

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

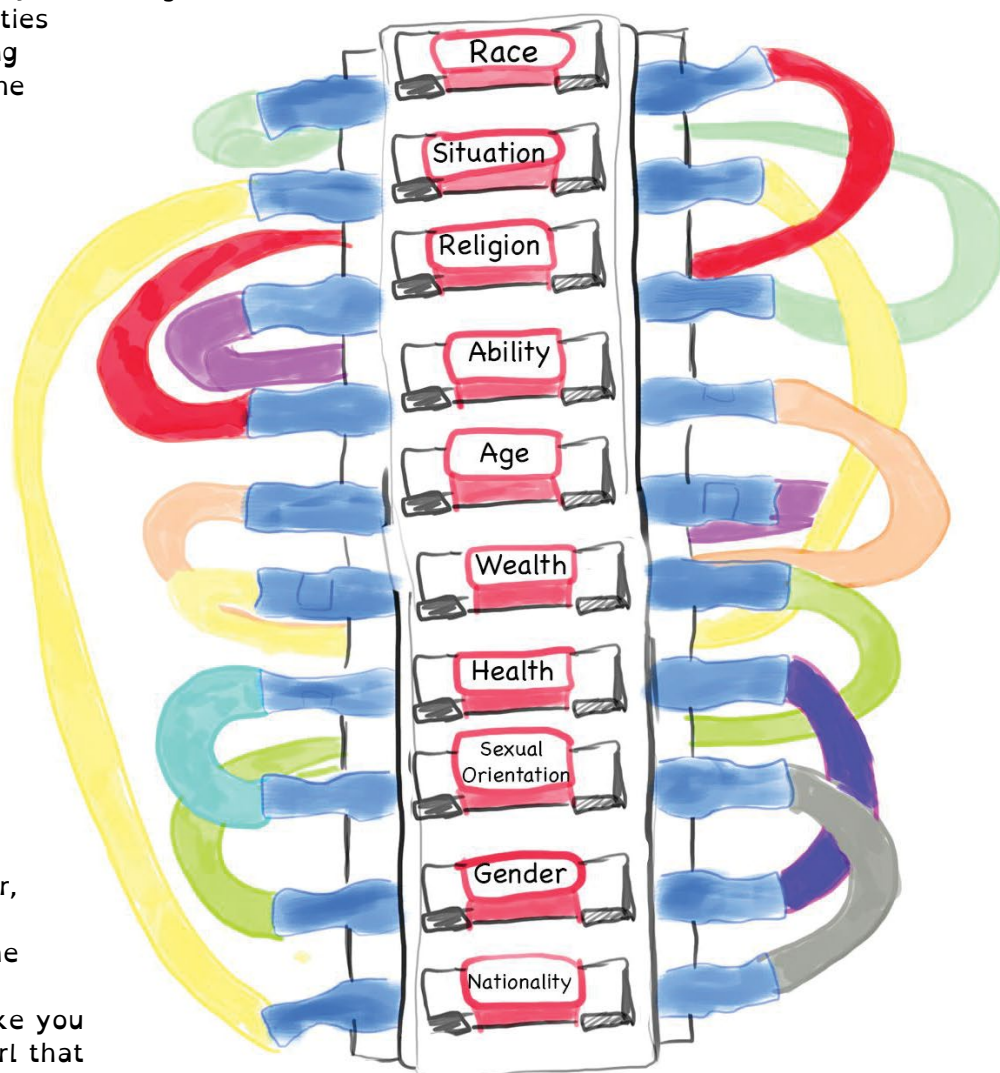
What does your life look like at this very moment? What will life have in store for you?

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.



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.

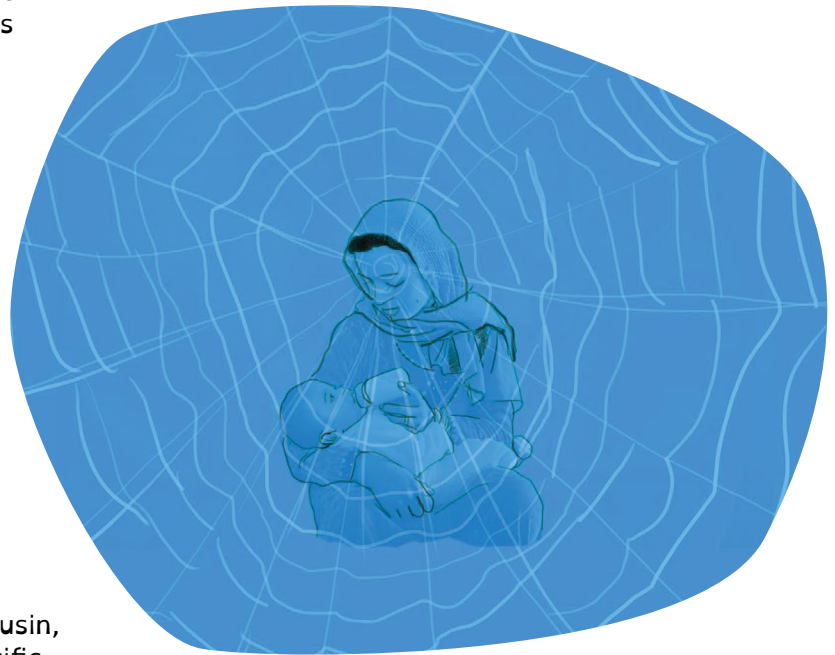
I invite you to read Fatima's story and follow her journey through the challenges she faces from discriminatory systems, and the impact that these have on her and her baby.

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.

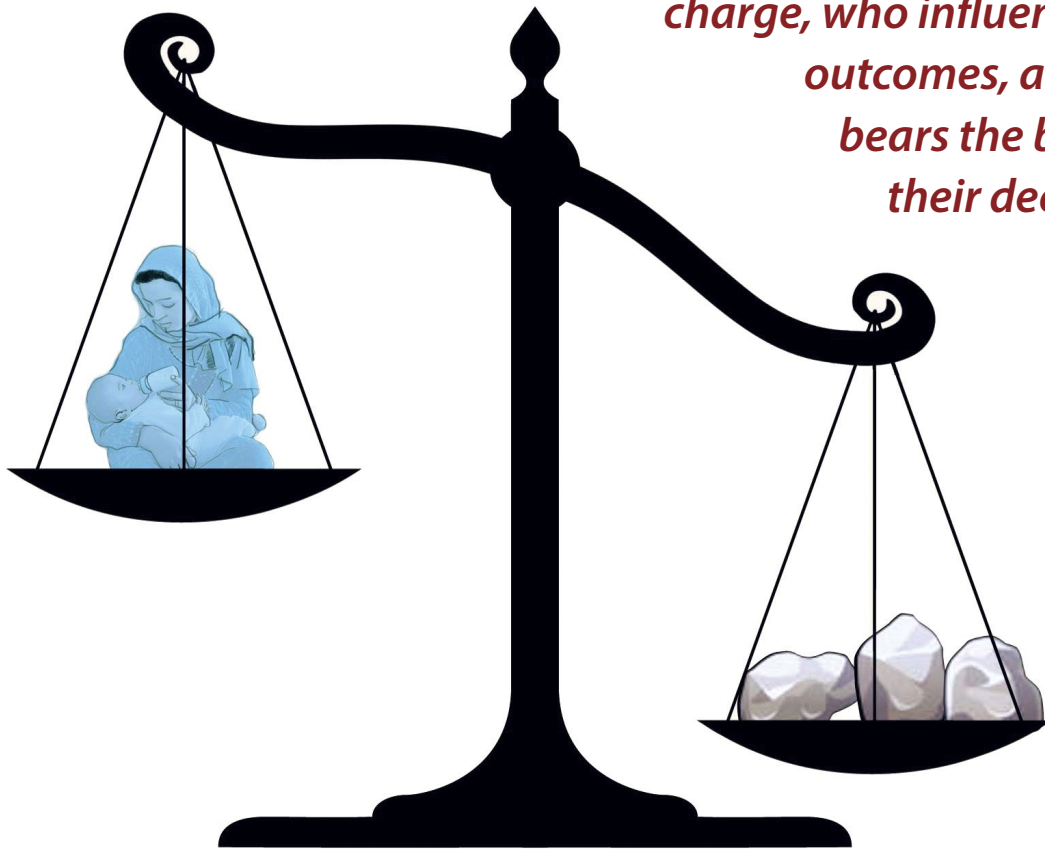
We see in the course of work that the macro-systems in Lebanon (a state which is neither signatory to the 1954 Convention on the Status of Stateless Persons nor the 1961 Convention on the Reduction of Statelessness) have a direct effect on the statelessness individuals and their families. Unfortunately, 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.



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

Pablo Picasso.

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

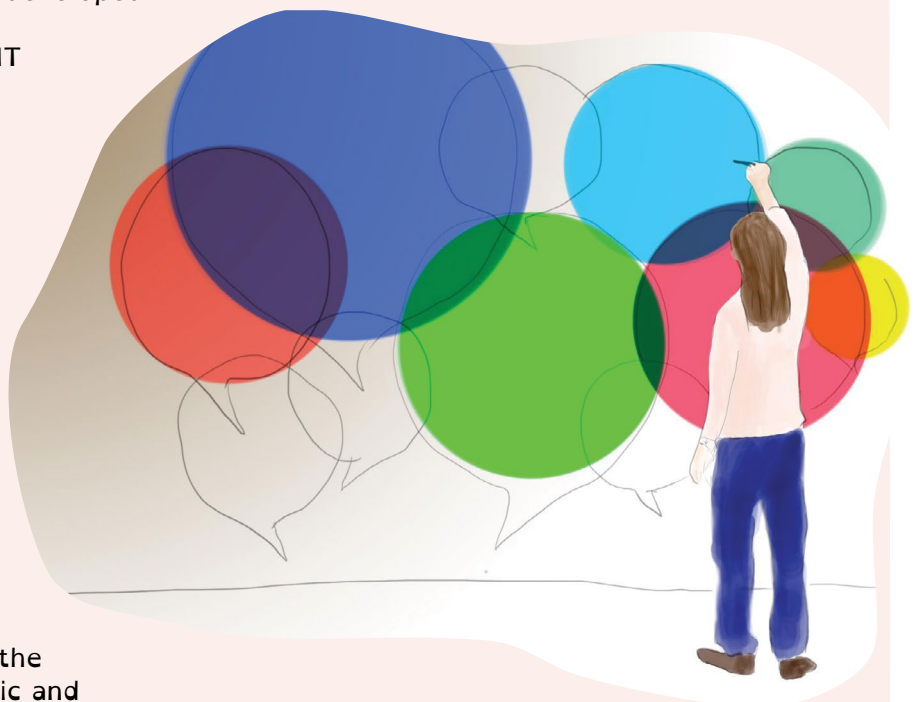
The absence of Fatima's father has a major impact on her life and that of her daughter: his absence is the direct cause of their facing the experience of social exclusion. The Lebanese system, especially the legislative framework (along with a number of other areas), firstly impedes their registration 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 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

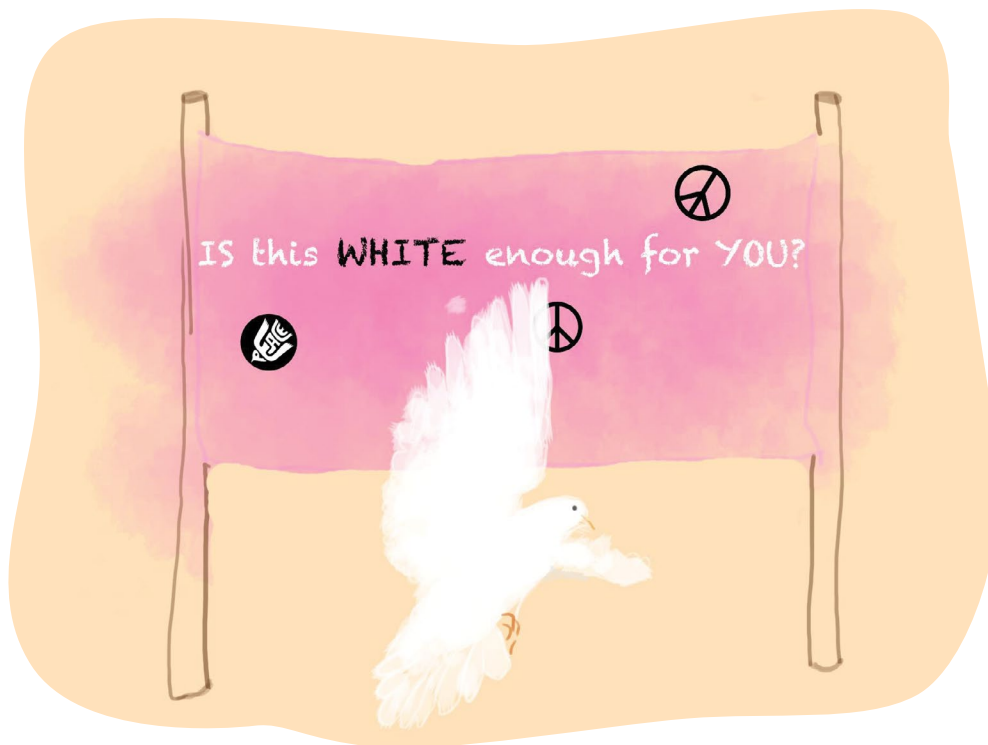
You may not always be conscious of this, but you are yourself living in a world where many systems contribute to and influence the way you live. Each and every individual on this planet is placed within a socio-ecological system. You might find yourself at the centre of an effectively functioning constellation 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?



When society is able to see the capacity of people instead of the disabilities it will flourish...



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?"



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

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."

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.”

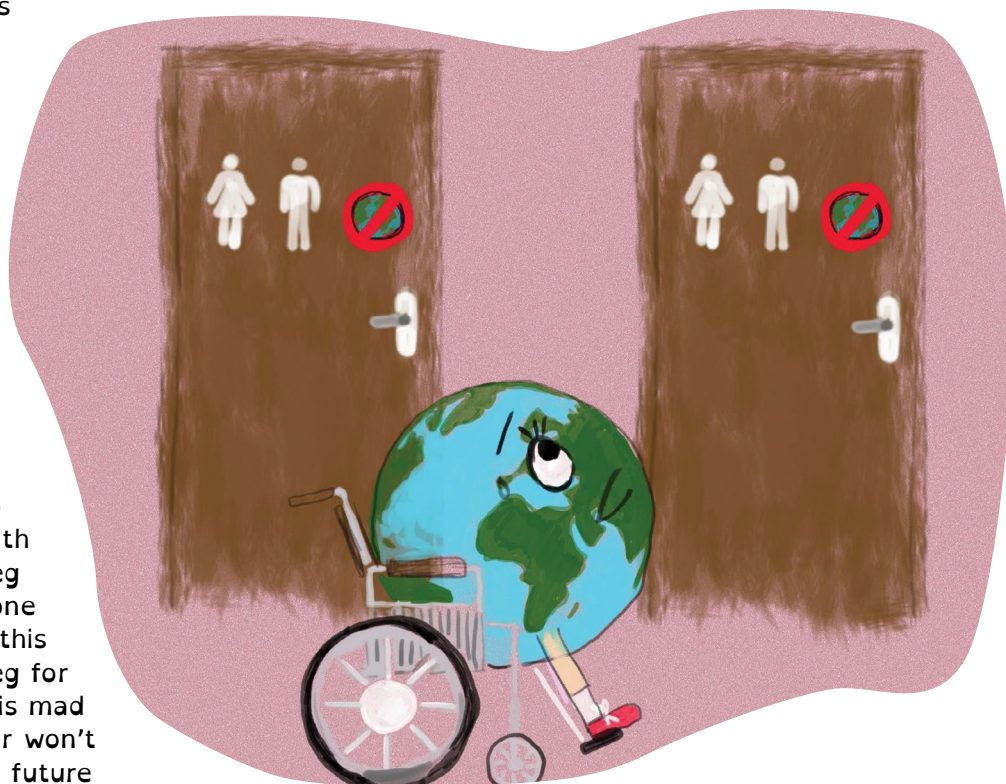
– Audre Lorde

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.

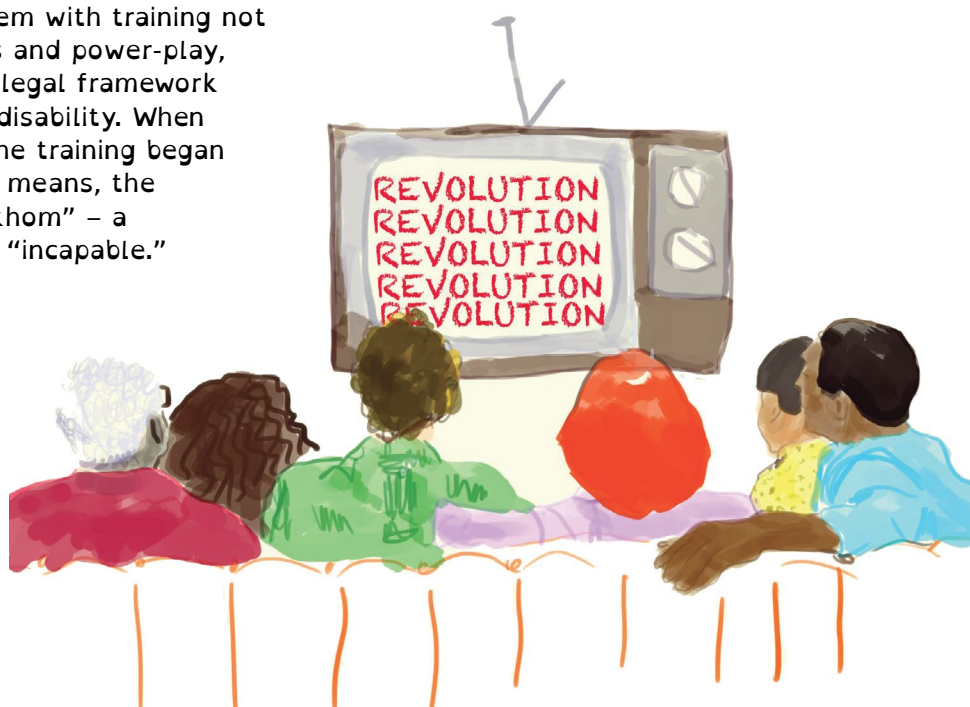
In order to find schools that were both prepared to enrol Imran and were suited to his needs, we reached out to the Disabled People's Organisations (DPOs). The director of one such DPO observed, "But he doesn't have a psychosocial disability." He took out a copy of the law and read out loud: "Psychosocial 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.

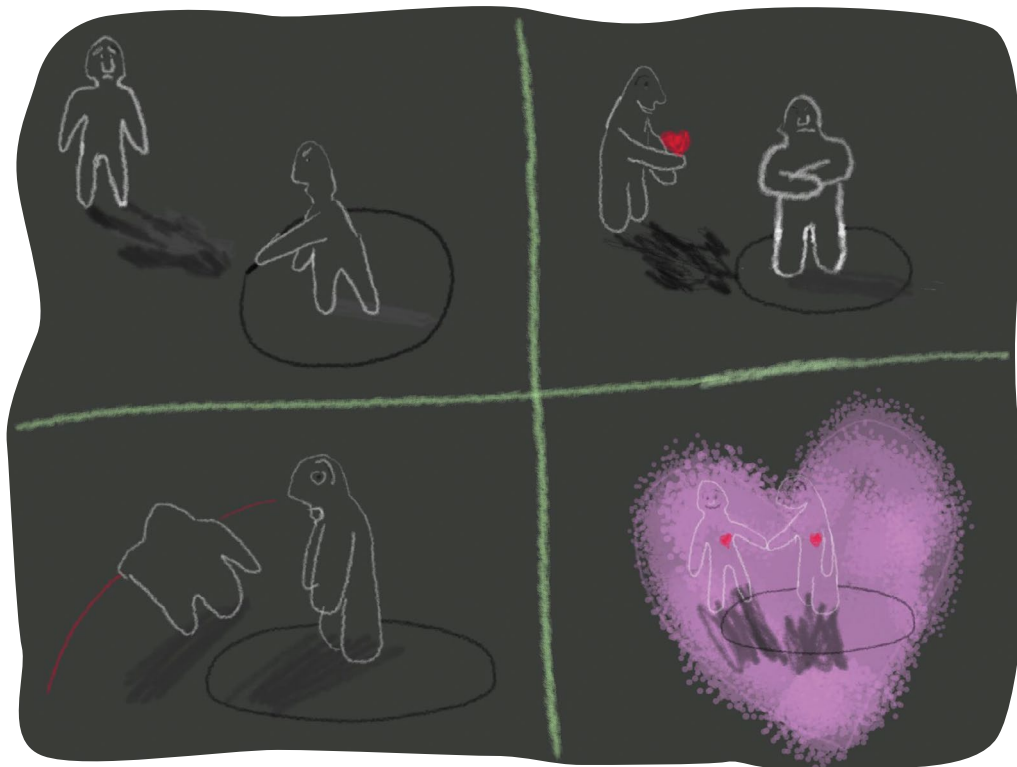
My colleagues and I wished to promote a social definition of disability. When society fails to accommodate people who have a certain condition, it is the society that is disabled. We needed to start a revolution that would question the medical definition of disability and promote a social definition 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.

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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.

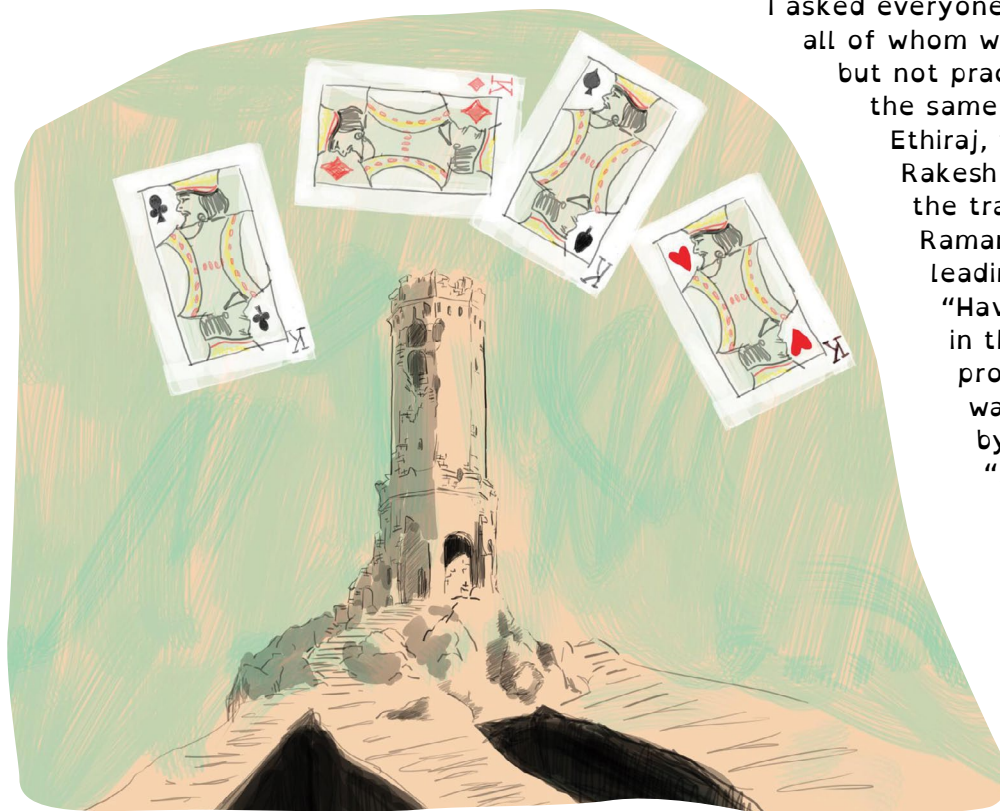
Having now read to this point in the chapter, I would like you to go back to the visual you drafted at the start of this chapter, the one with the systems that surround, cover and influence you, both positively and negatively. Are there opportunities for you to stand up, like Rosa Parks did? What can 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



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

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.


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?

