

## 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



## 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<sup>1</sup> 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.





## 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

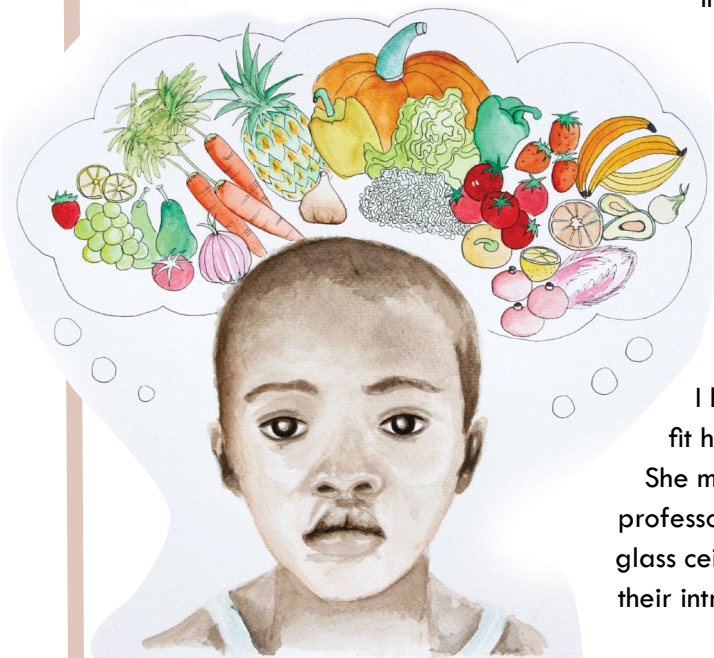
in Geneva who has never been to Kenya. I


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.

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.



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



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". Mmmm! 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.

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.

*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.*



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."

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. Embracing 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*

## 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.”



## 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

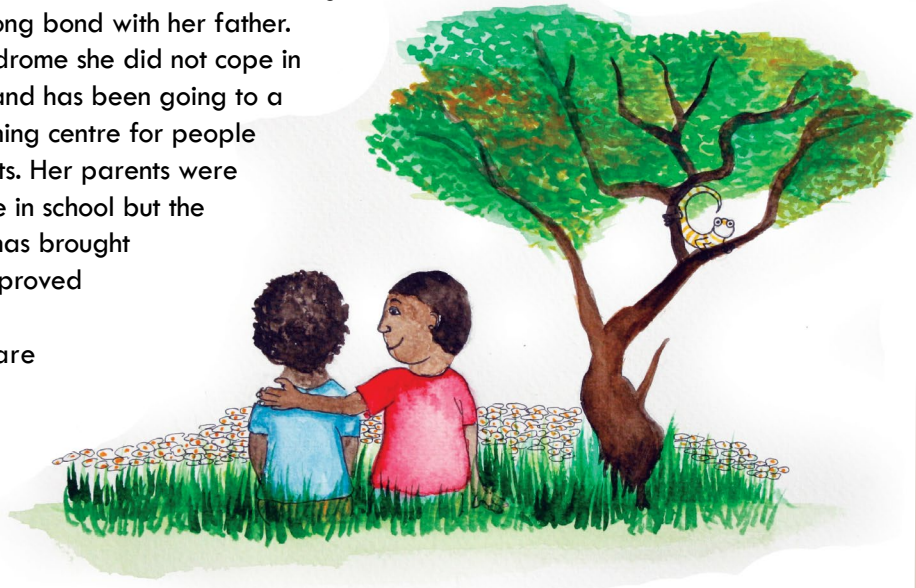
protect herself from strange

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 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.

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.



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





### 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.*



## 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.”

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!’”

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

## 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 LGBTQI accepted.”





Anan laughs at the memory: “My parents called me and asked why I was going to a conference in Manila 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.

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.”

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

### **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\\_lv3xA](https://www.youtube.com/watch?v=GGUiy_lv3xA) to see a video of a shadow play about the life of a transgender person in the Lao PDR.

[www.facebook.com/proudtobeuslaos](http://www.facebook.com/proudtobeuslaos)

## 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.

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.

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



## 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."

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.

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



## 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

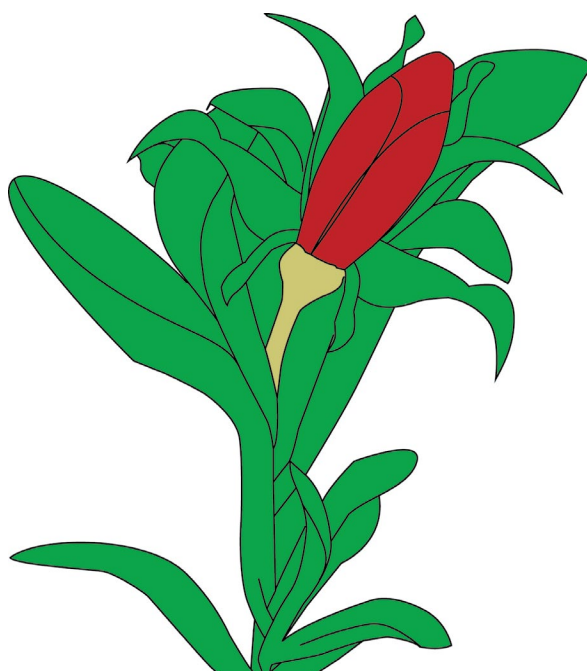
What we can do  
Is seeing the human beings  
The societies  
We are part of

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*



## 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.

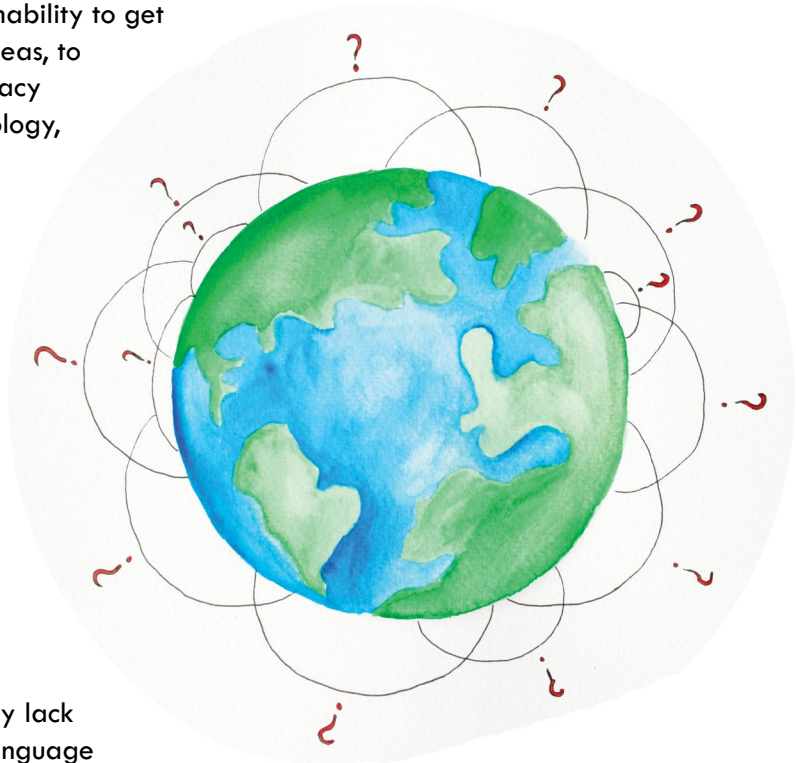
This reminded me of what happened in West Africa in 2014-15, when the region faced the worst-ever Ebola epidemic. More than 10,000 people died in that epidemic. It ravaged the families and long-term health of many, and it destroyed the nascent health systems of three countries. Yet, with better information 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.

