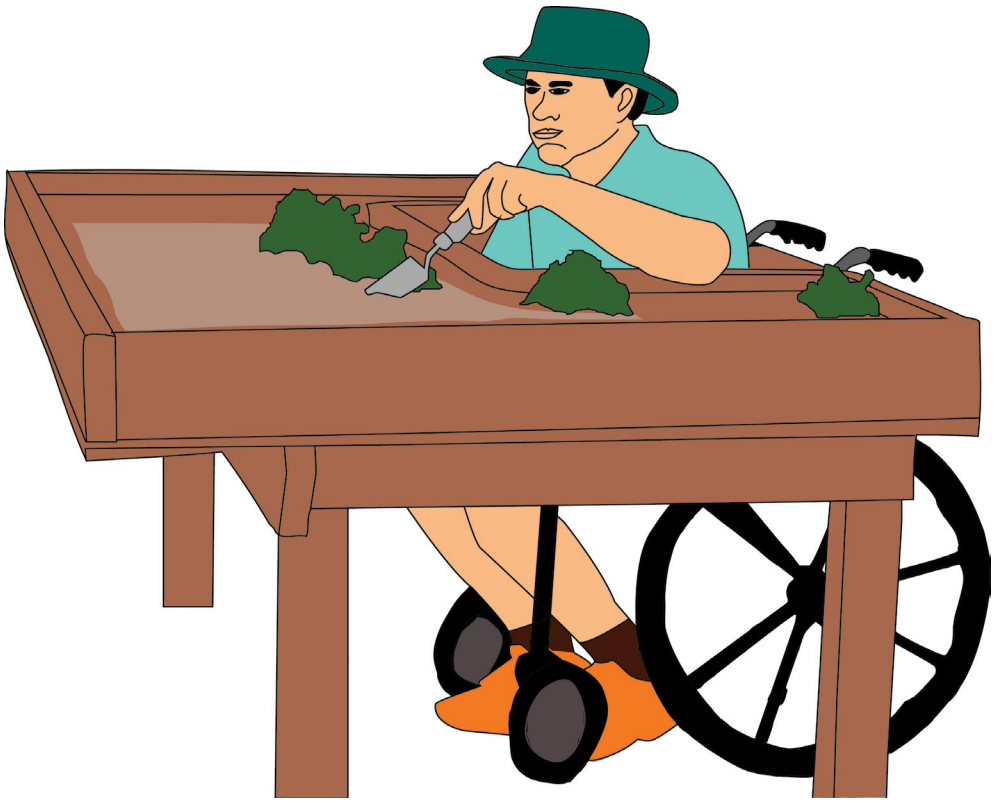




Personal futures planning is a playful and flexible way to make new plans for your life – and to carry them out. You gather your family around you, along with friends and professional assistants, and work your way through a visualisation process. At first, you map your current situation: what your interests and talents are. You then elaborate on these using creative thinking strategies. What could your contribution to society be? What are the socially valued roles you would like to take up? Who would you like to invite to your plan? A graphic facilitator records all the information graphically on a big piece of paper. You are always in the lead: the plan will only include what you think is important.

After five months, Fynn became a member of the community garden. Another member of the community garden wanted to share his garden with him. Other gardeners helped to make the garden accessible for Fynn's wheelchair. He also became a member of the library. He doesn't read children's books anymore, but selects beautiful, large books about trees, those with nice big photos in. He became a teacher-assistant in the drama club and a supporter of the sports team of his niece. Now his niece visits him at home very frequently, and her team likes him very much. When a new sports hall was built, they didn't take into account that Fynn also had to sit up in the galleries. Now all supporters join him downstairs when the teams are playing.

Fynn told his story at the project meeting where all social service clients, their families, assistants and support organisations see each other to share their stories, knowledge and dilemmas. Though he couldn't tell it in spoken words, his appearance spoke for itself: he looked right into the audience, smiling. Everyone had assumed Fynn didn't like big groups, or too much noise, or too much attention. But his countenance showed this was far from true: the happiness on his face spoke volumes.



Though he couldn't tell it in spoken words, his appearance spoke for itself

Inclusive agricultural development

Being regarded as real farmers

Ed has shared reflective practice principles that help us to see our true identity, express it, and find ways forward towards an inclusive community. Caroline has emphasised the long-term commitment that lies behind change that truly "rewires the system," from work colleagues, to company, to community and wider society. Anouk complemented this with her description of a co-creative process towards inclusion. This final story about facilitating inclusion comes from Jürgen's work with agricultural extension and innovation. We again see the importance of reflective practice and personal drive (the importance of "me"), as well as co-creation, but here we also review how institutions and society "exclude" and what this means for practitioners who want to support people who dare to change.

> *"you have to invest in people, in the facilitators, over an extended period*

I am really serious, and I learned that this is special

For eight years, I worked with two special colleagues in Zimbabwe to develop our "facilitation for change" approach. In the beginning, we had no clue how to do it. How do you help extension officers become more inclusive and supportive of innovation? We started by just using our common sense.

I grew up on a farm and my father never tolerated anyone looking down upon him. I think this is where I developed the ability to relate to everyone just as they are. This is one of the most basic capacities we need to cultivate and develop as facilitators of inclusive development processes.

When we distilled the essence of the approach that was successful in Zimbabwe, we took it to South Africa. You will read about that in a moment. What surprised us was that we managed to replicate the approach in just two years.

We worked intensively with extension workers: we helped them to reflect on the effects of their actions and to study the social dynamics. There is something very basic about how humans organise. I have taken this approach to many other places in the world and it just works everywhere, again and again. The thing is: you have to invest in people, in the facilitators, over an extended period. Stay away from short-term training interventions.

I also realise that part of the success is related to "me." I now work mainly with senior managers and directors of large public organisations, including pan-African and global organisations, basically using the same approach described below. The other day one of them told me: "You are really serious!" "What do you mean," I asked? "No, you are *really* serious. You really want to help us," he replied. I learned that it is apparently not normal to be serious about social change. I am very serious about it. I want to see communities, organisations, societies deal with unfair situations and progress together. You cannot achieve this if you do not have a deep drive.

Facilitation for change

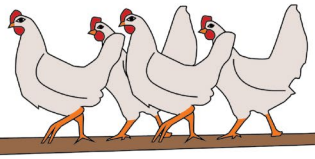
– by Jürgen –

The agriculture extension officers in Limpopo province, South Africa, used to work mainly with a few better-off farmers, while the majority of small farmers were left largely untouched by their services. With the introduction of the process known as "facilitation for change," the many different needs of farmers are now taken into consideration, including those from both small and better-off farms.

Facilitation for change has energised the farmers into starting interest groups. These have come into being because individual farmers felt that they could not tackle the range of issues they face on their own: challenges such as high chicken mortality, low maize yield, soil erosion, and difficulty in accessing inputs and markets. Most farmers in Limpopo have a mixed farming system, so one farmer can belong to several groups, according to their need.

Poultry interest group

An indigenous poultry farmer in Mbahela explains how the poultry group came to be formed: "Chicken mortality rate was very high, with some farmers left with just one or two chickens. We did not know the cause of death. The extension officer, together with the farmers, took one of the dead chickens to a veterinarian for examination. It was then discovered that the disease was New Castle and we were given the proper medication. We then felt that we needed to come together to deal with this problem jointly. When we started we were only nine, but now we are so many."



The interests of individual farmers are now also expressed and heard in the One-Extension Committee: each interest group selects two or more members to be part of this umbrella organisation. In the past, the farmers used to be dependent on the extension officer for providing help. Now, they can link up directly with external service providers through their own elected local leaders. The On-Extension Committee umbrella organisation can connect to agriculture experts, cooperatives and the local government to provide support, advice and assistance for the interest groups.

Another change is that women have also taken the opportunity to take up leadership positions.

"Traditionally, women were not taken seriously when it comes to decision making. Now we have changed, we give them the respect they deserve and we do not mind to be led by them."

– male farmer from Limpopo

Experiments on new farming technologies used to be carried out by outsiders. Farmers were not even asked whether the technology was suitable for their conditions, or if they could afford it. The farmers often did not understand what was done and why it was done. The results of the experiments were not shared with them. Now, farmers have become more self-reliant in solving their problems. They also allow them to plant crops of their choice at the time they think suitable, rather than when set by the extension services.

The changes also benefit the environment. Extension officers encourage the farmers to use organic farming methods, which they (the extension officers) used to regard as primitive. Farmers are also encouraged to practice intercropping, which was earlier discouraged by the extension services.

"That man over there is one of the extension officers who did not allow us to use intercropping, but he has changed."

– Limpopo farmer, pointing out an extension officer in the audience

How facilitation contributed

Because agriculture's challenges are complex they need to be dealt with in a sophisticated manner. This means we aim to enhance people's adaptive capacities and to address all the factors that contribute to their challenges, including those that are social in origin (behaviour and practice), economic (markets and resource mobilisation), ecological (natural resource conservation) and organisational (leadership). We facilitate what is in effect a long, systemic, learning process. The key to facilitation is the successful integration of technical advice and research into a social innovation process that is inclusive of all farmers.

What matters most, however, is how this complex facilitation approach to inclusive development is put into practice.

Facilitation for trust building

In Limpopo, prior to the intervention, only a select number of farmers used to benefit from the extension services, namely those who could afford to buy fertilisers. This created resentment and hostility towards the extension officers, as well as to the minority of farmers who benefitted. One of the farmers who did not belong to any of the extension projects reflects the common perception of these marginalised farmers: "We were not regarded as real farmers, only those in projects were." In the past, not only were few farmers reached by extension but many community development initiatives failed to achieve the desired impact. This has made the communities sceptical and pessimistic about such initiatives. As one farmer observed, "We have seen many projects being introduced, year after year, but what have we benefited from them? – Here we are, we are still poor."

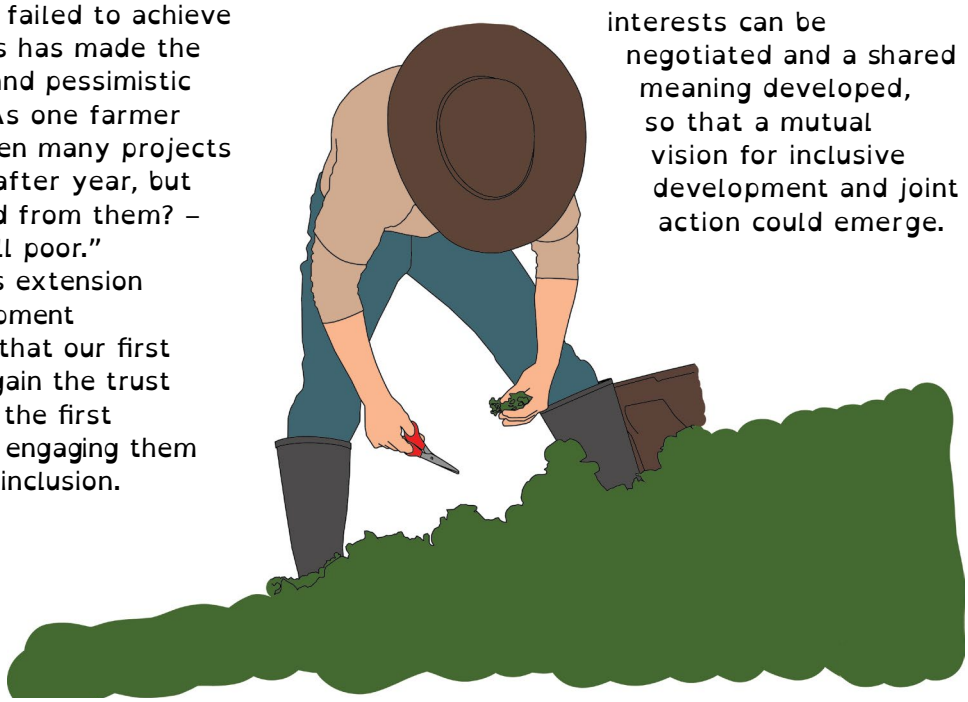
The mistrust towards extension officers and the development initiatives necessitated that our first action should be to (re)gain the trust of the people. This was the first important step towards engaging them in the process of social inclusion.

> *"We were not regarded as real farmers, only those in projects were.*

The challenge was to find ways of convincing the communities that the new approach is somehow different – and to convince the extension officers that they have to change their attitude towards the farmers who are marginalised, so that they can begin to work with everybody in a more inclusive manner.

Facilitation for an inclusive development vision

Once a certain level of trust had been achieved, the farmers were then helped to acquire a new sense of direction and orientation. We supported the gradual development of a joint vision: imagining how change can be brought about. It is a vision about what inclusive development means. This process was also about what the different actors might do differently. Through critical questioning, probing, discussion and the use of a range of facilitation tools, their divergent views were explored and (controversial) perspectives debated. This process produces a "constructive controversy," in which the different interests can be negotiated and a shared meaning developed, so that a mutual vision for inclusive development and joint action could emerge.



Facilitation for self-organisation

The backbone of the change process is to mobilise the energy of the local people to collectively organise and take action to address the broader development challenges they are faced with. The emphasis on "self-organising" is critical here, as this helps to ensure that process is oriented to making things happen (actions) rather than to thinking about what should happen (planning). The emphasis of this process is not focused on creating the structure of the organisation, but towards building the foundations upon which the organisation will be based, from where it will take action. There are two critical facilitation processes here:

- **Facilitation for differentiation** – A community is not a homogenous entity, but comprises various social units with different and sometimes conflicting perspectives, values, and interests. The interests of men and the rich often dominate, and the voices of the women (despite their large numbers), the poor, and youth remain largely unheard. When we consciously make their social exclusion a topic of discussion, this creates the foundations from which these issues can be debated, and from which the ways forward can be found.
  The different interests of the farmers, based on the challenges they faced, became the basis for creating local organisations. This gave the different social groups their individual space in which to freely express and discuss their perspectives on these issues, something which they would be more reluctant to do in the wider community. The interest groups enabled them to explore the nature of the social exclusion they face, and the causes and the consequences of that exclusion for them. With facilitation, people can analyse what helps them work better together and what impedes this. This awareness can help trigger the energy required to deal with the issues they face – and for them to do so in their own way.

> *The capacity to self-organise is evident in African societies.*

- **Facilitation for group formation** – The capacity to self-organise is evident in African societies. People organise for funerals, weddings and other events. With facilitation, people can draw lessons about the patterns of successful and unsuccessful forms of organisation. Agricultural development organisations are often male dominated and dysfunctional. The structures of these organisations are analysed, and a space for strengthening them, or for forming new ones better geared towards dealing with different interests of farmers, negotiated. The choice of whether to strengthen the existing organisations or to form new ones is based on deep analysis by the farmers. Often those with similar interests choose to come together to form a new group, as in the case of the poultry interest group (see box above).

Facilitation for leadership to emerge

Traditionally, the selection of leadership is often based on politics, ethnicity, personal relations or status, rather than the individual's leadership qualities and record of action. In many cases the leaders hold multiple positions. This may lead to them dominating a community. Over the centuries, rural communities have developed complex systems of norms and values: these have become so "normal" that people are not even aware of them. Modern society and its values may contradict or challenge these traditional ways of doing things, and this often creates serious conflicts that affect participation and cooperation. This is often the underlying cause of why many situations become "politicised," where all is seen in the light of who says what or does what.

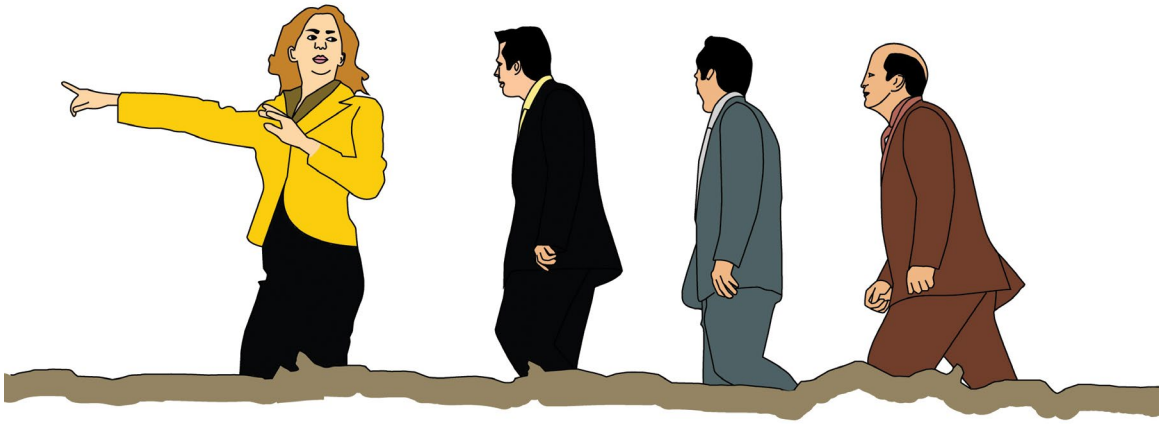
Facilitation can make a significant contribution by challenging people to depoliticise issues, engaging them in negotiation processes where they focus on tasks, roles and functions, rather than on the individuals and their ethnic group or political affiliation. The basic principle for process design is that "who should do it, comes last." Left without facilitation, people often first address who should do it and then the structure for doing it – and only then look at what needs to be done! Facilitation can depoliticise this by taking people, one very small step at a time, through the process required to tackle an issue, starting from "what do we want to achieve?" then moving to "how do we achieve it?" and "how do we organise ourselves?" to "what capacity do we require?" before finally addressing "what functions do we require to make it work?"

> *The goal is to use facilitation to unblock the debate and enable dialogue and negotiation to take place.*

Only when the criteria and terms of reference for the positions and functions are clear and transparent – including the criteria for how to remove people/leaders if they do not perform – should you then address the "who should do it?" question. This approach can help people to accept each other in their roles in the group, irrespective of who they are and where they come from, as long as they meet the criteria and can contribute to the common vision.

Women in leadership roles

In many rural communities, women are not supposed to be leaders. In Limpopo province, women were not allowed in the chief's kraal, the highest decision-making body in the village. Yet modern society (and government policy) promotes equity and a move towards more women in leadership roles. Facilitation for change can help people to analyse the origins and impact of the issues, taboos and power structures that block women from taking up leadership roles. The goal is to use facilitation to unblock the debate and enable dialogue and negotiation to take place. In the process, new norms and values (such as unity, inclusion, learning through self-reflection, sharing, trying) were created by the different interest groups. This has resulted in men accepting women in leadership roles.



Facilitation for ownership and creative self-reliance

Earlier, the extension officers used to use a supply-driven, top-down approach, addressing the needs of a small number of farmers, who were expected to more-or-less blindly follow their instructions. The smallholder farmers assumed a passive role and, as a result, were excluded from the mainstream economy. They felt they were "victims" in this situation. Behind such behaviour we can observe common cultural patterns, including "the culture of silence," "the blame culture" and the "wait and see culture," all of which suppress people's potentials and strengths, and hinder development efforts.

Facilitation is about unearthing and breaking these patterns and challenging people to realise that the solutions to the community's problems lie within the community itself. To achieve this, examples are analysed, and patterns explored.

Sometimes, the facilitators need to take a provocative stand in order to challenge what remains unspoken. During the course of the facilitation, the patterns that begin to emerge reveal themselves to be detrimental to the wellbeing of the community. People start to explore how they can escape from this trap and to discover their "sources of power" to change things.

> *Encourage people to see opportunities instead of finding reasons why things cannot work or why they cannot do things.*

Taking a provocative stand

When people say they feel like the victims of a situation, the facilitator challenges them: how does it feel to be a victim, does it feel good? Does it make you proud? Does having good excuses for your situation make you feel proud? Then what does make you proud?

So . . . if all these issues were not there, what would be different?

In a problem-focused development approach, "a problem" is often seen as a stumbling block, with very little that one can do to overcome it. This blocks people's ability to think clearly and reduces their positive energy. Facilitation focuses on stimulating people's thinking in a solution-based manner. Encourage people to see opportunities instead of finding reasons why things cannot work or why they cannot do things. Looking for opportunities makes people more creative and entrepreneurial in trying to seek out alternatives and potential solutions.

Facilitation for horizontal learning *and* vertical connection

Top-down approaches to agricultural extension do not take into account the farmer's ideas and solutions. Yet each community has innovators, people who have the curiosity to try out new ideas based on their own knowledge and own resources. Many development practitioners are advocates of recognising and utilising the innovations and knowledge of such farmers in order to ensure the sustainability of agriculture.

The facilitator needs to find ways to identify these innovators and to support them in exposing their innovations to the broader community. Once again, first building trust is essential because innovators do things that are not in the mainstream, and their practices are not always accepted locally.

For instance, in Limpopo, the innovations the innovator farmers introduced were regarded by many as "primitive." This made the innovative farmers uncomfortable with sharing their experiences freely. In this circumstance, the challenge for the extension officers was to show genuine interest and to express their desire to learn from the farmers' experiences.

Developing an *innovation system*, in which people can learn and respond freely, depends on ensuring successful collaboration between the different actors involved. This includes those who share an interest within the group, as well as those from other groups, those from outside the community, and experts. The goal should be to create a platform where the different actors can come together, negotiate their interests, and learn to collaborate. Achieving this was one of the success factors in Limpopo province.

The process is to first identify whether or not there is a need to link up in this manner, and to then identify relevant actors and bring them together. They should then be allowed to negotiate their interests and helped to establish a common goal. From the outset, the platform should provide the actors with clearly defined benefits and roles. With this level of clarity, each of the actors will learn along the way to make the innovation system work for them.

Mrs Mulaudzi of Mbahela explains her zero-grazing innovation

"I started practicing goat zero-grazing before 1998. When I started I only had two goats, which I kept in my kitchen. No one in the village knew about my practice because I was hiding it from them because I did not want to be called names. In 1999, an extension officer who was walking around the village identifying local innovators and innovations spotted me and wanted to know more about what I was doing and why I was doing it. At first, I did not trust him, so I did not open up to him, but after a while I realised that he was well meaning and I then developed trust and was free to share with him.

"The extension officer then encouraged me to build a kraal outside my house. This helped to free up my kitchen. I feed my goats with green Napier grass and legumes, which I get from my fellow farmers, and use the maize bran that remains after milling my maize, as a supplement. I make sure that I feed my goats twice a day and give them water to drink in the evenings. I mix the local herbs with water to treat their internal parasites. Now I feel free to share my experience with other farmers, and I am happy to know that there is another farmer in our village who has also started practicing zero grazing as well."

Facilitation for feedback and reflection

The "culture of silence" is prominent in rural communities. People tend not to challenge things even when they see that they are detrimental to the individual or the community's development. It is normal to think in terms of "*either you are for me or against me.*" What is lacking is a third way of engaging without dividing. Facilitation for change can challenge this in a subtle manner by promoting openness and transparency, both of which are fundamental to constructive criticism, shared responsibility, and promoting social inclusion. In a culture of feedback, sharing and reflection, it is normal for people to ask why certain things are happening the way they are, in order to get to the crux of the problems. This is core in helping people to differentiate between facts and personal attacks. The feedback culture creates space for individuals to use their potential to move forward.

The deeper meaning of facilitation in this chapter

"We are inclined to think of reflection as something quiet and personal. My argument here is that reflection is action-oriented, social and political. Its 'product' is praxis (informed, committed action), the most eloquent and socially significant form of human action."

– Stephen Kemmis

Facilitation plays an important role in triggering the process of social inclusion. Its deeper meaning is often underestimated. In the context of inclusive development, facilitation is a means for stimulating fundamental change in individuals, organisations, communities and societies. This kind of facilitation is inspired by action learning and organisational change theories (Argyris and Schön, 1974; Schein, 1992); systemic approaches (Bateson 1972, Senge, 1990; Midgley, 2002) as well as training for transformation (Hope and Timel, 1984).

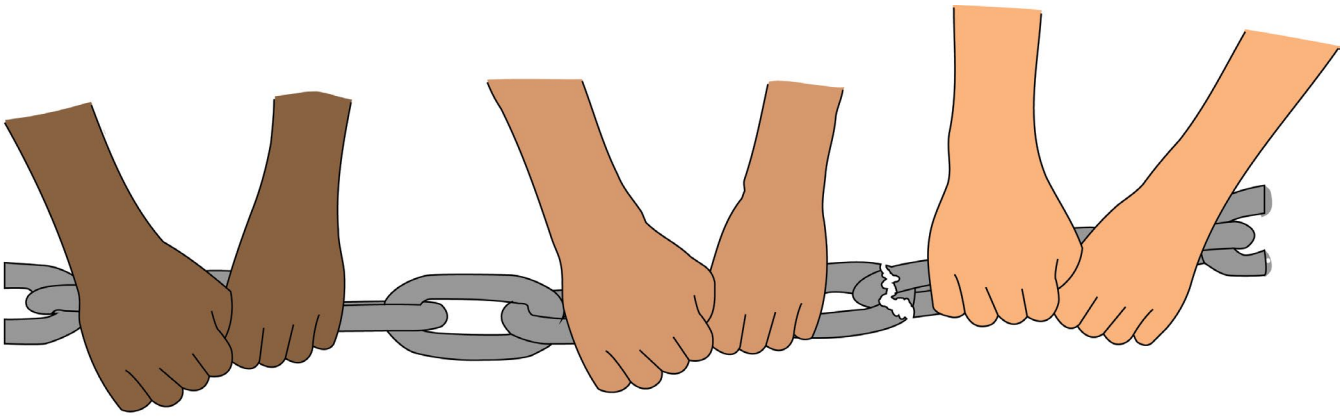
This chapter has highlighted the dimension of inclusion in these facilitation theories. The dynamics in society means that some people are left out, and feel left out. The risk is that those so excluded can lose hope, isolate themselves, and lead unproductive, or angry and violent lives. In order to accompany people who dare to change, it is not enough to create an "enabling environment" – you have to be fully present to them in their journey. This requires looking deep within yourself first, before you can accompany others on their, often painful, path to reconnect to hope.

People with intellectual disabilities will need ongoing accompaniment throughout their working life, and this calls for a long-term, personal commitment.

What motivates *you*? Perhaps you deeply want to see communities, organisations, societies deal with unfair situations and desire to co-create progress. What drives you to accompany others on the long path to a more inclusive society?

In all the stories in this chapter, marginalised people have been given space to express their identity and to discuss their issues. This is all about strengthening people's confidence through action, in their own sphere, where they know something, and can do things. The crux is in making people feel proud again, believing that they can do things and can be successful: that they are needed and necessary. This is the "point of return," where the hurdles to be crossed start to become lower and lower with each little success: it is then that people dare to tackle the bigger hurdles and start to feel competent to do so.

One common challenge in helping others regain confidence in this way, is that, once the person has tasted the feeling of success, they can overreach themselves, tackling a hurdle that is still too high for their present capabilities – they then end up terribly disappointed. Managing their disappointment is a critical part of managing their "staircase of confidence."



An inclusive facilitation practice can unearth and break the patterns of exclusion – by helping people to make progress together and by helping them to recognise and make the most of their diversity. To be effective in this requires a critical perspective on oneself: do you have the openness and boldness to really look at your intervention honestly, without just wanting to look good (to yourself or others) or to do good? It's this depth of honesty which enables the writers in this chapter to really challenge themselves and, ultimately, to go deep enough to help find the ideas and solutions to the situations that exclude.

Though the short-termism of the present environment works against such longer-term investment in developing deeply reflective practitioners, we need to have the courage to keep working on this together. The tide will turn eventually, and when it does, we will be ready to support ever more inclusive development practitioners.

What it takes

Seeing people as they are
With dreams
And beliefs
That make them get stuck

Exclusion is painful
Builds a wall
A safe place in your mind
A hopeless place

Rediscovering hope
Means living through
That pain again

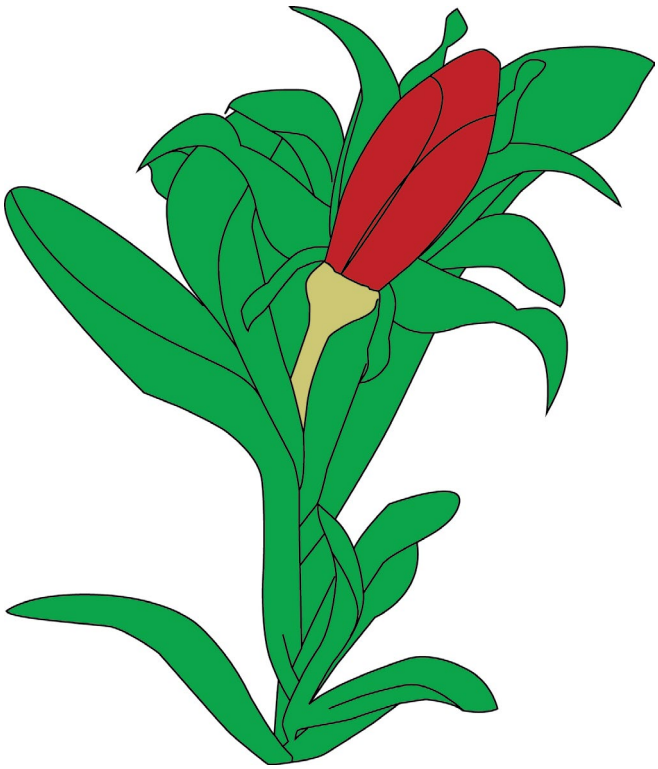
What we can do
Is seeing the human beings
The societies
We are part of

This is who we are

The thing to do
Is to be quiet
To let the pain come
So that the healing can begin

This is not who we want to be

– by Lucia



PERSONAL STORY 8

Tomorrow's Freedom of Information

Using language as a tool for inclusion

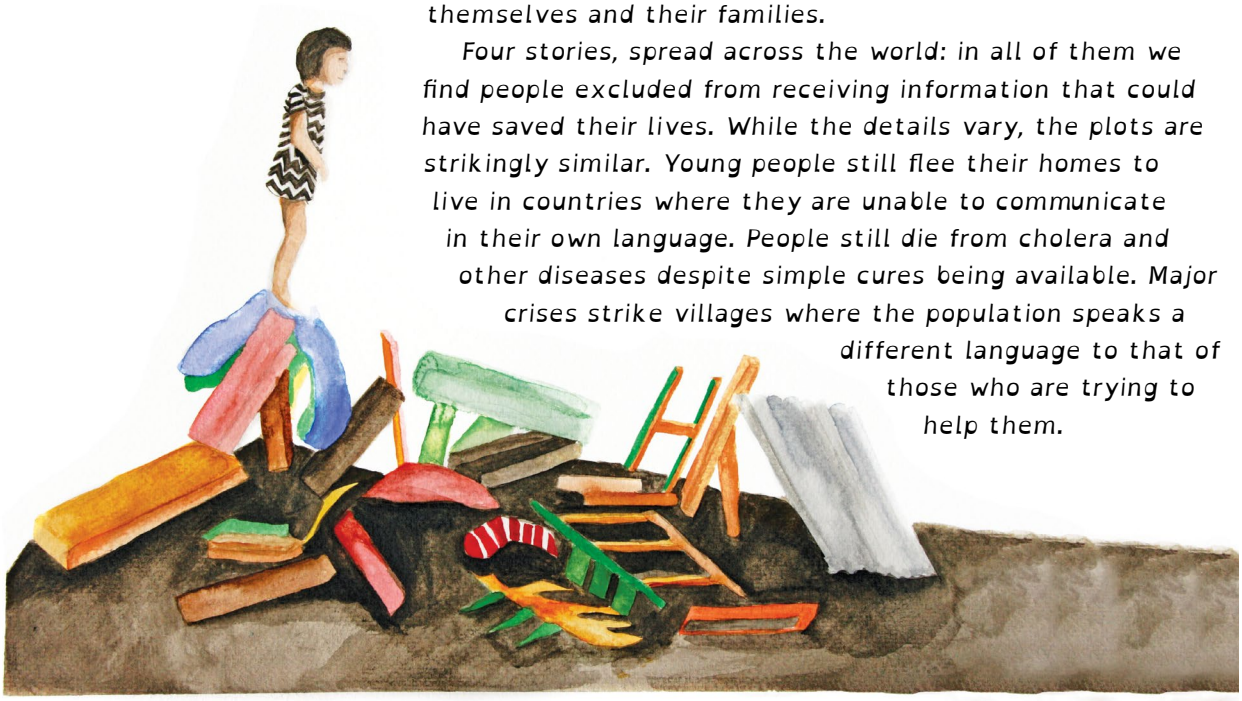
– by Rebecca, Translators without Borders –

Yesterday, I heard a difficult story from a teacher in Greece. A refugee student of hers accidentally swallowed a pin from her headscarf. She felt panicked and very scared – the teacher could see that from her face. She needed to get help, but she could not explain what had happened: she spoke Dari and the teacher spoke Greek. It took hours to sort out the problem.

Meanwhile, in Yemen, cholera has taken hold. More than 250,000 cases this year, 1,500 deaths so far, and climbing. The disease continues to spread, despite volumes of available information about how to prevent and cure it. A leading doctor at the World Health Organisation said to me that part of the problem is that people do not understand that cholera is the same thing as the persistent diarrhoea they are experiencing. This lack of understanding is deadly.

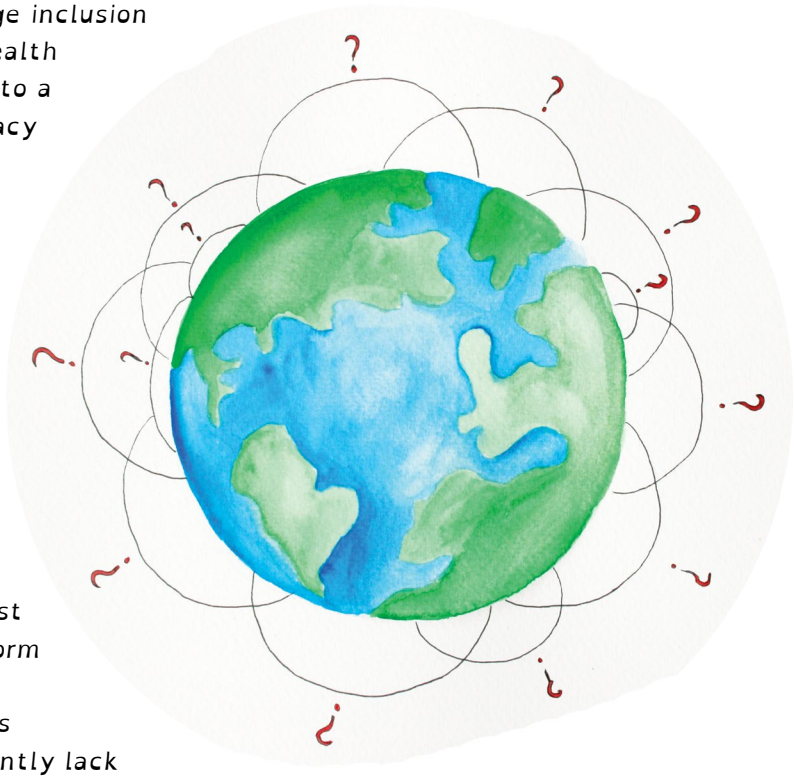
This reminded me of what happened in West Africa in 2014-15, when the region faced the worst-ever Ebola epidemic. More than 10,000 people died in that epidemic. It ravaged the families and long-term health of many, and it destroyed the nascent health systems of three countries. Yet, with better information in the right languages, so much could have been saved. As Claudia Evers, the Médecins sans Frontières Ebola Emergency Coordinator for Guinea, said, "If people had been given proper messages, all this could have been prevented."

In late 2013, Typhoon Haiyan slammed into the Philippines, killing thousands and devastating homes across southeast Asia. Despite warnings of the danger, many people did not leave the coast. Why, rescuers asked, had people not left their homes? Days later, reports came in that one English-language news report had warned of a "big wave" rather than a typhoon. Tagalog, Waray and Cebuano speakers simply did not make the connection of this to the advent of a major typhoon and stayed at home, thereby endangering themselves and their families.



Four stories, spread across the world: in all of them we find people excluded from receiving information that could have saved their lives. While the details vary, the plots are strikingly similar. Young people still flee their homes to live in countries where they are unable to communicate in their own language. People still die from cholera and other diseases despite simple cures being available. Major crises strike villages where the population speaks a different language to that of those who are trying to help them.

Disenfranchisement: language is today one of the major issues of inclusion in humanitarian response. The commonality across these stories is the lack of free access to trusted information in languages understood by millions, or billions, of people. The reasons for this lack of language inclusion run from the inability to get health information into remote areas, to a lack of education and low literacy rates, to minimal access to technology, to pure lack of incentives or will to provide information in marginalised languages. Whatever the reasons, those who do not receive understandable information lack the power to solve their own problems. They rely on the goodwill of others who have access to information, or the good fortune that someone they trust provides the information in a form they can understand.



What happens if we give this power to the billions who currently lack it? We know that the power of language has been shown time and again to increase engagement and understanding. We know through our work that simple information in mother-tongue languages is much more likely to be understood. We also know that education in the mother tongue at an early age increases attendance at school and improves outcomes. And we know that understandable information is empowering. As Jessica Lomelin of Plan International commented after the Ebola crisis, "The need to communicate in local languages is not just about delivery of information but . . . is an emotional tool: having the ability to speak comfortably in your local native language is key. It's at the heart of communicating with communities."

Translating and interpreting from one language to another is costly, unless it is coupled with technology. Ultimately, we need to use language technology to unlock the vaults of information available in the major commercial languages. Technology is dramatically improving machine translation among most European languages, and even into Arabic from French or German. The promise of neural machine translation, using a new computer architecture that enables machines to learn, is exciting, especially for the major companies who rely on machine translation.

"Throughout human history, language has been a barrier to communication. It's amazing . . . we get to live in a time when technology can change that. Understanding someone's language brings you closer to them, and I'm looking forward to making universal translation a reality."

– Mark Zuckerberg

The day when automatic translation will also become reality for the billions of people whose languages are not commercially important is still a fair way off. Neural machine translation requires massive parallel data sets: even statistical machine translation requires upwards of a million strings to create a viable engine. This amount of data does not yet exist in many languages. But the promise of building it, thereby allowing a Hausa or Somali speaker to actually translate the information they want and need – either in text or audio – would be a game-changer in humanitarian response. It would empower, truly putting the community in control. With commitments from major technology developers, such as Facebook, Google and Microsoft, we can get there.

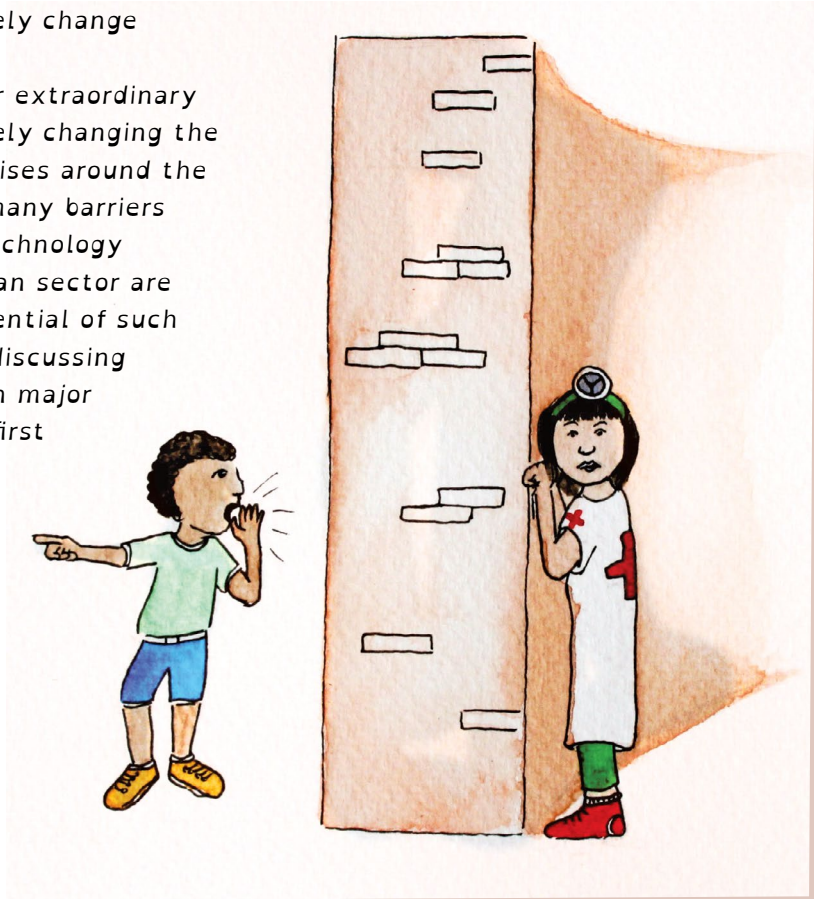
Language access to information opens up an entire world, not just with regard to basic health and protection information, but for online education, for providing medical information in remote areas, and the cultural information that enriches lives. This is especially true for illiterate populations, who are disproportionately women. It would also allow developers to create apps specifically designed for refugees living in camps, giving them access in their own languages to vital cash, food and work possibilities.

Access to information is not the only answer. True language inclusion also means ensuring that we also listen, in the right language. Too often humanitarian response is designed and executed without direct participation from the affected population. There are mechanisms in development to get feedback from affected populations, but rarely are those who speak marginalised languages included in controlling or influencing the international response.

Again, technology is at the core of better listening and the sharing of ideas across languages. In the major "world languages," people can now speak on a conference call in Spanish and immediately be understood by English colleagues. Bringing these kinds of technologies to marginalised languages and crisis relief would be revolutionary, with the potential to completely change humanitarian response.

Language technologies offer extraordinary promise for inclusion, completely changing the way we react to all kinds of crises around the globe. Though there are still many barriers to making this a reality, big technology companies and the humanitarian sector are both beginning to see the potential of such technology. They are already discussing how to create open datasets in major marginalised languages, a big first step to developing better language tools.

Information is the great equaliser. To reach true inclusion for billions of people, we must break down the language barriers that reduce the flow of information to and from the people who need it.



Tips for more inclusive communication

Know your audience – *Are they literate, educated, proficient in dominant languages? Does their ability to communicate vary with age, gender or socio-economic standing? These questions should be answered before any content is created. If you don't know the answers, find out!*

Simplify your source text and create terminologies in target languages – *One hundred words of simplified text in Hausa, for example, will go much further than detailed explanations in English. If the target language does not have a way to properly describe an important concept that you use repeatedly in English (e.g., gender-based violence), it will not be translated properly and different translators will translate it differently. Simplifying the source text will eliminate most problems. Glossaries and terminologies in the target languages are key to improving translation and increasing consistency: they are also useful for field staff in crisis situations.*

Listen and respond – *Even if you communicate effectively, you may find the target audience needs have changed, the content is not useful, or they are getting other contradictory information. Monitoring of in-language public messages, through traditional media, SMS or social media, can provide a useful picture of the current situation that cannot be assessed using the main (dominant) response language. In Greece, monitoring of Arabic and Farsi communication during the refugee crisis in 2015 revealed that there was deep confusion in terms of what comprised a "boat," a "raft," or a "ferry."*

Consider transcreation or locally produced content – *Often even the best translations do not convey the same meaning or emotion as the original text. Transcreation is the process of creating content in another language that is focused on the same meaning, even if the text is completely different from the original. When the goal encompasses behavioural change or that of conveying very difficult messages, transcreation is a good alternative. You might also find that the message you want to convey exists in locally produced content, or even in an art form. Working with these kinds of content can improve inclusion.*

Provide interpreter training – *In many humanitarian response situations there is a severe lack of language help, especially of interpreters, who are often the most important "messengers" for people in need. Too often, an untrained staff person or volunteer is pulled in to assist. Giving an untrained interpreter or cultural mediator a bit of training, or even some simple resources, can make a big difference.*

Embrace language technology – *Ultimately, language technology will open doors for billions of people. We must create more content in more marginalised languages, making it possible to increase language data in those languages. Ensuring your content is open access will enable machine translation engines to make a good start.*

Postscript:

This *Barefoot Guide* and inclusive language

As an Editorial Team, we discussed how we could make this guide inclusive – after all, we also need to walk the talk! We have always encouraged translations into other languages but this time we wanted to go further.

We got in touch with Translators without Borders (TWB) and started to discuss this. They suggested editing the guide so that it would be easily translatable and more accessible for those for whom English is not their first language. They also offered to do audio versions in English and in other languages.

"Sounds great!" we said, but can we see an example of this first? We gave them a chapter to work on. When they sent it back, we were shocked. The metaphors and poetry that we felt was such an important part of the *Barefoot Guides* were gone. For us, it felt a bit like reading a textbook.

How could we keep the richness of the stories and the ideas and still be accessible? We went back to TWB. They asked, "Where do you want to be on the line between a simple technical handbook and a novel?"

Good question: we explained why the stories and the variety of voices are so important to us. We talked about how we want to produce something that is more than a toolkit. We want readers to learn by engaging with the stories and the metaphors. We want the different voices to be heard.

We also recognise that there is a tension between what we want and something that is easy for non-native speakers to read and translate. Truly accessible English is simple English.

So, we decided to keep our "original" version *and* to also produce a plain English version that is more easily translatable, in that it has fewer of the metaphors and idioms that might be difficult for everyone to understand. We will also produce some translated versions to start us off (translation and layout costs money – so, if you are interested in having the guide in your language and can fund this, please do get in touch!) as well as audio versions in English and two other languages.

Is it a perfect solution? No. Is it a start? Yes.

What have we learnt?

We need to think about accessibility and language right from the start when developing guides. And we must recognise the tension between the kind of language we think inspires and the type of language that is easily accessible and translatable. We need to keep challenging ourselves to do better – and we will.

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Mission Inclusion

Stories and practices of building a world where all belong

Many
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Include
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CHAPTER 2

Rewire the System

Changing the rules for inclusion

CHAPTER 3

Heal the Wings and Learn to Fly

Improving social accountability for better access to services

CHAPTER 4

WALK THE TALK

Striving for inclusive organisations

CHAPTER 5

WALKING ALONGSIDE

Supporting people to dare to change

The Barefoot Guide
Connection
Transforming ourselves... Transforming the world