



TO FACE LIFE

A report on the global situation for
women with disabilities

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MyRight is the Swedish disability rights movement's umbrella organisation for international development work. MyRight's vision is a world in which all people with disabilities enjoy equal rights and opportunities for a decent life in inclusive communities. This work is based on the UN Convention on the Rights of Persons with Disabilities and is driven by MyRight and its 23 member organisations in collaboration with partnership organisations in ten countries on four continents. MyRight has country offices in Bolivia, Nicaragua, Rwanda, Tanzania, Nepal, Sri Lanka, Bosnia and Herzegovina. Various projects are run in these countries, with the aim of strengthening the local organisations and driving developments so that people with disabilities can have greater access to their rights.

Swedish Asthma and Allergy Association

Swedish Autism and Asperger Association

DHR - Association for a society without obstacles to mobility

FBIS - Swedish Hemophilia Society

FSDB - Association of the Swedish Deafblind

FUB - Swedish National Association for Persons with Intellectual Disability

HIV-Sweden - Swedish National Association for HIV Positive People

Swedish Heart and Lung Association

HRF - Swedish Association of Hard of Hearing People

RBUS - Swedish National Association for Disabled Children and Young People

Swedish Rheumatism Association

Swedish National Association Attention

Swedish National Association "Grunden"

RSMH - Swedish National Association for Social and Mental Health

SDI - National Swedish Deaf Sports Association

SDR - Swedish National Association of the Deaf

SDR - Swedish National Youth Association of the Deaf

SEF - Swedish Epilepsy Association

SRF - Swedish Association of the Visually Impaired

STIL – Stockholm Cooperative for Independent Living

Swedish Parasports Federation

UH – Hard of Hearing Young People Sweden

US - Young People with Visual impairment Sweden

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SUMMARY

Women with disabilities face double discrimination. This takes the form of systematic abuses of rights and fewer opportunities for influence and power. These women seldom appear in statistics, but it is evident that girls with disabilities do not have access to schooling and education to the same extent as other children, they are subjected to discrimination in the labour market and are at greater risk of being subjected to violence and attack. Women with disabilities are also subjected to discrimination when it comes to healthcare and sexual and reproductive health rights.

Through the global sustainable development goals in Agenda 2030, countries all over the world have committed to including everyone in work for sustainable development. This also includes marginalised and particularly vulnerable groups such as women with disabilities.

Sustainable development goal number 5 is about gender equality. The targets within the goal contain several commitments in areas where women with disabilities are particularly vulnerable.

The partnership projects that MyRight and its member organisations are running offer an opportunity for the sharing of experiences, and awareness is generated of what it is like to live

with a disability when you are also a woman. By making visible women with disabilities or women who are a close relative of a person with a disability, these projects contribute to positive social development while at the same time providing an opportunity for individuals to take control of their own lives. Those who testify to this in this report include participants from three member organisations: Wenche Willumsen, Fredrik Canerstam and Liiso Åkerberg.

In the report we also meet Kanchana Pradeepa de Silva from Sri Lanka, Hidayat Alawi from Tanzania and Donatilla Kanimba from Rwanda, who have all been involved and engaged in MyRight's and its member organisations' projects. They offer their views on what it is like to live as a woman with a disability in their own countries. They also give accounts of their own life stories, the discrimination they have encountered, but also of the empowerment they have achieved and what this has meant.

At the end of the report, MyRight offers recommendations about how we can contribute to achieving the global sustainable development goal for gender equality from a disability perspective. We are aiming at the government and other decision-makers, but also offer tips to activists in civil society organisations on



how they can work to make sure that women with disabilities are included and do not suffer discrimination.

The Swedish National Board of Health and Welfare¹ defines disability and functional impediment as follows: Disability is a reduction in physical, psychological or intellectual functional capacity. Functional impediment is the restriction that a disability causes for an individual in relation to his/her surroundings.

***You can find
recommendations
to decision-makers
and activists
on pages 43-44***

1. The Swedish National Board of Health and Welfare
http://www.socialstyrelsen.se/fragorochsvar/funktionsnedsattningochfunktio#an-chor_2

CONTENTS

Foreword	6
Discrimination reinforces poverty among women with disabilities	8
Poverty and the absence of rights	10
Poverty disempowers people	12
Even in the statistics, women are left in the shadows	12
Schools in particular exclude girls with disabilities	15
Closed labour market and unpaid, low-status work in the home	17
Increased risks of violence and attack	17
Reduced access to healthcare and reproductive health services	18
Less political involvement – at all levels	19
The UN convention on disabilities highlights the rights of women	20
The UN convention on women’s rights	20
Agenda 2030 – clear goals for women and persons with disabilities	21
Feminist foreign policy lacks focus on women with disabilities	24
Society’s lack of gender equality has an impact everywhere - experiences from the field	26
Women who make a difference – stories from Sri Lanka, Tanzania and Rwanda	30
Kanchana wants to open the door for women through sport	31
Hidaya guides other women following her own tough journey	35
Donatilla – the blind girl who was displaced and became a role model	39
Recommendations	43
Sources	46



FOREWORD

In 2009 in Stockholm, a young Yetnebersh Nigussie was taking part in one of MyRight's international CPD programmes on issues relating to disabilities. Eight years later, the Right Livelihood Foundation presents the alternative Nobel Prize to the very same Yetnebersh Nigussie. As Secretary General of MyRight and an active member of the visually impaired movement in Sweden and internationally, this makes me incredibly proud! Yetnebersh Nigussie now has two academic qualifications and is a prominent human rights activist. But this was not considered likely when, at the age of five, Yetnebersh suffered a visual impairment. Yet her disability has, in an unlikely way, come to her rescue, as thanks to it she managed to avoid being married off at a young age, which is otherwise the tradition in the part of Ethiopia from where she comes. Her parents also let her have an education, which is far from common for girls in her situation. Since then, she has been using her education and engagement to fight for girls and women with disabilities and their right to an education.

It is a fact that many girls with disabilities do not receive the education that is their right. Nine out of every ten children with disabilities in low-income countries do not attend school, and

the picture is even bleaker for girls in that group. Furthermore, they are born into and forced to live with a level of double discrimination that is difficult to imagine. This then follows them through life in the form of prejudices and shame associated with everything from intellectual ability and sexuality, opportunities for education, opportunities in the labour market, to attacks from society as the time eventually comes to form their own family and have children. Women and girls with disabilities are also at greater risk of being subjected to violence and sexual attacks, both as children and when they reach adult age.

Over the many years that I have been working with issues relating to disabilities at an international level, I have seen a need to work strategically in various ways to provide women with an opportunity to empower themselves. This can involve making sure that women always have access to the same information as the men in the organisation where they are working. It can also take the form of arranging separate meetings, as in these contexts women are prepared to become more involved. The main lesson that I have learned is that women must be actively given scope to be able to have their voices heard and that they must be allowed to participate on the same terms as men.

Goal five in Agenda 2030 is about gender equality and the right of all girls and women to shape their own lives and contribute to the development of society, to have their legitimate access to sexual and reproductive health, to have the right to own property and to achieve the same positions of power as men. The goal also states that all forms of violence against women must stop. The message of Agenda 2030 is quite clear: Leave No One Behind! In order that goal five can become a reality, all of the countries in the world must see the bleak reality in which girls and women with disabilities often live and act accordingly, otherwise the sustainable development goal of gender equality will never be achieved.

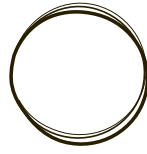
In our recommendations in this report, we are aiming at, among others, decision-makers in Sweden who want to pursue a feminist foreign policy. We would like to see a clearer disability perspective in this work, otherwise there is a serious risk that the group comprising women with disabilities will also become invisible here.

Girls and women like Yetnebersh, who time after time defy a terrible situation, offer clear evidence that another reality is possible. I am struck by the energy and force that exist within these women, even when no one believed in them or asked for their strengths. When these women have been given a forum in which they

can strengthen each other and tools to wage their own battles to reclaim their rights, a force is released that is impressive.

In this report, several women, who either have disabilities themselves or have children with disabilities, give an account of how they managed to change their own lives and those of their relatives, their fellow women and other people. This applies to people both with and without disabilities. This is a task that required an incredible amount of strength as well as a very great deal of courage. We are all obliged to take their experiences seriously and to work actively to ensure that all girls with disabilities can have a better future.

Tiina Nummi-Södergren
Secretary General, MyRight



DISCRIMINATION

REINFORCES POVERTY AMONG WOMEN WITH DISABILITIES

People with disabilities are among the poorest and most marginalised groups in the world. The situation is worst for all of the girls and women with disabilities who are forced to encounter many different forms of discrimination. They are widely subjected to poverty, violence, attacks, stigmatisation and rights being violated. This is the group that is lagging furthest behind as the global society aims to achieve the objective of a gender-equal world without poverty. If Agenda 2030 is to be realised, the situation facing these forgotten, hidden girls and women must be highlighted – and changed.

In September 2015, the countries of the world agreed on Agenda 2030, a global development policy for a sustainable future, in which poverty shall be eradicated and a gender-equal world shall prevail. The objectives are to be fulfilled in 2030.

The battle against poverty has produced results over the last 35 years, with a significant reduction in extreme poverty in the world. It is estimated that between 1981 and 2013 the number of people living in extreme poverty fell from 1.9 billion to 767 million, while the global population increased by almost 2.5 billion inhabitants. This is, of course, a tremendous improvement.

But alongside this trend, the gaps between individuals and groups have increased. This is about inequality that is often based on age, ethnic origin, economic or social status.

Another form of inequality is the one that affects people because of their gender – or because they are living with disabilities. Or both.

Being subjected to the triple discrimination that comes from being born with the “wrong gender”, living in poverty and being disabled means that all elements of life are pervaded by tough challenges. All forms of discrimination also have an amplifying effect on the other ones.

The correlations between development, poverty and disability are clear. A person who is poor is at greater risk of having a disability, and someone who has a disability is at greater risk of being in poverty¹.

Agenda 2030 has made it clear that no one is to be excluded any more. Yet so far this is precisely what many of the world’s poor women with

1 WHO. World report on disability, page 10, 2011.

disabilities have been exposed to. If the new objectives are to be realised, this is therefore one of the groups that must be prioritised.

It is not a small group. The UN's development agency, UNDP, estimates that there are one billion people in the world who are living with some form of disability². The limited research that exists in this area also reveals that girls and women represent the majority of these persons. The situation is even more pronounced in poor countries, where more than one woman in five is believed to be living with at least one form of disability³.

There are considered to be many reasons why there are far more women than men who are living with disabilities in developing countries. Not only do women suffer injuries because of deficiencies in the field of reproductive health and maternity care, women also have a longer average life expectancy than men. Other causes

are connected to the lower social and economic status of girls and women compared with boys and men. One of the effects is that they may be given a smaller proportion of the household's resources⁴. Women are also at greater risk of suffering a disability because of gender-based injustices with regard to access to different kinds of services. Girls and women who fall ill have less access to care compared with boys and men, especially in poor countries where the nearest healthcare provider may be a long way away⁵.

In most societies, persons with disabilities, regardless of gender, are among the most marginalised, and in poor environments this can have devastating consequences. At the same time, the absence of gender equality is a major problem all over the world. The systematic gender discrimination that prevails in many of the world's countries therefore has a particularly hard impact on women with disabilities.

2. UNDP. Human Development Report Overview, page 5, 2016.

3. WHO. World report on disability page 28, 2011.

4. UN WOMEN. Making the SDGs count for women and girls with disabilities, page 2, 2017.

5. <https://www.hrw.org/legacy/women/disabled.html>





POVERTY AND THE ABSENCE OF RIGHTS

According to the latest edition of the Human Development Report, which is published annually by the UN's development programme UNDP, one in three of the world's citizens is still living at low levels of human development.

Almost 1.5 billion people are around the world are living in multidimensional poverty, a term used to describe more aspects of poverty than the purely economic aspect. It is about the ability of people to eat their fill of nutritious food and avoid being undernourished. It is also about having access to clean drinking water and thus being able to avoid suffering any of the large number of water-borne diseases. But it is also about the right to be able to go to school, the opportunity to access healthcare when it is needed, to have an influence over their own lives and their future – and the right to be able to feel safe.

People who live with disabilities are often denied many of these rights, and this report will highlight how this is particularly true of women.

The limit for extreme poverty has been set at the equivalent of 1.9 dollars a day, about 17 Swedish kronor, according to the World Bank's definition. This figure takes into account the general price level in each individual country and is a kind of base level for what is required for a person to be able to survive⁶. Another way of measuring poverty is to study how many

people are forced to remain undernourished. It is estimated that in the modern world one person out of nine is still going hungry.

The lack of equality between the genders is reflected in poverty, where girls and women are generally harder hit by poverty than boys and men⁷. Most of the world's poorest people live in rural areas in developing countries, where they provide for themselves on their own small farms. Much of the work is done by women. But the lack of equality can also be seen in agriculture, making poverty worse and increasing the risk of food shortages. Women who make a living from agriculture find it more difficult than men, for instances, to be given entitlement to land and access to credit and other support.

The lack of equality hits everyone. The UN's food and agriculture organisation, FAO, showed in a report that if the world's female small-scale farmers had the same conditions as men, their proportion of food production could increase by between 20 and 30 per cent. This could in turn provide food for up to 150 million people⁸.

7. (ibid.)

8. <http://www.worldbank.org/en/region/afr/publication/>

6. <https://unicef.se/fakta/fattigdom>

The fact that the battle against poverty is inextricably linked to the issue of gender equality is confirmed by, among others, the UNDP, which emphasises that work for a sustainable future requires an increased focus on strengthening the rights of girls and women.

Poverty is a strong contributory factor to disability. It has already been well-documented that undernourishment in pregnant women and small children results in increased risks of delayed development and disabilities in children⁹. Undernourishment can have a negative impact on a pregnant woman's foetus, and small children who lack important nutrients can be affected in their development. It is estimated, for example, that between 250,000 and 500,000 children go blind every year because of vitamin A deficiency, something that could easily be prevented by means of vitamin supplements¹⁰.

Disabilities can also result in undernourish-

ment, when families with limited resources do not prioritise children with disabilities as highly as other family members at the dining table.

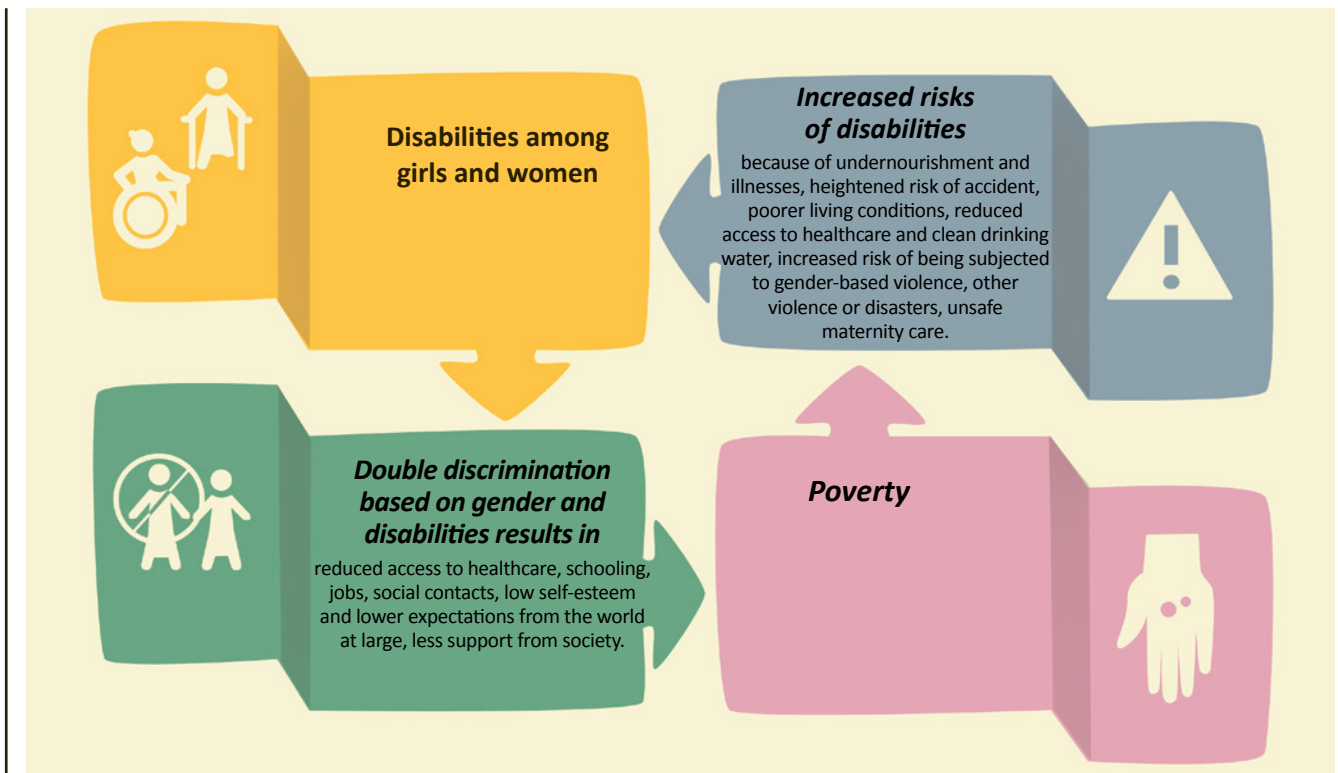
At the same time, disabilities have a tendency to lock people into poverty. Families where one or more people are living with disabilities run an increased risk of living in poverty. One reason for this is that working time is lost when time is spent on care¹¹. It is often the responsibility of women to take care of children born with disabilities.

Disability has a distinct tendency to lower the already low status of women. It is essentially about cultural values and traditions. In poor countries it is also common that ignorance of disabilities results in the emergence of myths, such as that they are curses that have struck the family, or that disabilities are contagious¹². Further on in this report, Hidaya Alawi from Tanzania gives an account of the consequences that this ignorance can have, for both mothers and their children.

levelling-the-field-improving-opportunities-for-women-farmers-in-africa

9. UNICEF. Stronger Together Nutrition-Disability Links and Synergies Briefing Note, page 3, 2011.
10. UNICEF. Children and Young People with Disabilities Fact Sheet, page 27, 2013.

11. UNICEF. Children and Young People with Disabilities Fact Sheet, page 16, 2013.
12. UNICEF. Children and Young People with Disabilities Fact Sheet, page 4, 2013.





POVERTY DISEMPOWERS PEOPLE

People who are suffering poverty are often denied their human rights and have poorer opportunities to influence their lives themselves. This is particularly evident in people who are living with disabilities – and even more evident in women.

Many global studies have shown that people who are living with disabilities, and their families, are at far higher risk than others of suffering both social and economic injustices. The World Health Organisation (WHO) confirms that people with disabilities are subjected to abuses of their human rights as they are denied care, education, work and the opportunity to become involved in politics¹³.

The situation is even worse for women, according to information from the International Disability and Development Consortium, IDDC. This is because girls and women with disabilities are offered fewer opportunities to take part in decision-making processes and have poorer access to areas such as healthcare, education and the labour market¹⁴.

EVEN IN THE STATISTICS, WOMEN ARE LEFT IN THE SHADOWS

Initiatives to fight poverty require background knowledge – in the form of reliable, comparable statistics. But even if the link between poverty and disability has been clearly identified, there is a major lack of global statistics on people with disabilities. There is an even bigger lack of basic facts that specifically highlight the situation of girls and women.

In societies where people with disabilities are subjected to stigmatisation, statistics can be misleading and there is a high number of unrecorded cases. This is revealed by, for example,

13. WHO. World Report on Disability, page 9, 2011.

14. IDDC. Factsheet Women and girls with disabilities, 2016.

studies in Sierra Leone¹⁵. In environments where people with disabilities are considered to have less value as humans, parents and relatives can choose to keep their relatives hidden. Children who are born with disabilities are sometimes not even registered by the authorities.

Another contributory factor to the lack of statistics might be that people with disabilities have not been prioritised by the global society to the same extent as other groups. Critics believe that this is a group that has not only been rendered invisible in their local communities, but also in global development work.

At the same time, the WHO emphasises how important reliable and relevant statistics are when it comes to people with disabilities, in order to make it possible to structure various political initiatives. The UN body would ideally like to have standardised data that can be compared between countries. This should make it possible to increase knowledge of the effects of various initiatives and be important in order to compare how well different countries are succeeding in applying the UN Convention on Rights for Persons with Disabilities¹⁶.

The statistics available on people with disabilities often fail to take into account that the situation is different for men and women. This is despite the fact that it is obvious that girls and women in most areas face even more and bigger obstacles.

The number of initiatives aimed specifically at girls and women with disabilities remains limited. The same is also true of financial resources invested in this group. Girls and women with disabilities are also often invisible in national legislation and public initiatives. This is emphasised by UN Secretary-General António Guterres in a report on the situation of women and girls with disabilities that was published in July 2017. He also confirms that this is a group that attracts little attention in global discussions and agreements.

15. UNESCO. GAW 2014 Facts-Figures, page 1, 2014.

16. <http://www.who.int/disabilities/data/en/>

António Guterres also points out that the rights of girls and women with disabilities are usually sorted into contexts that apply for all people with disabilities, or for girls and women in general. This is despite the fact that this is a specific group that faces many forms of discrimination, each of which has a reinforcing effect on the others¹⁷.

The Secretary-General also emphasises that one of the biggest challenges involves the lack of statistics. He confirms that there is a pressing need to obtain data that is broken down by disability, gender and age. This is necessary for a greater understanding and to be able to make sure that women and girls with disabilities are included and have their rights safeguarded. The lack of statistics is a major obstacle for the development of this group, confirms António Guterres¹⁸.

Even if the statistics are incomplete, experts and people with extensive experience of practical fieldwork agree that people with disabilities are often among the poorest and most discriminated in society. The ones most marginalised of all are girls and women.

International bodies have also produced some estimates of the global situation

17. UN. Situation of women and girls with disabilities and the Status of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto Report of the Secretary-General, page 17, 2017.

18. Situation of women and girls with disabilities and the Status of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto Report of the Secretary-General, United Nations, page 7, 2017.

↘ It is estimated that more than one billion people, or 15 per cent of the world's population, are living with at least one form of disability, and up to 200 million of these experience significant functional impediments in their lives. There are more women than men living with disabilities, according to the UN's entity UN Women, which reports that the figures are 19 and 12 per cent respectively¹⁹. The difference is even more pronounced in low-income countries, where just over 22 per cent of women and around 14 per cent of men have disabilities²⁰.

↘ One household in four has a family member with a disability. This means that an estimated two billion people worldwide live with someone who has a disability²¹. It is usually the responsibility of women to take care of children born with disabilities.

↘ It is estimated that almost 80 per cent of those living with disabilities live in developing countries²². In all age groups, the proportion of people with disabilities is higher among people in low- and middle-income countries than in high-income countries²³.

↘ Women who live with disabilities are at a significantly greater risk of suffering socio-economic injustices than others. These include poverty, access to education, good health and healthcare, and access to work.

↘ Depending on the source, it is estimated that there are between 93 and 150 million children in the world living with at least one form of disability²⁴.

↘ Almost nine out of ten children living with disabilities in developing countries do not attend school²⁵. There are no reliable figures for girls, but there is much evidence to suggest that the figures are even worse for them, as they often encounter even tougher challenges than boys do.

↘ Child mortality among children with disabilities can be no less than 80 per cent in countries where the average mortality rate for children below the age of five has fallen to below 20 per cent²⁶.

19. <http://www.unwomen.org/en/news/stories/2015/12/empowering-and-including-women-and-girls-with-disabilities>

20. WHO. World report on disability page 28, 2011.

21. UN. Disability and the Millennium Development Goals, page viii, 2011.

22. Sida. Mänskliga rättigheter för personer med funktionsnedsättning [*Human rights for people with disabilities*], page 14, 2009.

23. UNESCO. GAW 2014 Facts-Figures, page 1, 2014.

24. UNICEF. Children and Young People with Disabilities Fact Sheet, page 10, 2013

25. UN. Disability and the Millennium Development Goals, page 18, 2011.

26. UNICEF. Children and Young People with Disabilities Fact Sheet, page 10, 2013



SCHOOLS IN PARTICULAR EXCLUDE GIRLS WITH DISABILITIES

There has been a rapid increase in recent years at a global level in the proportion of children who are given an opportunity to go to school. Yet very many children with disabilities are still never given this opportunity. This is particularly true for girls.*

Despite the progress made in recent years, the UN's children's fund UNICEF estimates that there are still at least 61 million young children in the world who have been deprived of their right to go to school. No fewer than 263 million children and young people between the ages of 6 and 17 do not attend school²⁷.

Children with disabilities attend school to a lesser extent than other children. One of the most common causes of this is poverty, while another can be the stigma that disability often carries for families in developing countries, especially for the mothers. This stigmatisation means that the society around them looks down on families where someone has a disability. Another reason why children with disabilities have lower levels of school attendance is that many schools are not accessible for children with special needs, and that teachers often lack the training they would need.

This exclusion is seen particularly among gi-

rls with disabilities. The WHO points to surveys showing that such girls are even less likely than boys to complete primary school²⁸.

One problem in particular that affects girls in developing countries is the lack of running water at many schools, as well as the lack of functional and separate toilets. Parents are in many cases unwilling to send their daughters to school if there are no separate toilets for boys and girls²⁹.

This often represents a special obstacle for girls who have reached puberty. If they are also living with a disability, there is a major risk that they will suffer double discrimination. This is because they are girls, but also because these girls can have particularly strong needs for functional and private toilet areas and they may also need assistance in connection with visiting the toilet.

In many countries in the world, girls are considered to be less valuable than boys, as they are not expected to be able to contribute

27. IDDC. Factsheet Women and girls with disabilities, 2016.

28. WHO. World report on disability page 206, 2011.

29. <https://unicef.se/fakta/utbildning>

* <http://uis.unesco.org/en/news/263-million-children-and-youth-are-out-school>

to providing for the family in the future. This works against girls' schooling in general, but in particular against girls with disabilities, as families often choose to give higher priority to the education of other siblings.

The lack of education means that these children and young people do not receive the knowledge of health issues and illnesses that can be crucial for their lives. This is knowledge that can be particularly important for girls with disabilities, who often face bigger risks than other children.

The United Nations Girls' Education Initiative (UNGEI) confirms that in many

developing countries where they have invested in free schooling for everyone, the result has often been enormous class sizes and too few teachers. In a classroom where one single teacher has to help up to a hundred pupils, there are few opportunities to provide the assistance that girls with disabilities can need. This results in these girls being largely overlooked³⁰.

Even though there is a major lack of reliable statistics, older research shows that the literacy rate among adults with disabilities in general is just three per cent, while the figure for women with disabilities is down at only one per cent³¹.

Dormitory at the Masaka Resource Center in Kigali, Rwanda.



30. UNGEI. Still left behind: Pathways to inclusive education for girls with disabilities, page 16, 2017.

31. UNESCO. Paper commissioned for the EFA Global Monitoring Report 2003/4, The Leap to Equality, page 3, 2003.



CLOSED LABOUR MARKET AND UNPAID, LOW-STATUS WORK IN THE HOME

All people with disabilities are at significant risk of suffering discrimination in the labour market. The situation is the most difficult for women. The few who do manage to find a proper job often receive a wage that is lower than the one offered to men with disabilities or other women.

When women with disabilities are perceived as being of less value – because of both their gender and their disabilities – their opportunities to have an education are reduced. This in turn makes it more difficult for them to get a job and earn their own money, which often results in their becoming totally dependent on their relatives.

The WHO highlights a survey of 51 countries in the world, which shows that fewer than one in five women with disabilities have a job. This is far lower than for men with disabilities, and also far lower than for other women³².

Many girls and women who live with disabilities are instead occupied with tasks in the home that do not generate any income in the form of wages. They are therefore at much greater risk of suffering poverty and being forced to live in a position of dependence on others. Having an identity that is only associated with housework can also reinforce the stig-

matism that affects women with disabilities.

Both men and women who live with disabilities are at far greater risk of living in poverty. But women with disabilities have fewer opportunities to get an education. This reduces their opportunities to get a job that can contribute to helping them out of poverty. If, however, these women were given the opportunity to become financially independent to a greater extent, their status as productive and contributing family members would at the same time be enhanced.

INCREASED RISK OF VIOLENCE AND ATTACK

Studies show that girls and women who live with disabilities are at a greatly heightened risk of suffering gender-based violence and sexual attacks. This vulnerability reflects the very low status of these women in many societies.

32. World Report on Disability, WHO World Bank, page 237, 2011.

Women with disabilities suffer a high degree of social isolation, stigmatisation, uneven power relationships and inadequate access to support³³. Such factors contribute to their also being at up to three times as high a risk of suffering violence and sexual attacks compared with other women³⁴.

The organisation ADD International confirms that girls and women who live with disabilities are even considered to be non-people in certain societies³⁵. Despite this, many initiatives that aim to reduce violence against women do not include measures that are targeted at the special dangers that threaten women with disabilities.

The perpetrator is often a family member, a partner or another person on whom the victim is dependent. Smaller studies conducted locally show that a very large proportion of girls and women with disabilities are subjected to both emotional and physical attacks to a far greater extent than others. This risks becoming even more common in connection with humanitarian crises, as the protective networks are further weakened³⁶.

Rehabilitation International refers to a study conducted in the Indian state of Odisha in 2004. This showed that virtually all girls and women with disabilities were subjected to violence in their homes, and that one quarter of all women with intellectual disabilities had been raped³⁷. The organisation also states that it is not unusual for sex offenders to consciously select women with disabilities, as they are in less of a position to report the crime.

The UN's programme for AIDS prevention, UNAIDS, also states that it is twice as common for women who have been subjected to violence by their partner to contract HIV³⁸.

REDUCED ACCESS TO HEALTHCARE AND REPRODUCTIVE HEALTH SERVICES

Women with disabilities have less access to sex education and reproductive health services than other women, partly because they are not considered to be able to have an active sex life. This means that these women are at greater risk of suffering both HIV and other sexually transmitted diseases³⁹.

Women with disabilities are often considered to be asexual⁴⁰. When relatives do not believe that a girl or woman with a disability is sexually active, this can restrict their opportunities to obtain both information and help in issues relating to HIV and other sexually transmitted diseases.

The human rights organisation Human Rights Watch emphasises that all risk factors surrounding HIV are particularly evident in women and girls with disabilities. These include poverty, stigmatisation, inadequate ability to make a man use a condom, increased risk of being subjected to violence and rape, and inadequate access to service and information. Women with disabilities also find it far more difficult to gain access to antiretroviral drugs, as they often have major problems in getting to healthcare centres⁴¹.

When HRW in Uganda interviewed women with disabilities who had been subjected to rape, many of the victims stated that they had been unable to undergo an HIV test afterwards as they were unable to make their way to a clinic. There are also myths in some countries to the effect that sexual relations with a virgin can cure AIDS. This something that is a particular danger to girls and women with disabilities, as they

33. ADD. Disability and gender-based violence, 2017.

34. DFID. Disability, Poverty and Development, page 3, 2000.

35. ADD. Disability and gender-based violence, page 1, 2017.

36. Women Refugee Commission, Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings, page 1, 2015.

37. RI. Fact-Sheet Women and Disability, page 2, 2010.

38. UNAIDS. Report on the global AIDS epidemic, page

7, 2013.

39. RI. Fact-Sheet Women and Disability, page 2, 2010.

40. ADD. Disability and gender based violence.

41. Human Rights Watch. Human rights for women and children with disabilities, page 8, 2012.

are considered to be asexual and also often find it more difficult to defend themselves against perpetrators.

HRW also reports that women with disabilities in various parts of the world are denied their reproductive and sexual rights by means of enforced sterilisation. This often takes place when the surrounding community and relatives believe that sterilisation should be carried out in the girls' and women's "own interests"⁴².

Girls and women with disabilities often have limited access to services in the area of sexual and reproductive health or access to sex education. This is particularly true in the case of girls with intellectual disabilities⁴³. Many actors working with issues relating to sexual and reproductive health also lack the tools and knowledge required in order to adapt information material and other initiatives for girls with disabilities.

The inadequate access to sexual and reproductive health and associated rights is one of the biggest problems for girls and women with disabilities. This is because these women are denied the right to make their own, considered decisions about sexual relations, contraception and other forms of reproductive healthcare⁴⁴.

LESS POLITICAL INVOLVEMENT – AT ALL LEVELS

Women who live with disabilities encounter a number of obstacles that make it far more difficult for them to take part in decision-making processes. This is true not only in the field

of politics, but also in many other organisations that work with issues relating to rights.

Even in organisations that work for people with disabilities, the proportion of women in senior positions is low⁴⁵. Girls and women who live with disabilities are often excluded when decisions are made and lobbying work is carried out on issues that concern their lives. The views of "experts" or other actors are often given precedence instead⁴⁶.

At the same time, many organisations that work for gender equality are not aware of the social challenges faced by girls and women with disabilities⁴⁷. Despite the fact that both disability and gender affiliation are important reasons why people are excluded, the two issues are usually treated separately.

42. Human Rights Watch. Human rights for women and children with disabilities, page 6, 2012.

43. UN. Situation of women and girls with disabilities and the Status of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto Report of the Secretary-General, United Nations, page 6, 2017.

44. UN WOMEN. Making the SDGs count for women and girls with disabilities, page 2, 2017.

45. ADD. Disability and gender based violence.

46. UN WOMEN. Making the SDGs count for women and girls with disabilities, page 2, 2017.

47. UNGEI. Still left behind: Pathways to inclusive education for girls with disabilities, page 7, 2017.



The girls Tatu and Nuru playing while their mothers are educated at the House of Hope in Dar es Salaam, Tanzania.

THE UN CONVENTION ON DISABILITIES HIGHLIGHTS THE RIGHTS OF WOMEN

The UN Convention on the Rights of Persons with Disabilities was adopted by the general assembly at the end of 2006 and has been in force in Sweden since 2009. The Convention clearly emphasises the need to pay particular attention to the situation of girls and women.

All laws and all public activities in Sweden must comply with the articles in the Convention. The same also applies for all other countries that have ratified the Convention. The Convention aims to promote, protect and safeguard human rights and basic freedoms for people with disabilities. With regard to women with disabilities, the Convention makes it very clear that this group faces special challenges, including various forms of discrimination.

According to Article 6 of the Convention, countries that have ratified the Convention shall “take all appropriate measures” to ensure that women and girls with disabilities are guaranteed “full and equal enjoyment by them of all human

rights and fundamental freedoms”. Furthermore, State Parties shall “take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention”.

People with disabilities are naturally also covered by other conventions and by the UN’s Universal Declaration on Human Rights. The purpose of the UN Convention on Rights for Persons with Disabilities is to reinforce the protection that these persons already have in other conventions. The objective is to remove those obstacles that prevent people with disabilities from having the opportunity to exercise their human rights.

THE UN CONVENTION ON WOMEN’S RIGHTS

The UN Convention on Women’s Rights was adopted by the general assembly in 1979. The aim of the Convention on Women’s Rights is to eradicate all forms of discrimination against women. Sweden was one of the first countries to ratify the document.

The UN's Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) is a framework that aims to guarantee equal rights for women and men. It emphasises the obligation of participating states by means of law and practice to eradicate all forms of discrimination against women on the basis of gender. Among other things, all states shall guarantee that women's rights are respected, including their right not to be subjected to abuse, sexual violence or harassment.

The Convention on Women's Rights confirms that governments must take action against discrimination, not only in public administration but also "take all appropriate measures to eliminate discrimination against women by any person, organization or enterprise".

AGENDA 2030 - CLEAR GOALS FOR WOMEN AND PEOPLE WITH DISABILITIES

Until 2015, the UN's eight Millennium Development Goals formed the basis of global development policy. One of the goals was about promoting gender quality. But there was no clear target for all of the people in the world who live with disabilities. In Agenda 2030, however, the global community confirmed that the world's women and people with disabilities shall be prioritised groups.

The situation for people with disabilities was not mentioned at all in the millennium development goals. When new global objectives had to be created, the international disability rights movement worked to ensure that the new goals should be more inclusive and fair. The International Disability Alliance (IDA) and the International Disability and Development Consortium (IDDC) demanded that the goals should focus on one of the poorest, most marginalised groups in the world

– people with disabilities. The IDA believed that the absence of initiatives for poor people with disabilities from the millennium development goals had meant that they were in practice impossible to achieve⁴⁸. When the world's countries met at a UN summit in September 2015 and adopted the global sustainable development goals in Agenda 2030, it was evident that this work had borne fruit. People with disabilities are mentioned specifically on eleven occasions in Agenda 2030, and seven of the 17 general goals contain explicit references to disabilities. Examples include goals 4, 8, 10, 11 and 17. The global development agenda also puts a strong focus on the issue of gender equality in goal 5, which confirms that gender equality is a precondition for sustainable and peaceful development in the world.

Agenda 2030 covers all of the countries in the world and officially entered into force in January 2016. As the name indicates, the aim is that the goals will have been achieved by 2030. All countries have undertaken to guide the world towards a sustainable, fair future in which peace prevails, human rights are protected, environmental destruction has been reduced and the climate is cared for.

The goals shall be achieved for all people at all levels of society. Most strongly emphasised is the need to reach the most vulnerable and marginalised people, with the keywords being "Leave No One Behind". This means that people with disabilities, women in particular, must be one of the most highly prioritised groups.

UN Women is one of many institutions to emphasise that Agenda 2030 represents a major opportunity. Agenda 2030 also brings a moral responsibility for the global community to prioritise the rights and needs of women with disabilities⁴⁹. According to UN Women, the issue of disabilities must therefore be included in all initiatives in order to strengthen women and achieve gender equality.

48. <http://www.internationaldisabilityalliance.org/content/millennium-development-goals>

49. UN WOMEN. Making the SDGs count for women and girls with disabilities, 2017.

GOAL NUMBER 4 – QUALITY EDUCATION FOR ALL

Goal 4 is about ensuring inclusive and equitable quality education and promoting lifelong learning opportunities for all. It emphasises that there must be educational environments that are adapted for children and adults with disabilities. By 2030 there shall be “equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities”.

GOAL NUMBER 5 – GENDER EQUALITY

Goal 5 is about achieving gender equality and empowering all women and girls. It emphasises that gender equality is a goal in its own right and a precondition for sustainable and peaceful development. The goal confirms that gender equality only prevails when women and men, girls and boys, have equal rights, conditions, opportunities and power to shape their own lives and contribute to the development of society. It is about the fair distribution of power, influence and resources in society. The generally subservient position of power among women and girls in relation to men and boys must stop. Social norms and customs that sanction inequality and violence against women and girls must be changed.

The targets also contain several commitments in areas where women with disabilities are particularly vulnerable. Among other things, violence against women in all forms must be eradicated. General access to sexual and reproductive health services and reproductive rights must be guaranteed, unpaid caring and household work must be acknowledged and women must be given equal rights to financial resources, the opportunity to own and control land and other forms of property.

GOAL NUMBER 8 – DECENT WORKING CONDITIONS AND ECONOMIC GROWTH

Goal 8 is about promoting inclusive and sustainable economic growth, as well as decent work for all. One of the targets is “full and productive employment and decent work for all women and men, including for young people and persons with disabilities”.

GOAL 10 – REDUCED INEQUALITY

This goal aims to reduce inequality within and between countries and to make sure that all people are included in the economy and decision-making. One of the targets is to make it possible by 2030 for all people, irrespective of age, gender, disability, race, ethnicity, origin, religion or economic or other status, to be included in social, economic and political life.

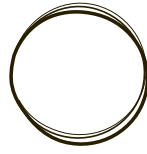
GOAL 11 – SUSTAINABLE CITIES AND COMMUNITIES

This goal is about making cities and settlements inclusive, safe, resilient and sustainable. More than half of the world's population now live in cities, a figure that is expected to rise to 70 per cent within 35 years. This means that many cities are continuing to grow quickly, and urbanisation has resulted in almost one billion people who are believed to be living in slum-like conditions. In order to create sustainable urban development, according to this goal the world must pay special attention to people with disabilities, children and the needs of older persons.

Goal 11 includes two targets that relate directly to persons with disabilities. By the year 2030, the world's cities must provide access to "safe, affordable, accessible and sustainable transport systems for all". The target also makes demands for significant investments in public transport, "with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons". The other target is about providing access to "safe, inclusive and accessible, green and public spaces, in particular for women and children, older persons and persons with disabilities".

GOAL 17 – IMPLEMENTATION AND GLOBAL PARTNERSHIP

In this goal, the global community confirms that it will require intensive global engagement for it to be possible to implement Agenda 2030. One decisive issue in achieving success involves obtaining good figures and statistics about the situation in various countries. One of the targets is therefore to enhance support for building capacity in developing countries by 2020.



FEMINIST FOREIGN POLICY LACKS FOCUS ON WOMEN WITH DISABILITIES

The Swedish government ensured that Sweden was the first country in the world to launch a specifically feminist foreign policy when it came to power in 2014. Yet in international work on gender quality and reducing poverty there is rarely mention in Swedish debate of the fact that girls and women with disabilities are by far one of the most vulnerable groups in the world.

The Convention on the Rights of Persons with Disabilities shall be one of the guiding principles of Swedish development policy. In 2003, the Swedish Parliament pushed through the Swedish global development policy (PGU), which confirms that the battle against poverty in the world shall be characterised by an entitlement perspective.

As we have seen earlier in this report, girls and women with disabilities in developing countries are one of the groups that is particularly vulnerable to discrimination, and many are living in extreme poverty. People with disabilities, in particular girls and women, should therefore be given special priority if the watchwords “Leave No One Behind” are to be realised.

Maria Andersson Willner is a member of the Swedish Parliament’s foreign affairs committee for the Social Democrats and has a particular interest in issues relating to global development. She says that members of the Swedish Parlia-

ment have far too little knowledge and awareness of the fact that people with disabilities are significantly more affected by poverty and other injustices.

“It’s my perception that the level of knowledge is too low. We don’t talk about the correlation that exists between disability and poverty, which is strange bearing in mind how strong that correlation is. During my three years in the Swedish Parliament, I’d never heard of this before and that’s awful,” she says.

MyRight’s report “Conquering the World”, which was issued in summer 2017, was something of an eye-opener for Maria Andersson Willner. She believes that the Swedish government, with its explicitly feminist foreign policy, should be leading the way in work to improve the situation for women suffering discrimination because of disability.

“This isn’t being emphasised enough in the political discourse or in our policy documents.

The issue of people with disabilities is really important if we're serious about eradicating poverty. It's essentially about human rights and the equal value of all," says Maria Andersson Willner.

For her own part, she plans to strive to bring about change by keeping a close eye on what happens when aid strategies are drawn up and by asking more questions. In debates, she intends to make sure that she raises the issue of the special challenges faced by women with disabilities.

"We might not make decisions on strategies in the Swedish Parliament, but we have the opportunity – and as the party of government also the responsibility – to get to grips with these issues. I hope that the opposition is also willing to do this," she says.

As an example of how important it can be to have a cross-party consensus, Maria Andersson Willner mentions the way most parliamentary parties currently view issues relating to sexual and reproductive health.

"Seven out of eight parties would go absolutely mad if the government – of whichever colour – were to do something that diverted from the clear approach that Sweden is pursuing in these issues. Imagine if we could get that focus on the issue of disability in development work. That would be a dream."

Maria Johansson is Chair of the feminist organisation Forum – Women and Disability in Sweden (FQ). She has been working for 15 years to enhance the rights of people with disabilities, has reduced mobility herself and uses a wheelchair. Maria Johansson has on many occasions been part of the Swedish government delegation to what are known as Conferences of State Parties within the UN Convention on the Rights of Persons with Disabilities.

She points out that the problems faced by girls and women with disabilities in developing countries also exist in Sweden.

"The group that always ends up at the bottom of the scale is girls and women with disabilities. This is true in Sweden and even more so in developing countries. But here too, discrimination

can be twofold, with inequality and disability amplifying one another," says Maria Johansson.

She believes that with its experiences, FQ should be able to contribute to Swedish development policy.

"It's incredibly important that Sweden and Sida make sure that they don't forget girls and women with disabilities. This is a fundamental issue. Now that we have a government that describes itself as feminist, they mustn't forget this group – otherwise they won't be credible," she says.

Maria Johansson believes that Agenda 2030, with its focus on both gender equality and rights for people with disabilities, is an incredibly important instrument. But she points out that it is a global commitment. She feels that many authorities, companies, municipalities and county councils, also in Sweden, are completely overlooking what the agenda means when it comes to gender equality and rights for people with disabilities.

"I'm not so sure that people have really understood what Agenda 2030 is, but we won't be achieving the goals as long as people with disabilities are not included. There are many of us who have mentioned this, but sometimes it's as though people simply aren't listening," says Maria Johansson.

She points out that the lack of gender equality is also evident in many international bodies. One telling example is the international committee that monitors and follows the implementation of the UN Convention on Rights for Persons with Disabilities. It consists of 18 members – only one of whom is a woman.

"That's embarrassing and it's a major scandal. At the last election there were three women to vote for, but they didn't even manage that. It's so bad it just shouldn't be possible. I'm no proponent of quotas, but this is such a clear sign that they can't cope with this. Half of the places should be reserved for women," says Maria Johansson.

In her international work, she has on many occasions encountered people who have been amazed to learn that women with disabilities



also encounter problems in Sweden.

This is something that challenges their perceptions of Sweden.

“Many people also say how important it is that Sweden, which in many ways has a positive profile at an international level, continues to lead the way. They believe that the rest of the world depends on us to lead the way in these issues – Sweden is needed to spur on their home countries,” says Maria Johansson.

Social Democrat Maria Andersson Willner is somewhat “in two minds” about the extent to which Sweden should take on the leader’s jersey in work for women with disabilities.

“I don’t so much believe that we should stand up at conferences and say that ‘we’re leading the way’, although I do believe that we do this anyway in many areas. We shouldn’t depict ourselves as the saviour of the world. I think we should set an example in the practical work we carry out, that’s more important.”

To set an example by focusing specifically on

women with disabilities?

“Absolutely. I believe that it’s important to be clear about this in the aid budget,” concludes Maria Andersson Willner.

SOCIETY’S LACK OF GENDER EQUALITY HAS AN IMPACT EVERYWHERE – EXPERIENCES FROM THE FIELD

The discrimination encountered by women who live with disabilities is fed by the general lack of gender equality that prevails in many developing countries. This is the experience of Swedish representatives of MyRight’s member organisations through their collaboration with local partnership organisations out in the field.

This is an analysis that is also shared by Karen Andrae from the UK, an independent consultant with a focus on international development, gender equality and issues relating to inclusion. She has extensive experience of examining the situation facing women with disabilities in developing countries, and emphasises that gender-based injustices impact on, among other things, opportunities for women to have access to education, healthcare and work.

“The lack of gender equality is perhaps the biggest challenge, and it’s even tougher for women with disabilities,” emphasises Karen Andrae.

She says that discrimination against women with disabilities has its origins in major social problems, and mentions a study of gender-based violence on which she worked recently in Tanzania. It was striking there that so many of the women in the study considered in their own minds that everything that had gone wrong for them in their lives related to their disabilities. This was despite the fact that there was much to suggest that the cause was underlying problems of uneven power relationships between men and women – injustices that also affect women without disabilities.

“I also recognise that from other discussions, that it’s common for people to put the whole blame on the actual disability. But that’s also to miss a major element of the problem. And you can’t solve problems of poverty without also doing something about the lack of gender equality,” says Karen Andrae.

Wenche Willumsen spent many years working for MyRight’s member organisation the Organization for a Society without Physical Disability (DHR), before she retired in 2016. Her responsibilities at DHR included international issues. She was involved in projects that DHR ran for many years through MyRight and the association’s partner organisations in many African countries and in Sri Lanka. The aim of all these projects was to support the work of local organisations for both men and women with disabilities.

“But we always paid special attention to women and had parts of the projects that were aimed at women,” she explains.

Now that she is retired, Wenche Willumsen is engaged in activities including being on the board of Forum – Women and Disability in Sweden (FQ). She believes that it is evident that the lack of gender equality that prevails in societies in general is clearly reflected and becomes even more pronounced when it comes to the position given to women with disabilities.

“When you’re already being discriminated against as a woman, it’s even more tangible if you also have a disability that means you’re not considered to be a complete human being,” she says.

By way of example, Wenche Willumsen mentions the situation in rural Sri Lanka. One recurring problem for women with disabilities there is that they are not allowed to leave their homes unless they are accompanied by a male relative. Nor are they allowed to visit the meetings of the local organisations on their own. She feels that the lack of faith in the women’s own ability also has a negative impact on their own self-image.

“There’s a major lack of awareness in general of issues such as feminism and issues relating to women. Many women with disabilities have also been given a self-image that makes them feel totally defenceless.”

Wenche Willumsen herself has reduced mobility in her arms and believes that her own travels out in the field can be significant. This is because she can show that a woman, despite her disability, can not only hold a position in society, but also travel long distances and have a family.

“That’s important as these women are often considered to be worthless, as not worth having. I recall one woman we were working with who only had one hand, and in due course she married a man who didn’t have any disability. The fact that this man wanted her, despite her disability, was considered to be a very big thing. All the other qualities she had weren’t valued, just what she lacked.”

Wenche Willumsen also believes that international collaboration has given her a lot in return.

“It provides perspective and a sense of affinity. Even if they are at different levels, we all encounter discrimination and prejudices, and we can recognise ourselves in one another and in our physical shortcomings.”

Despite what continues to be a tough situation, Wenche Willumsen believes that there has been some progress in work on women’s rights. This is a view that is confirmed by her successor, Fredrik Canerstam, who is responsible for DHR’s international projects. As an example of this, he mentions how women with disabilities in the poor province of Monaragala in Sri Lanka organised a large demonstration the other year to demand their rights.

“The situation for women and gender equality was really bad in Monaragala. One of the biggest problems of all is the situation of women. One example is that many women are not allowed to go to meetings on their own. So the fact that they could organise a march for gender equality that brought together 400 people really was a big deal,” explains Fredrik Canerstam.

He says that the work carried out by the local partner organisation, WOPD, represents a big difference for many people. As an example, Fredrik Canerstam mentions how one woman in Monaragala has succeeded in becoming perhaps the country’s very first teacher who is herself living with a disability. Thanks to the local organisation, the school where she works has achieved much better accessibility than most other schools in the country.

Fredrik Canerstam says that the extensive work carried out over time by his predecessor in highlighting the situation of women also produced results at the very top of the country’s national organisation for people with disabilities, SLFRD. Half of its board members are now women. He emphasises that most of the work that has produced results is not down to the local partner organisation, but to the local activists.

“But with regard to gender equality in particular, we’ve made a difference, we’ve been

very clear about what we want to achieve in this area,” says Fredrik Canerstam.

DHR has made it a requirement that WOPD must focus more on work with gender equality, including the creation of a leadership programme that is aimed at women. Fredrik Canerstam believes at the same time that DHR can also learn from the partner organisations.

“As a Swedish organisation, we can see how closely to the members they work, and that there’s such an incredible level of enthusiasm,” says Fredrik Canerstam.

Liiso Åkerberg is active in MyRight’s member organisation the Swedish National Association for Disabled Children and Young People (RBU). They have an international initiative and are running a project via MyRight through the local partner organisation Asbath in Tanzania. Asbath is a parents’ organisation for children with spina bifida and/or hydrocephalus, or water on the brain as it was once known. You can read more about this project in the portrait of Hidayat Alawi later on in this report.

Liiso Åkerberg highlights another perspective that has a major impact on the lives of many women, namely how their lives can change if they have a child born with a disability.

“Most women we meet who are living with disabilities are doing so by taking care of a child. It can be like a punishment for women to have such a child,” says Liiso Åkerberg.

Many women who have a child with a disability are abandoned by their husband. Others can be frozen out by their own families or by their entire home village. Because of a lack of knowledge, it is common for relatives and neighbours to believe that there are evil forces behind the child’s disability. It is for this reason that Liiso Åkerberg believes that Asbath’s work to increase acceptance is incredibly important.

Those working in RBU’s partnership with Asbath are themselves parents of children with spina bifida or hydrocephalus. Liiso Åkerberg gave birth to a daughter with spina bifida 31 years ago, and now they are both involved in RBU and have visited the project in Tanzania together.

“It contributes to recognition and they’re fascinated when they meet my daughter. Partly because they realise that we too can be affected, and partly because she shows them that you can still live such a good life, that you can travel to Tanzania and live on your own, take care of yourself and run a business.”

The lack of financial gender equality is one of the many challenges that mothers of children with spina bifida and/or hydrocephalus can face. It can be difficult for a poor mother in a rural area to raise the money needed to take her child to a hospital. Especially as the needs of men often come first, according to Liiso Åkerberg.

“And if a mother has the courage to make sure that the child has the operation it needs, but it still doesn’t go well for the child, they can be made to live with a great deal of guilt,” she concludes.

Hannes Juhlin Lagrelius is on the board of MyRight and is also an administrator for international development collaboration within the Swedish Association of the Visually Impaired (SRF). This is an organisation that maintains partnerships with local organisations in many low and middle-income countries, including Rwanda, Nepal and Nicaragua.

He also points out that women with disabilities encounter structural discrimination in various areas that have an amplifying effect on each other. He believes that this is something that is overlooked by many working in the area of development. For a woman who also belongs to an ethnic minority or is an LGBTQ person, an additional dimension is added. Another example is low-caste women in South Asia. When Hannes Juhlin Lagrelius visited Nepal a few years ago, the partner organisation there had recently been given information about a case in a remote village up in the mountains.

“They’d been made aware that there was a girl in the village who was blind and was being regularly subjected to sexual attacks. She had no chance to either defend herself or to recognise the perpetrators, and she didn’t know where to turn for support,” explains Hannes Juhlin Lagrelius.

The partner organisation Nepal Association of the Blind reported that the girl had on one occasion been raped seven times during one single day. The local organisation decided to take urgent action.

“This isn’t something that these organisations usually do, but sometimes there’s no other option. They went and collected the girl in the village and took her with them. She was, of course, traumatised.”

The girl was taken to a home for women with visual impairments that had been set up with Swedish aid in the capital city of Kathmandu, where she was given protection and support by the organisation.

Hannes Juhlin Lagrelius emphasises that visiting activities that the partner organisations carry out in the field are extremely important in being able to change the attitudes of relatives to those close to them with disabilities. This is because visiting work is performed by people who have disabilities themselves, which means that they can serve as role models.

“If, for example, a person comes from an organisation with a white cane, this shows the families being visited that it is possible to create the conditions for a dignified life for their girl too. That’s when you can achieve genuine changes in behaviour.” Hannes Juhlin Lagrelius believes that this can be particularly relevant for girls, as parents are often especially resistant to sending a girl with a disability to school. When the local organisations receive information that girls with disabilities are being kept at home, they therefore often get in touch with parents to discuss the situation.

Mothers and children at one of the courses run by the House of Hope on caring for children with spina bifida and hydrocephalus.





WOMEN WHO MAKE A DIFFERENCE – STORIES FROM SRI LANKA, TANZANIA AND RWANDA

This report highlights some of all the problems and injustices facing women with disabilities in poor environments. At the same time there are strong women everywhere who are engaged in a tireless battle for their own and other people's rights, and who are combating the prejudices and ignorance of those around them. In the next section we meet three of these women: Kanchana Pradeepa de Silva, Hidaya Alawi and Donatilla Kanimba. They come from three different countries, but they still have a very great deal in common. They all use their own experiences to work, within MyRight's partner organisations, to improve the situation for other women.



SRI LANKA

Inhabitants: 22 million.

Capital city: The administrative capital is Sri Jayewardenpura Kotte, while the major city of Colombo is the country's commercial capital.

Just over 40 per cent of the population are below the age of 25.

A woman in Sri Lanka gives birth to an average of 2.09 children. With the aid of family planning, the birth rate has been kept down compared with other developing countries.

The Sinhalese constitute just over 75 per

cent of the population, while Tamils make up around 18 per cent. The country also has a Muslim minority.

The average age of women giving birth for the first time is 25.4.

Maternal mortality: 30 deaths per 100,000 births. In the list of countries where maternal mortality is highest, Sri Lanka is in 118th place out of 184 countries that were compared.

The literacy rate among all women is estimated at around 92 per cent, slightly lower than among men.

It is estimated that a girl attends school for an average of 14 years (same as for boys).

The average life expectancy is around 77, for women it is 80.

Sri Lanka has seen strong economic growth since the 26-year-long conflict in the country came to an end in 2009. The civil war started because of tensions between the majority Sinhalese population and the Tamil minority, and ended after the government forces had beaten the Tamil rebels (LTTE).

The country is viewed as a middle-income country in the lower class but is heavily in debt and depends on aid. Although the GDP per capita is twice as high as in neighbouring India, many inhabitants are still poor. The economy is based on agriculture and light industry.

(Source: Landguiden and CIA Factbook)

Sri Lanka ratified the Convention on the Rights of Persons with Disabilities in February 2016.

Kanchana Pradeepa de Silva is Chair of the Sri Lanka Foundation for the Rehabilitation of the Disabled (SLFRD). She fights in particular to reach out to girls and women with disabilities, who in many cases live in isolation from the rest of society. MyRight's member organisation the Organization for a Society without Physical Disability (DHR) has a partnership with SLFRD and Sri Lanka's national organisation for people with disabilities, the Disability Organisations Joint Front (DOJF). The purpose is to strengthen the local organisations, conduct lobbying work and strive to ensure that people with disabilities have greater opportunities for education and self-reliance.

KANCHANA WANTS TO OPEN THE DOOR FOR WOMEN THROUGH SPORT

When she was young, Kanchana Pradeepa de Silva viewed her disability as a punishment for sins that made life barely worth living. Now she is instead living an independent and active life with a good job in which she can drive her own car to train at the sports stadium. But what she is really passionate about is her work to give more women with disabilities the opportunity to break out of their isolation.

Kanchana
Pradeepa de Silva





Kanchana
Pradeepa
de Silva

Thanks to sport, Kanchana has been able to do things that she could not have imagined when she was a young girl growing up in rural Sri Lanka. As a member of the national sitting volleyball team, she has had the chance to travel to Italy, Korea, India and China to represent her country.

“Being able to travel abroad as a person with a disability was something I couldn’t even have dreamt of in the past,” she says.

Having reached the age of 42, she realises that her own sporting career, which alongside volleyball and rowing mainly involved athletics, is coming to an end. Kanchana’s goal is rather to encourage sport to open the door to the world at large for other girls and women who are living with disabilities.

This is despite the fact that the road to achieving this remains a long one – there are still very few women with disabilities who are actively involved in some form of sport.

We meet at the Diyagama Mahinda Rajapak-

sa Stadium just outside the major city of Colombo, an arena that was named after Sri Lanka’s former prime minister. He was in power when the government army, after decades of bloody civil war, succeeded in crushing the Tamil separatist organisation LTTE in 2009. To the amazement of many, the same prime minister lost his position after ten years in power in connection with the election in 2015.

The afternoon sun is baking the brownish green grass surface of the arena, the inner area of which is surrounded by worn running tracks and a bank of concrete terracing. Well-trained young people in shorts and running tops bring out a rattling trolley of hurdles, which they place on the track. They then sprint back and forth over the hurdles, seemingly untroubled by the thirty-degree heat.

For girls with disabilities, the hurdles that have to be overcome in order to take part in sport are of a completely different nature. Kanchana emphasises how important it is that these

girls also have the opportunity to exercise and meet friends. This is particularly important in a country like Sri Lanka, where many girls and women with disabilities are kept more or less locked up at home by their families. This creates isolation from the rest of society, which also risks resulting in more health problems.

“It’s much more common for girls to be kept out of sight at home compared with boys. Many parents don’t want their daughters to come out in public. Some are ashamed, while others are worried that their daughters might get into difficulties,” explains Kanchana.

Through her work at SLFRD, Kanchana wants above all to pass on information that can result in changed attitudes in rural areas. It is mainly a matter of breaking the isolation that affects so many people with disabilities. Outward-looking activities such as playing sport with others can play a decisive role here, she believes. “Girls with disabilities are at a particularly high risk of attacks such as rape, which they then keep concealed from those around them. If you start an activity you make new contacts, and it’s then easier to talk about such things with other people and get the support that’s required to have the courage to report it to the police,” says Kanchana.

Early every weekend morning, no later than six o’clock, she makes the half-hour journey from her home to the stadium to practise the discus and javelin.

She is wearing blue and white training gear and walks perfectly easily with the aid of a crutch as we make our way towards the discus circle. Kanchana has been paralysed in her right leg from birth, and until she was well into her adult years she found it far more difficult to walk than she does now.

One day, when she was training, a couple of men came up to her and said that help was available. The men were soldiers and maybe had colleagues who had been helped after being injured in the war. They advised Kanchana to obtain some leg braces and also knew where they could be bought.

“Once I’d bought the leg braces it was much easier to walk, previously I’d had to haul myself along. This is just one example of how important it is to be able to get out into society, that’s how we can get the knowledge we need. That’s why I’m so keen to help other people to also get a better life, by giving them access to the information they need,” says Kanchana with conviction. She has come to our meeting with a binder filled with press cuttings from her own career and a large bundle of medals. Kanchana is still active in a number of sports. She has still not given up on the dream of taking part in the Paralympics, even though she is now hoping rather to be able to take part one day as a trainer or coach of a ladies’ team. Kanchana says that she now has a very good life. She lives at home with her parents, but thanks to her job she is not financially dependent on them like so many other people with disabilities.

When she was young, her view of existence was nothing like as positive.

“At that time I often cried because of my disability. I didn’t want to live any more. The whole of society looks down on people with disabilities, and that’s also created a lot of suffering in my life. As a young person I thought that my disability was the result of some form of sin.”

In the rural area where she grew up, simply being able to get to the school bus was a challenge.

“Initially my mother carried me all the long way to the bus stop, where the school bus collected me.”

Thanks to support from the family, she was not only able to complete primary school, but also studied all the way to university. She now works with social insurance matters at the country’s Ministry of Finance. But getting there was no easy task.

“I’ve encountered many obstacles in my professional life and met many people who believe that a woman with a disability cannot perform the same job as others,” she recounts. Kanchana devotes most of the time left over after working

in the office and at training to work on enhancing the rights of people with disabilities. As well as being Chair of SLFRD, she is also Deputy Chair of the national organisation DOJF.

She is currently one of very few people with disabilities in Sri Lanka to have both a driving licence and her own car. The car has been adapted to meet Kanchana's needs with help from Sweden, thanks to contacts that Kanchana made through her involvement in associations. The car itself was a surprise gift from her big brother on her birthday two years ago.

"When I was given the car people said it was stupid, as I'd never be able to drive myself and would always be dependent on others to drive me. But now I drive myself everywhere. If you just have a target and a strong will, you can achieve most things," says Kanchana.

She now hopes that SLFRD will be able to take action to ensure that the manual control that she uses will start to be manufactured locally, so that more people in the same situation are able to enjoy the freedom that it means to be able to drive your own car.

The next day we meet again in SLFRD's combined office and workshop in the centre of Colombo, where people with disabilities work to manufacture aids for others with special needs. The ceiling fans are operating at full power inside the small office areas, and work on welding and assembly is taking place out in the small inner courtyard.

Kanchana has changed her training gear for a burgundy-coloured, gold-edged sari. Today there will be some office work, first of all a short spell here in the office and then on to the regular job at the Ministry of Finance. When we are ready, she jumps into her black car and turns it around quickly and expertly in the small car park to face in the correct direction of travel, before nipping smartly into a gap among all the three-wheelers and trucks thundering past on the busy street.



TANZANIA

Inhabitants: 52 million

Capital city: Officially Dodoma, but in practice the city of Dar es Salaam, home to five million, serves as the capital.

Almost one third of the population live in cities.

The majority of the population are Christians. There is also a large Muslim minority.

Just over two thirds of all Tanzanians are below the age of 25.

Population growth has remained high and an average woman in Tanzania gives birth to 4.8 children.

The average age of women giving birth for the first time is 19.6.

Maternal mortality: 398 deaths per 100,000 births. In the list of countries where maternal mortality is highest, Tanzania is in 23rd place out of 184 countries that were compared.

The average life expectancy is 62, for women it is just over 63.

The literacy rate among men is estimated at 83 per cent. It is much lower among women at just 73 per cent.

It is estimated that a woman attends school for an average of 8 years, just as long as men.

Economy: Tanzania is one of the poorest countries in the world in terms of income per capita. Yet tourism and the country's vast natural resources mean that the growth rate is high. Agriculture is, however, the most important economic sector and employs almost 80 per cent of the population.

(Source: Landguiden and CIA Factbook)

Tanzania ratified the Convention on the Rights of Persons with Disabilities at the end of 2009.

The Swedish National Association for Disabled Children and Young People (RBU) is running a project via MyRight in partnership with the local organisation Asbath in Tanzania. At the House of Hope outside the major city Dar es Salaam, mothers of children diagnosed with spina bifida and hydrocephalus (water on the brain) have an opportunity to learn how they can help their children in purely practical terms. They also receive the support they need in order to be able to see a future in an environment where having a child with a disability often carries a major stigma.

HIDAYA GUIDES OTHER WOMEN FOLLOWING HER OWN TOUGH JOURNEY

When Hidaya Alawi was 20 years old and gave birth to her first child, the first thing she heard from healthcare staff was that her baby was “abnormal”. Her daughter Amina was born with spina bifida. Like many other women in the same situation, Hidaya thought that this was all because she herself had done something wrong. Hidaya has now dedicated her life to providing other women with an opportunity to replace those feelings of guilt with knowledge of how they can help themselves and their children to have a functioning future.

After a long journey through the noisy traffic in the central areas of the major city of Dar es Salaam, past modern buildings and areas with very basic houses with rusty sheet-metal roofs, suddenly the landscape becomes greener and the air fresher. The clusters of houses and markets along the road gradually give way to fields.

When we arrive at Asbath’s centre, the House of Hope, the hubbub of the big city has been re-



Eflazia Kasiam with her daughter Lovems Emanuel, taking part in education about care at the House of Hope in Dar es Salaam, Tanzania

placed by birdsong and the gentle rustling of giant trees and palms. A small group of apes stand looking at us from a sand hill a short way away, before they disappear in a flash up into the treetops.

Many of the women and children who attend the centre come from the rural areas of Tanzania. Here they live in a clean and tidy dormitory with a chequered floor and have the chance to learn how to take care of their children. They are also told that it is not their fault that the children were born with spina bifida or hydrocephalus, and nor is it their fault if their husbands and families chose to abandon them. Because that is not an unusual scenario, explains Hidaya Alawi.

“Many women who have children with spina bifida or hydrocephalus are abandoned by their husbands. We have a woman with us just now who’s been rejected by her husband and her family. Her child has hydrocephalus. At the moment we’re considering how we in Asbath can help her when she goes back.”

It is the accepted custom in rural areas of Tanzania that responsibilities for children rest with mothers. During our visit there are eight women at the centre together with their children. They have come here to acquire practical knowledge of how they can take care of their children. But Hidaya emphasises that their stay here is initially often about something else.

“The first thing is that the mothers must to accept the situation facing them and their children. Many of the women come from a long way away and they travel here alone. They have no knowledge of the challenges that these children face.”

Hidaya says that it is usual for mothers of children with this disability to seek help from local traditional healers, or “witch-doctors”, which often results in children dying because they never receive the proper care that they need.

Hidaya herself is 39 years old now and is clearly proud of both the work of the House of Hope and her own journey. During our conversation she speaks English, but she switches to Swahili when discussing more private matters. She knows from her own experience how difficult the situation can be for a new mother

of a child with spina bifida. Before her daughter Amina was born, she had married a man who offered her a way out of a family situation characterised by severe poverty and all her brothers being in prison.

Getting married seemed like the only alternative. Yet Hidaya was very strong-willed as a young woman and one of the demands she made in order to get married was that she should be able to continue her studies and have an education. After the birth, she was not at all as certain that life could turn out the way she had imagined.

“Now I feel happy to have had my child. But just after I’d given birth to my daughter I wondered whether I’d ever be able to achieve my goals. Taking care of a child with a disability takes a lot of time,” she says.

She received no support at all from healthcare staff immediately after the birth.

“When the nurse saw my child, she said that the child was abnormal and showed a wound on her back. I tried to get more information from the doctors, but the answers they gave just confused me.”

Nor did she receive any support from the child’s father. He had problems with drugs and more or less disappeared from the family’s life. But Hidaya spent the first years living with her daughter at the home of the man’s family. At the time she was forced to live together with a mother-in-law who believed that it was Hidaya’s fault that the girl had been born with spina bifida.

“She rejected the child and said that she was a curse and an accident for the family. In my family there’s another child who was born with Down’s syndrome, so she said that it came from my family.

At the parents-in-law’s family home, Amina’s grandmother used to lock the door to her room so that the grandchild would not be able to creep in there.

“When visitors came, she used to tell them not to touch my daughter because there was a risk that her ‘disease’ would be passed on.”

Life at the home of the mother-in-law was unpleasant during the four years it took before



she divorced her absent husband.

“It was difficult, with constant arguments. Sometimes I moved back home to my family for a couple of weeks, but then I moved back again. I was married, after all,” she says.

It is not unusual for children born with disabilities in poor countries to be considered to have been cursed, as punishment for the sins of the parents, and especially the woman. In Hidaya’s case, her own family believed instead that it was the mother-in-law who had placed a curse on the girl. So they turned to a traditional healer, a so-called witch-doctor.

“But the witch-doctor said that there was no curse, but that the child was God’s creation. I was supported by my family because I cried so much. They said that I should trust in God to help the child.”

Thanks to the fact that Hidaya came into contact with an organisation, she was able to make sure that Amina received care at a private clinic, where Hidaya also learned how to take care of her daughter.

In due course the organisation also helped

Hidaya to access additional education and a job. She educates other new mothers about spina bifida and hydrocephalus. This is a job she has been doing for more than ten years. She has been Chair of Asbath for a year.

Hidaya starts a new lesson for the women currently at the centre. The women sit down with their children on two large rugs in an outside room with a tiled floor. The roof offers protection from the hailstorm that suddenly arrives, replacing the strong sunshine.

“It’s very important that you use clean water and that first of all you wash your hands carefully,” says Hidaya as she shows the mothers how to help their children with the catheter they need in order to be able to meet their needs.

The women listen attentively and ask questions, while holding their children in their arms or letting them rest on one of the large cushions that are scattered on the rugs. The concentrated atmosphere is broken occasionally by laughter, as one of the women makes an interjection.

The help on offer here at the centre is unique, but the parents’ association Asbath also has

Hidaya Alawi providing education for a group of women at the House of Hope.



several local associations out in the country that offer education. The organisation also organises meetings with authority representatives and local healthcare clinics, in order to increase their knowledge of spina bifida and hydrocephalus.

“Many doctors and nurses have very poor knowledge,” says Hidaya.

Hidaya now lives without a husband together with her daughter and her younger son on the other side of town, which means a long bus journey to work every day.

Things have gone well for her daughter. Amina is now 18 years old, and thanks to Hidaya’s engagement and contacts she has managed to have an education at a private school. She is now at upper secondary school and dreams of studying medicine, reports Hidaya with pride. Amina can do most things for herself and knows when she needs to go to the toilet.

But far from all children who are born with spina bifida or hydrocephalus are as fortunate as Amina, who has had access to both care and a parent who has understood her special needs.

“When a child with a disability is born, the blame is often placed on the women. The local population often believes that it is because the mother has previously used contraceptive pills, for example. But it’s even more common for people to believe that the reason is trouble in the family during the pregnancy, or that the woman has been bewitched.”

Hidaya never forgets what it felt like during the first few years after she had given birth to Amina. During that time she believed that she had caused the girl’s disability herself, by bringing down a curse or by having taken the wrong medicine for her recurring stomach problems. It was only when Amina was given help at a proper clinic that Hidaya found out that spina bifida can be caused by a lack of folic acid, and that her daughter’s condition had nothing to do with medication or any curse.

“I was so happy and I thanked God when I realised that I wasn’t the one who had caused the problem. I promised that I’d take care of this child,” says Hidaya.

RWANDA

Inhabitants: Around 12 million in an area smaller than Småland.

Capital city: Kigali, about one million inhabitants.

Rwanda is one of the most densely populated countries in Africa.

60 per cent of the population are below the age of 25.

The vast majority of the population are Christians.

The average life expectancy is just over 60, slightly higher for women.

In recent years the country has succeeded in reducing the rapid population growth with the aid of increased access to contraception.

In 2005 the average Rwandan woman gave birth to 5.6 children. In 2016 the figure had fallen to 4.5 children.

A woman is on average 23 years old when she gives birth to her first child.

Maternal mortality: 290 deaths per 100,000 births. In the list of countries where maternal mortality is highest, Rwanda is in 35th place out of 184 countries that were compared.

It is estimated that both boys and girls attend school for 11 years.

The literacy rate among men is estimated at 73 per cent, while the figure for women is 68 per cent.

Economy: Almost 90 per cent of Rwanda’s population work in agriculture. The country’s foreign income comes primarily from tourism, coffee, tea and minerals. The genocide in 1994 resulted in large parts of the population ending up in poverty. Since the genocide, the country has steadily rebuilt and the economy has improved significantly. Since 2003 the annual rate of growth has been between 7 and 8 per cent. According to public information,

however, in 2015 39 per cent of the population were still below the poverty line.

President Paul Kagame has been governing the country since the turn of the century.

(Source: Landguiden and CIA Factbook)

Rwanda ratified the Convention on the Rights of Persons with Disabilities in 2008.

Donatilla Kanimba is Chair and one of the founders of the Rwanda Union of the Blind (RUB). The Swedish Association of the Visually Impaired and the RUB work together to educate, engage and provide a voice for people with visual impairments in Rwanda. The partnership takes place through MyRight, and also aims to enhance the rights of the visually impaired, which is also an important goal for all of the RUB's local organisations in the country.

DONATILLA – THE BLIND GIRL WHO WAS DISPLACED AND BECAME A ROLE MODEL

Donatilla Kanimba started her life with most odds against her. She had been forced at an early stage to flee her home country of Rwanda together with her parents, was blind and was also a girl in a society where boys always enjoy a higher status. She is now 60 years old and has not only succeeded in realising most of her aims on a private level. She has also built up an organisation that has changed the lives of many blind and visually impaired Rwandans.

Rwanda's capital city Kigali is in an incredibly beautiful location, with perfect asphalt roads that wind their way up the many green hills around which the city is anchored. The climate

is mild, most things are well-ordered and clean, and the traffic is relatively calm. Developments have moved quickly in the country and in many ways the future looks bright for the population, despite the terrible recent history that Rwanda has experienced. But large parts of the population still live in poverty, even though this is less obvious in the capital, where there is now no shortage of either fine restaurants or trendy bars with swimming pools at the smartest hotels.

Yet for those living with disabilities, especially women, there is still much to be done.

Things were not this well-ordered in Kigali when Donatilla returned to the country of her birth in 1996, just two years after the genocide. At that time you could barely even find a sandwich at one of the few cafés there were in the city, she explains. The lack of night-life and restaurants was almost a culture shock for Donatilla, who had grown up and been shaped by the far more modern big city of Nairobi in Kenya.

What enticed her to come back was the opportunity to become involved in building up the organisation that she had helped to found from her home at the time in Kenya, the Rwanda Union for the Blind (RUB). The organisation had been formed in order to fight on behalf of all the blind and visually impaired Rwandans who at the time were hardly ever seen in public, apart from in the role of beggars.

“When we started the RUB it was a totally new thing in Rwanda, an organisation for disabilities that was run by people who had a disability themselves,” says Donatilla.

Since then, she and the RUB have played a very important role in work to improve the lives of blind and visually impaired people, by lobbying and offering education to individuals. And by encouraging people to have the courage to get out from their confinement at home. But the initial period also involved purely humanitarian initiatives for the RUB.

“Following the genocide, many blind people were confused and were being forced to look after themselves, as their relatives had been displaced or killed. It was awful. Some of them



Donatilla
Kanimba

had only been able to survive thanks to generous neighbours,” explains Donatilla.

She is sitting in a leather office chair at the RBU’s head office, which is in an attractive old building at the edge of a lush valley in central Kigali. Donatilla exudes a commanding presence, speaks perfect English and before the interview she asks astute counter-questions in order to have the conditions for her involvement clarified in full.

She has been blind since she suffered an eye disease at the age of five, probably a disease that usually affects only boys, she says. Although she was never given a clear answer. In the previous year, 1961, her family had been forced to flee to the neighbouring country of Burundi to escape the ethnic violence that had broken out in Rwanda. It was the same kind of ethnic violence, although much worse in its scope, that would focus the eyes of the world on this small country in East Africa 33 years later.

When Donatilla became blind, her parents were told about a boarding school near Nairobi that specialised in educating blind and visually impaired children. This resulted in Donatilla once more changing her homeland, as she moved into the Kenyan boarding as a lone six-year-old.

“I was incredibly lucky to have the opportunity to go to that school. At the time there were only three such schools in Kenya, and the one I went to was the oldest and best in the country.

Thanks to that I had an education.”

She was only able to travel home and see her parents in Burundi once a year, but she finished with top grades and was then awarded a grant to enable her to continue her studies at university in Nairobi. But it was not an easy journey. Donatilla was the only blind student in her year, and the university offered no aids whatsoever.

“In time I found help, thanks to a Catholic organisation, and had course literature read aloud to me, but to begin with I had to rely other students to help me with reading. When the exams came along, it was up to me to contact teachers to remind them that I was also there and I needed to take the tests. There were no procedures about how it should be done, so I was forced to make my own arrangements with teachers.

Sometimes I was given access to my own typewriter, at other times I had to do an oral exam.”

Despite these difficulties, Donatilla almost always succeeded in getting top marks in the exams.

“I had a strong desire and was firmly resolved to get myself a university education and then a job. After all, I achieved top marks before, so why shouldn’t I study at university?”

And that is what happened. After a couple of similar jobs, her engagement with the rights of people with disabilities took off when she started working for the Kenyan Union for the Blind.

When the political situation in her homeland finally calmed down, she realised that there was a great deal to do in the war-ravaged nation. She founded the RUB together with another Rwandan in exile, and in 1996 the time came for Donatilla to travel back to the country she had left at the age of four.

“By then my own family had also moved back.

The RUB also needed someone who could get the organisation up and running, and that was me,” she says.

The RUB now has 75 local departments all over the country and also runs an education centre, the Masaka Resource Center in Kigali. It is

a short journey by road outside the city, in a few blocks of single-storey brick buildings. The setting is rural and the centre is surrounded by its own plantations. Since the beginning 17 years ago, almost 750 visually impaired and blind people have undergone a six-month rehabilitation course here, one that has in many cases changed their lives. At the centre they learn, among other things, Braille and agricultural work, but above all to be confident enough to do things for themselves and to realise how much they can actually do, despite their disability. Their immediate family members are also given help to understand their true competences.

Working to boost self-confidence is particularly important for the many girls and women who come to the centre, emphasises Donatilla.

“Women often have poorer self-confidence than men. This is to do with how things are in our culture, where the man is traditionally in charge and is considered to be the head of the family. Boys are considered to be worth more than girls, and men are valued more highly than women. A woman who loses her sight essentially loses all of her rights.”

Just over half of those offered education at the centre are women and girls. Almost everyone who comes here is very cautious and hesitant

at first. Many of them have lived a life in which their abilities have never had the chance to blossom, they have instead been helped by their relatives to do most things. Even when it comes to many of the everyday tasks that they prove that they can do well themselves after just a few months at the centre. This is perhaps the first time that they have been able to go out and walk on their own. Initially, most visually impaired and blind people need to build up confidence in their own ability.

“With the women, this means that we must start right from the beginning,” explains Donatilla.

The RUB is also working at a local level to empower women. This takes place through special women’s committees in the local associations.

“This gives women an opportunity to discuss their problems. And if problems are discovered that they are unable to resolve themselves, they can come to us at head office as we try to help.”

One typical example is when the husband of a visually impaired or blind woman has announced that he wants to take a wife. This usually results in the first wife in due course being mistreated and maybe even cast out.

“When we become aware of something like this, we have to act by making contact with the



local authorities and make demands that the first wife must be able to arrange a divorce so that she receives her share of the joint property,” says Donatilla.

Another recurring problem for women is that relatives do not consider that a blind family member has the same right to property as others. “It’s a problem that women with visual impairments encounter more often than men,” says Donatilla. Even if she herself found it rather difficult to adapt to life in Kigali after having lived almost all her life in exile, she is now very happy in the city and has created her own roots here after having raised her sister’s four children on her own. Just after Donatilla had returned to Rwanda, her sister fell ill and died of cancer, leaving four children aged between five and fifteen. Initially the grandmother took care of the children, but Donatilla soon realised that this was too demanding a task for her mother, who was by then just over 70 years old.

“I decided then to move in with them, and it became my job to take care of the children. Bring up four children wasn’t easy, as I was totally unprepared for it. But it felt good at the same time, being part of a family and feeling that I was of value.”

Donatilla says that she took on responsibility for the children just as she was all geared up to devote her full commitment to her job. Now, all of a sudden, she was forced to try and combine both roles, while at the same time providing for six people instead of just herself.

“When these things happen, you have to make the best of it. For my part, there was no one to provide for me if I didn’t do it myself, as I didn’t have a husband, and there was no one else in my family who could look after me either,” says Donatilla.

Now only the youngest child is still living at home with her.

“The others have now grown up and moved out of the home. Two of them have children of their own, so now we have two new additions to the family,” says Donatilla, breaking out into a wide, proud smile.



Jeanne Uwingeneye taking part in rehabilitation at the Masaka Resource Center.



RECOMMENDATIONS

RECOMMENDATIONS TO THE GOVERNMENT AND OTHER DECISION-MAKERS

- 1] Include a disability perspective in feminist foreign policy.
- 2] Link sustainable development goal five on gender equality to the situation for women with disabilities. The inclusion of women with disabilities makes Sustainable Development Goal 5: Gender Equality possible.
- 3] More states must drive issues relating to the particularly vulnerable situation facing women with disabilities. Sweden has a unique role with a well-established disability rights movement and lofty ambitions with regard to gender equality issues. The Swedish government can raise these issues in many contexts in which it operates.
- 4] Lobby for the inclusion of women with disabilities in the world when drawing up aid strategies.
- 5] Work to achieve greater representation of women with disabilities in the international committee that monitors the implementation of the UN Convention on Rights for Persons with Disabilities.
- 6] Clearly highlight specific initiatives for women and girls with disabilities in the aid budget.
- 7] Adopt a cross-party approach to create a consensus on issues relating to women with disabilities.
- 8] Make sure that Sweden pursues a policy, world-wide and at home, to counteract the double discrimination often faced by women with disabilities.
- 9] Include disability organisations that work with a gender perspective in development partnerships. This must happen at all levels: structuring, implementation and execution.
- 10] Require that initiatives with Swedish development funding are also used to build and develop national statistical authorities in order to improve the statistics on people with disabilities, and in particular women with disabilities.
- 11] Provide greater support for studies and re-

search into the global situation for women with disabilities.

12] Mandate Sida to include women, men and children with disabilities when they measure initiatives and results.

13] Mandate Sida to identify whether Swedish collaborative partners have policies and procedures for anti-discrimination and inclusion within their respective organisations.

14] Mandate Sida to observe how aid recipients and cooperation partners work to include the disability perspective relating specifically to women with disabilities in initiatives.

15] Mandate Sida to map out and analyse how the authority is working at present with the disability perspective relating specifically to women with disabilities in the bilateral, regional, global and thematic implementation of strategy. This is in order to enhance knowledge among administrators in due course and to investigate how this perspective is currently included in work, and to prevent active exclusion.

LISTS OF TIPS FOR ACTIVISTS

Tips to those active within civil society organisations

1] Learn more about the global situation for women with disabilities and the link to the global sustainable development goals, ideally in collaboration with several organisations and parties.

2] Learn more about the UN Convention on Rights for Persons with Disabilities (UN-CRPD) and about the UN Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW).

3] Invite MyRight and those active on its projects who are working with women in the disability rights movement globally in order to acquire greater knowledge and to create a dialogue on issues concerning the global situation for women with disabilities.

4] Pass on your newly-acquired knowledge of double discrimination that is often aimed at women with disabilities and how different actors can work actively to counteract this being perpetuated.

5] Evaluate and analyse how your organisation can include women with disabilities in your activities. Take into account the situation of women with disabilities when you are working on important issues such as democracy, human rights and sexual and reproductive health rights (SRHR).

6] Are you running an international development project? Be aware of the double discrimination often faced by women with disabilities and work actively to include them in your activities. Include this perspective when planning, implementing and following up on partnership projects.

7] Make your organisation accessible to all, including people with disabilities. Create accessible meetings and materials. Adopt a long-term approach for structures that benefit diversity and combat discrimination.

8] Collaborate and maintain a dialogue with organisations that work with disability-related issues and/or gender-related issues.

9] Make sure that everyone in your organisation has access to the same information, regardless of gender.

10] Create a forum that guarantees that all participants feel safe to share their views.

11] Help MyRight to change the world by supporting our activities.

If you are actively involved in a disability rights organisation, you can also become members of MyRight and create your own partnership projects with partners in low- and medium-income countries.

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