



CONQUERING THE WORLD

A report on the links between poverty and disability

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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 partner 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.

Members of MyRight are:

Swedish Asthma and Allergy Association

Swedish Autism and Asperger Association

DHR – The Organization for a Society without Physical Disability

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

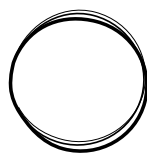
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SUMMARY

When people with disabilities are included, the conditions are created to eradicate extreme poverty in the world. This work involves many challenges, but also great opportunities.

It is clear that there are several links between poverty and disability. Poverty contributes to people being born with and living with disabilities. Functional impediments in societies all over the world also mean that people with disabilities continue to live in extreme poverty.

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 means marginalised and particularly vulnerable groups such as people with disabilities.

Sustainable development goal number 1 states that extreme poverty shall be ended for all people everywhere by 2030. All countries must strive to ensure that such work is possible. At an international level, Sweden can exert influence in the right direction through its global development policy. The Swedish government has confirmed that initiatives to combat poverty shall be characterised by a rights-based perspective. There are, however, still several challenges, not least from a disability perspective. The

government and aid agencies must acquire more knowledge about issues relating to people with disabilities. Better use needs to be made of expertise that exists in other authorities and actors in society at large, and the issue of disability and its link to global poverty needs to be continuously updated in various crucial areas such as the law, supplies and education.

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. By making use of and developing resources and abilities in people with disabilities, these projects are also making a contribution to positive social development. Three member organisations in the report bear witness to this. Carina Pettersson describes a project in Nepal in which the Swedish Autism and Asperger Association is involved there, Sven-Arne Persson from the Swedish National Association for Persons with Intellectual Disability (FUB) describes a project in which they are involved

in Nicaragua, and Hamaddah Mansour from the Swedish Association of the Visually Impaired (SRF) describes a project in which they are involved in Bosnia and Herzegovina.

In this report we also meet Sameera Sandarwan from Sri Lanka, who has restricted mobility, Sada Igikundi from Rwanda, who is deaf-blind, and Nindi Mtumwa Shafi from Tanzania, who is living with mental illness. They offer their personal accounts of the functional impediments they have experienced as a consequence of their disabilities. They also describe how they have found ways out of isolation and been given an opportunity to influence their own living conditions.

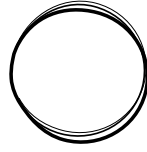
At the end of the report, MyRight offers recommendations about how we can contribute to achieving of the global sustainable development goal for poverty from a disability perspective. We are addressing the government and other decision-makers, but also offering tips to activists in the disability movement and civil society organisations working in the field of global development.

In line with the Swedish National Board of Health and Welfare¹, disability and functional impediment are described 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.

1 Swedish National Board of Health and Welfare http://www.socialstyrelsen.se/fragorochsvar/funktionsned-sattningochfunktio#anchor_2

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FOREWORD

MyRight's Secretary General Tiina Nummi-Södergren on her thirty-year involvement in disability issues internationally, and on the difference between something and nothing.

On my first visit to Sri Lanka in 1987, I met a young woman with a visual impairment who lived with her cousin's family. The woman wanted to contribute to providing for the family by sewing cloths and selling them at the market.

This was a young woman with hopes for the future and I am ashamed that at the time I underestimated her ability to change her life. I now know better and hope that things turned out well for that young Sri Lankan woman and her family.

Over the 30 years that I have had the privilege of working on an international level with disability issues, I have met farmers and craftspeople with disabilities who contribute to their family's income every day. The difference between something and nothing really is a very big one. The contribution is enormously important not only for the individual person, but also for the country in which that person lives and works.

MyRight's operations are rights-based and aim to strengthen individuals and organisations so that they can influence the societies in which

they live. One of MyRight's objectives is that people with disabilities and their families shall be able to live inclusively in the societies where they live and work. Another is to strengthen individuals so that they can take themselves out of poverty and contribute to providing for themselves and their families.

The UN Convention on Rights for Persons with Disabilities is an important tool in work to eradicate functional impediments all over the world. Agenda 2030 with its new sustainable development goals is a new, important precondition for no one having to be excluded any more.

The first goal about reduced poverty is key to achieving a sustainable world. And unless people with disabilities and their families are included in work to combat poverty, we will never be able to combat poverty in low-income countries or anywhere else. People with disabilities and their families are very much over-represented among extremely poor people.

It is positive that the group of people with disabilities is mentioned in many of the glob-

al goals. The fact that this group is addressed and demanded specifically is a precondition for reaching those who are living in extreme poverty. Maybe then we can finally start talking seriously about not excluding anyone.

In this report, MyRight wishes to illustrate the close link that exists between poverty and disability. We also wish to show that by giving those of us with disabilities the right opportunities, we can achieve greater empowerment and freedom, and also greater societal impact. Including people with disabilities in future global progress

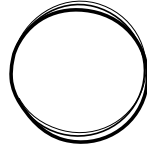
is the solution, and also a requirement if Agenda 2030 and the sustainable development goals are to become a reality. “Our solution: Inclusion.”

The report contains interviews with decision-makers and individuals from authorities, as well as people in Sweden and in the world at large who are active in or affected by one of our projects.

I hope that you, the reader, find this interesting and worth reading.

Sada Igikundiro





CLEAR LINKS

BETWEEN POVERTY AND DISABILITY.

No one should be left behind. These are the keywords in the global development policy that the world's nations agreed on in September 2015. All nations in the world have committed to creating a sustainable future and eradicating poverty by 2030. But for this to succeed, people with disabilities must also be included in a totally different way than is the case today.

Extreme poverty has declined significantly in recent decades. The number of people in extreme poverty was estimated to be 767 million people in 2013. This is a reduction compared with 1981, when 1.9 billion people were living in extreme poverty. Over the same period, the global population has increased from 4.5 billion to more than 7 billion inhabitants. So the proportion of people living in extreme poverty in the world has fallen rapidly over the last 35 years.

While many countries have experienced positive economic growth with reduced poverty, the gaps between individuals and groups have increased. This is about inequality that is often based on gender, age, ethnic origin, economic or social status – and not least of all disability.

The link between poverty, development and disability is clear, as people with disabilities are at greater risk of being poor, while at the same time poverty creates an increased risk of disabilities¹.

1. WHO. World Report on Disability, page 10. 2011.

The UN's development agency, UNDP, estimates that there are one billion people on earth who are living with some form of disability². In most societies, people with disabilities are among the most marginalised.

Injustice and discrimination against people with disabilities are often the result of inadequate knowledge in the local environment. It is not unusual in poor countries for ignorance of disabilities to result in the emergence of myths. Examples of myths are that disabilities are caused by curses that have been placed on the family or that disabilities are contagious³. Later in this report you can read about Nindi from Tanzania. Her account is an example of the potential consequences of a lack of knowledge about disabilities. Nindi describes how her family thought that she had been the victim of a curse when she suffered from mental illness.

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

3. UNICEF. Children and Young People with Disabilities Fact Sheet, page 4. 2013

The family took her to a local “traditional healer”, or “witch doctor”, who claimed to be able to help her, instead of giving her the support that she really needed.

If the world is serious about no one being left behind, it is clear that work to combat discrimination against people with disabilities must be prioritised. This is quite simply a precondition for Agenda 2030 becoming a reality.

ABOUT THE TERM ‘POVERTY’

One out of three of the world’s citizens live below “low levels of human development”, confirms the latest version of the UNDP’s annual Human Development Report. Almost 1.5 billion people are living in multi-dimensional poverty, a term used to describe more aspects of poverty than just the economic aspect.

Poverty relates to a person’s opportunity to be able to eat their fill of nutritious food and avoid being malnourished, to have access to clean drinking water and thus be able to avoid illnesses, the right to go to school, the opportunity to obtain healthcare and to have an influence over their own life and their future. As well as the right to be able to feel secure. People with disabilities are often denied many of these rights. The World Bank’s definition of whether a person is living in extreme poverty is set at when a person’s income is less than the equivalent of 1.9 dollars per day, approximately 17 Swedish kronor. 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 survive⁴.

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 going hungry.

Poverty is also a question of power

A person who is suffering poverty is often also denied their human rights and has poorer opportunities to change their life. This is particularly evident for people who are living with a disability.

The World Health Organization (WHO) confirms that disabilities are closely associated with human rights issues. People are subjected to gross injustices when they are denied healthcare, education, work and the opportunity for political participation because of their disabilities⁵. People are violated in the same way when they are the victims of violence, attacks and prejudice because of their disabilities.

A number of studies from various parts of the world have shown that people who live with disabilities and their families are at a significantly higher risk of suffering economic and social injustice than others.

Families in which one or more family members are living with disabilities can also be hard hit economically. Hours of work may be lost if someone needs to be cared for in the home, and other financial costs may also be incurred.

Many countries have no social security system. Without a security system, it is the families who have to make up for the shortcomings of society as best they can. Which naturally hits those hardest who are already poor or a living just on the verge of poverty.

The UN body the International Labour Organization (ILO) highlights the need for basic national social protection in one of its recommendations (number 202). The objective is that basic social protection shall constitute a floor and thus provide basic protection that also covers those who do not have a job and thus constitute the very poorest people. Basic social protection shall include all and is particularly important for especially vulnerable groups such as people with disabilities.

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

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



People who are poor are at greater risk of various forms of disabilities because of poor healthcare, malnutrition, inadequate access to clean water and working toilets. The fact that people who are poor live in hazardous environments and work in hazardous working conditions⁶ also increases the risk of disabilities. Poverty also forces people to live in poorer housing and close to dangerous traffic, which increases the risk of, for example, falling victim to traffic accidents. Poorer housing and fewer opportunities for protection also mean that conflicts and natural disasters hit poorest people the hardest. This represents another increased risk of suffering a disability.

The labour market is often essentially closed to people with disabilities. There are many challenges facing those who have succeeded in getting a job, and various obstacles make it difficult to keep a job.

6. UNICEF. Children and Young People with Disabilities Fact Sheet, page 6. 2013.

Malnutrition increases the risks

It has been well documented that malnutrition among pregnant women and small children risks resulting on delayed development and a greater risk of disabilities in children⁷.

If a pregnant woman is suffering from malnutrition, this can have a negative effect on the foetus and the child's physical and intellectual development. Children who lack important nutrients can be affected in their development. An iodine deficiency during the time when the brain is developing can result in disabilities, a vitamin A deficiency in blindness and a weakened immune system, while a folic acid deficiency increases the risk of a low birth weight and spina bifida⁸.

A vitamin A deficiency is a major global

7. UNICEF. Stronger Together Nutrition-Disability Links and Synergies Briefing Note, page 3. 2011.

8. <https://unicef.se/fakta/undernaring>

problem and is estimated to cause between 250,000 and 500,000 children to be born blind every year⁹. This is a problem that can easily be addressed with the aid of cheap vitamin A supplements.

Disability can also result in malnutrition. This happens when the family does not prioritise a person with a disability as highly as other family members at the dining table, and when a person with a disability does not always receive the help he/she needs in order to eat. A disability can also result in subsequent health problems for the person in question. This can happen when families for various reasons do not allow a relative to leave the home, which inhibits the person's physical and general development.

Fewer go to school

In recent years there has been a rapid global increase in the proportion of children going to school. But according to UNICEF, the UN children's fund, there are still at least 58 million children in the world who are being deprived of their right to go to school.

Children with disabilities attend school to a lesser extent compared with other children. Poverty is one of the most common causes. One contributory cause might also be that children are kept at home by their parents because of the stigma that disability represents for the family, i.e. society categorises people on the basis of properties, in this case disability, and devalues people on that basis. Mothers of children with disabilities are particularly hard hit by such stigmatisation in many societies. Another cause of low levels of school attendance for children with disabilities might be that schools are not accessible for students with special needs.

Older students with disabilities can also drop out of school when educational materials for students with, for example, impaired vision or hearing, are only designed for the youngest children. Another reason might be that parents do not see the same potential for a child with a disability as

for other siblings, and therefore do not prioritise that child's studies as highly.

For obvious reasons, children who do not attend school have much poorer prospects in the labour market and are at a much higher risk of ending up in poverty.

MAJOR LACK OF GLOBAL STATISTICS ON DISABILITIES

There is a lack of reliable global statistics about people with disabilities. There are many reasons for this. The hidden number can be high in societies where there is a stigma attached to disability. And if people are hidden from public view, it is not surprising that they are not included in statistics. One example of unrecorded figures comes from a survey conducted in Sierra Leone in 2004. The survey reported that there were only 3,300 people with an intellectual disability in the country. This was in conflict with a thorough national survey from the previous year, which stated that the actual figure was probably ten times higher¹⁰.

Some children who are born with disabilities are not even registered by the authorities.

The WHO points out that reliable, relevant statistics about people with disabilities are extremely important for the formulation of political initiatives. Ideally, the UN body would like to obtain standardised data that can be compared between countries. Standardised data would be important in gaining a better understanding of the impact of various initiatives. Data is also important in order to compare how different

9. UNICEF. Children and Young People with Disabilities Fact Sheet, page 27. 2013.

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

countries are carrying out work on the UN Convention on the Rights of Persons with Disabilities in practice¹¹.

Work is under way to change the UN's guidelines for the so-called household surveys, surveys that are conducted on an ongoing basis in many countries. If questions are asked regularly about the existence of disabilities in connection with household surveys, it could provide a better common statistical base.

Despite the inadequate statistics, bodies such as the WHO and the World Bank have produced estimates of the global situation:

↘ **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. This means that people who live with disabilities constitute the biggest minority in the world.**

↘ **It is estimated that almost 80 per cent of those living with a disability live in low- and middle-income countries¹². In these countries the proportion of people with disabilities in all age groups is higher than in high-income countries¹³.**

↘ **People who live with disabilities are at a significantly greater risk of suffering socioeconomic injustices than others. These include access to education, good health and healthcare, and also the labour market. They are also more likely to suffer poverty.**

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

12. SIDA. Human Rights for Persons with Disabilities, page 14. 2009.

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

↘ **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 disability¹⁴.**

↘ **Almost nine out of ten children living with disabilities in developing countries do not attend school¹⁵.**

↘ **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 cent¹⁶.**

↘ **Poverty is a strong contributory factor to disability. At the same time, disability has a tendency to lock people into poverty. Families where one or more are living with disabilities are at increased risk of living in poverty. One cause of poverty is that working time is lost because time is spent on care¹⁷.**

Inclusive initiatives can provide great societal benefits

A failure to carry out initiatives for people with disabilities is very expensive. Countries that do not give everyone the opportunity for education miss out on large amounts of potential income from people who could otherwise have contributed to those countries' development.

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

15. UNITED NATIONS. Disability and the Millennium Development Goals, page 18. 2011.

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

17. UNICEF. Children and Young People with Disabilities Fact Sheet, page 16. 2013.

A report launched in October 2016 by the International Disability and Development Consortium (IDDC) reveals that every year multi-billion amounts of income are lost to the world's low-income countries. Not investing in inclusive schools and workplaces is therefore contrary to economic logic.

The authors of the report highlight, among other countries, Bangladesh. It is estimated that every year this impoverished country loses out on income corresponding to 1.2 billion dollars because of a failure to invest in making sure that people with disabilities have an opportunity to get an education and be productive in work. This represents around 1.7 per cent of the impoverished country's gross domestic product¹⁸.

Furthermore, UNICEF, the UN children's fund, points out that inclusive education also has a positive impact on society at large. The positive impact is achieved by students without disabilities who attend inclusive schools gaining a better understanding of diversity. This also prepares them better for creating a society in which all people are included¹⁹.

UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities was adopted by the general assembly in December 2006. The Convention has been in force in Sweden since 2009. This means that all laws and all public activities in Sweden must comply with the articles in the Convention.

The Convention aims to promote, protect and safeguard human rights and fundamental freedoms for persons with disabilities.

Persons 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 persons with disabilities from having the opportunity to exercise their human rights.

From Millennium Development Goals to Agenda 2030

The UN's Millennium Development Goals were a set of eight goals that aimed to drastically reduce poverty and inequality in the world by the year 2015. The millennium development goals did not, however, have specific goals for all of the people around the world who are living with disabilities. But in the new global development goals, Agenda 2030, people with disabilities are one of the prioritised groups.

The world's countries agreed on the millennium development goals before the year 2000. But according to the International Disability Alliance (IDA), the lack of initiatives for hundreds of millions of poor people with disabilities in developing countries meant that it was in practice impossible to achieve the millennium development goals²⁰.

When the millennium development goals had to be reformulated to create new global objectives ahead of 2015, the international disability movement therefore worked to ensure that the new goals should be more inclusive and fair. The IDA and the International Disability and Development Consortium (IDDC) demanded that they should focus on the poorest, most marginalised groups in the world – people with disabilities. Another demand was that the global development goals should be in line with the UN's Convention on the Rights of Persons with Disabilities.

After many years of consultations with organisations, governments, business and other actors, the world's countries adopted Agenda 2030 at

18. IDDC. Costing Equity – the case for disability responsive education financing, page 10. 2016

19. UNICEF. State of the World's Children: Children with Disabilities, page 3. 2013

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

a UN summit meeting in September 2015. The new global sustainable development goals in Agenda 2030 contained a much broader initiative than had been presented in the millennium development goals. There are 17 new goals, which also include a large number of targets.

The millennium development goals made no mention at all of people with disabilities. By contrast, the new sustainable development goals mention them on eleven occasions. And seven of the 17 general goals include specific refer-

ences to disabilities. Examples include goals 4, 8, 10, 11 and 17.

Agenda 2030 covers all of the countries in the world and officially entered into force in January 2016. As the name indicates, the objectives shall have been fulfilled by the year 2030. Through the agenda, the world's countries undertake before then to create a sustainable, fair future in which peace prevails, human rights are protected, environmental destruction has been reduced and the climate is cared for.

AGENDA 2030 – SEVERAL GOALS WITH A FOCUS ON PERSONS WITH DISABILITIES

GOAL NUMBER 4 - QUALITY EDUCATION FOR ALL

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

GOAL NUMBER 8 - DECENT WORK AND ECONOMIC GROWTH

Goal 8 is to promote inclusive and sustainable economic growth, employment and decent work for all. One of the targets to achieve by 2030 is “full and productive employment and decent work for all women and men, including for young people and persons with disabilities”.

GOAL 10 – REDUCED INEQUALITIES

Goal 10 aims to reduce inequalities within and among countries. One of the targets is to make it possible by 2030 for all people, irrespective of age, gender, disability, ethnicity, origin, religion or economic or other status, to be included in social, economic and political life.

GOAL 11 – SUSTAINABLE CITIES AND COMMUNITIES

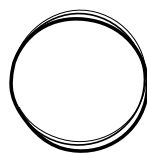
Goal 11 is about making cities and settlements inclusive, safe, resilient and sustainable. More than half of the world's population now live in cities. A figure that is expected to rise to 70 per cent within 35 years. This means that many cities are continuing to grow quickly, and urbanisation has resulted in almost one billion people who are believed to be living in slum-like conditions. **In order to create sustainable urban development, according to goal 11 the world must pay special attention to persons 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 states that by the year 2030 there shall be "universal access to safe, inclusive and accessible, green and public spaces, in particular for women and children, older persons and persons with disabilities".

GOAL 17 - PARTNERSHIPS FOR THE GOALS

Through goal 17, the global community confirms that it will require intensive global engagement for Agenda 2030 to be implemented. 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. This target shall be met by 2020. The reason for this enhanced support is to "increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts". The importance of reliable statistics is also emphasised in the UN's latest edition of the Human Development Report, in which the UN body confirms that it is crucial that the global community obtains data on which groups are lagging behind, where they are and what the reasons are.



CHALLENGES FOR SWEDISH DEVELOPMENT POLICY

The Convention on the Rights of Persons with Disabilities shall be one of the guiding principles of Swedish development policy. Work to improve the global situation for people with disabilities does, however, face challenges.

In 2003 the Riksdag forced through the Swedish Global Development Policy, known as PGU. In this, the Riksdag confirms that initiatives to combat poverty shall be characterised by a rights-based perspective. Ulrika Modéer, State Secretary for Isabella Lövin, Minister for International Development Cooperation, states that the government has performed “an overhaul” of this policy since it came into power. This means, among other things, that the Convention on Rights for Persons with Disabilities shall be one of a number of guiding principles. She points out that discrimination often has several overlapping causes, which can reinforce people’s vulnerability and poverty. Persons with disabilities are therefore one of the groups on which Sida shall maintain a focus.

“The government’s policy framework for Swedish development cooperation confirms that all authorities that are engaged in development cooperation shall work with the Convention on Rights for Persons with Disabilities. In this work, organisations can make a contribution

with their knowledge and experience,” believes Ulrika Modéer, continuing:

“I believe that many organisations possess competence in these issues that we perhaps do not have in the government or the aid agency, and this is where contributions can be made.”

Persons with disabilities are one of the groups that according to Agenda 2030 shall no longer be allowed to be left behind. Ulrika Modéer does, however, admit that there are challenges. These include making sure that administrators have an understanding of the situation facing persons with disabilities. This is about increasing knowledge in the authorities, not least at Sida.

“If we’re to make this pervade our work, we must be better at performing this analysis,” she says.

Ulrika Modéer emphasises the need for a broader view of the rights-based perspective – one that includes all of the reasons why people suffer discrimination.

“The rights-based perspective is a key issue for policy and development cooperation. All people shall be included, and that also includes persons

with disabilities. This is something we stress,” says Ulrika Modéer.

In order to achieve success, she believes that it is important that analytical work is not too wide-ranging, and also that strategies are also implementable.

“When you have to guarantee involvement, you have to find the simple keys for the authorities,”

Malin Ekman-Aldén is Director General of the Swedish Agency for Participation. The authority’s work focuses primarily on national issues. She herself has a visual impairment and has extensive experience on a personal level of working with disability issues internationally, including as Secretary General of MyRight.

Ekman-Aldén believes that her authority should be able to contribute knowledge that might not exist at Sida. But to be able to link resources to it, Sida must have that mandate, she says. Malin Ekman-Aldén points out that clear questions must be asked about the disability perspective in international work.

“The issue isn’t always on the agenda, so it’s important that those in the political arena show that this is an important aspect. If you’re to be able to follow up on the agenda 2030 goals based on a disability perspective, you must work with these issues on a global basis.”

One of the fundamental issues is the right to provide for oneself. In many parts of the world people with disabilities do not have the oppor-

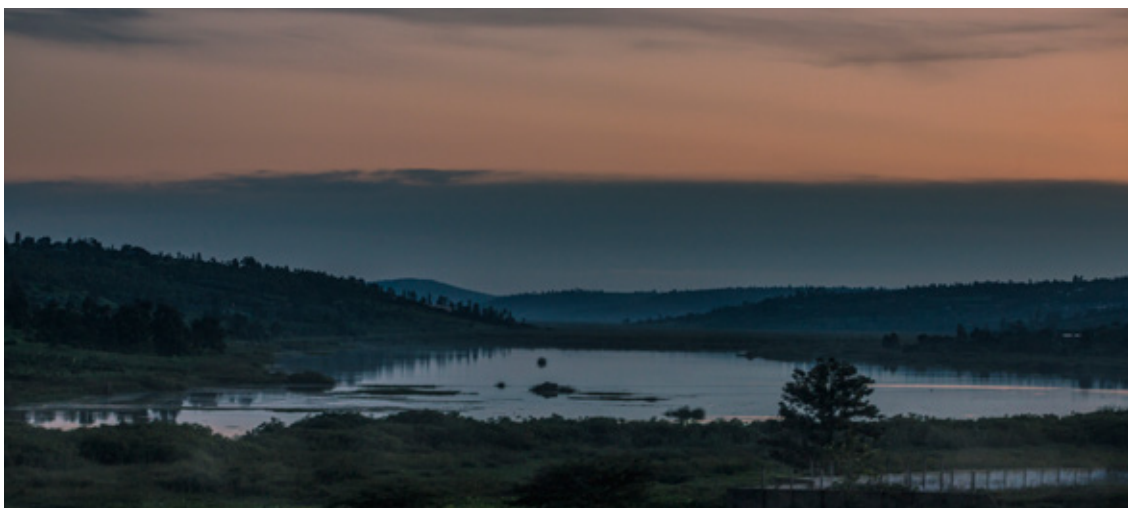
tunity to provide for themselves, by means of work or through an effective welfare system. This results in increased poverty, discrimination and vulnerability.

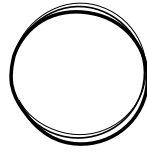
“In a poverty context, someone who is not contributing to the family’s subsistence becomes a burden, and this affects the whole view of disability, so this is an absolutely fundamental issue. It’s also about people’s self-image and self-esteem,” says Malin Ekman-Aldén.

The other issue that Ekman-Aldén wants to highlight is the fact that people are declared legally incompetent because of their disabilities. She says that there are still many legal systems in the world that cause people to have reduced rights because of their disabilities. This can relate to the ability to participate in elections, to plead one’s own case, to manage one’s own finances and the right to inherit.

“That’s a question of human dignity. Which is when legal rights become important, as otherwise they send out the signal that people have different values.”

At the same time, the issue of accessibility is a precondition for people’s rights being respected. There can be practical obstacles in the way, even if the legislation in itself is not discriminatory. “It can involve the absence of opportunities to exercise your rights, for example the fact that a polling station is not accessible,” says Malin Ekman-Aldén.





MYRIGHT'S SWEDISH MEMBER ORGANISATIONS – EXPERIENCES FROM THE FIELD

MyRight's 23 member organisations and their local partner organisations collaborate in ten countries around the world. The aim is to strengthen the local organisations and drive developments so that persons with disabilities can have greater access to their rights. Many engaged employees from Swedish member organisations bear witness to the fact that this work has produced results.

MyRight and its member organisations run projects in ten countries and have country offices in Bolivia, Nicaragua, Rwanda, Tanzania, Nepal, Sri Lanka, Bosnia and Herzegovina. Conversations with just some of the Swedish member organisations produce several concrete examples of how collaboration with local partner organisations can drive developments towards more inclusive communities.

The Swedish Autism and Asperger Association is running one of the projects together with its partner organisation the Autism Care Nepal Society. The Autism Care Nepal Society is a parents' organisation that, among other things, runs a school in Nepal's capital city Kathmandu. This is the only school of its kind in this impoverished South Asian country, explains Carina Pettersson from the Swedish Autism and Asperger Association. As a consequence of a study trip to Nepal, the Swedish Autism and Asperger Association initiated the partnership following a few tips about the local organisation via MyRight's local country coordinator.

When the partnership started in 2013, the organisations reached the joint conclusion that there were a few areas in which the Autism Care Nepal Society needed support. It was a matter of reinforcing the organisation and its outreach work to improve conditions for the target group and to work to improve knowledge of diagnostics in the area of healthcare. There was also a need for educational guidance in the classrooms. "It was a matter of an educational approach based on what the people are able to do, with a lot of work on clarifications and schedules, so that students can learn to work as independently as possible," says Carina Pettersson, who has been working in the Swedish association for 20 years.

Since then, Swedish educators have travelled to Kathmandu on several occasions to guide members of staff at the school, who are in many cases parents of students. The Swedish Autism and Asperger Association has also hosted a number of study visits, when teachers from the school in Nepal have been able to attend courses in Sweden.

Alongside school activities, representatives of the Autism Care Nepal Society also travel around Nepal to spread knowledge.

“Before the project in Nepal started, the Swedish Autism and Asperger Association had a partnership in Brazil,” explains Carina Pettersson. “Both partnerships have worked well. We’ve learned a lot from them too. We see how they can achieve a great deal with very modest funds. They are extremely professional, while at the same time they are in a difficult situation.”

Not all of those working at the Autism Care Nepal Society’s school are parents themselves, some are external employees.

“The organisation has very basic premises, but they seem to attract very good staff. That’s a really good achievement, bearing in mind that Nepal is one of the poorest countries in the world.

“The educators from Sweden who have been there and returned from time to time have noticed how staff have picked up ideas in the classroom. They’ve even produced a book that they will distribute across the country with the aid of the school authorities – a manual for teachers that will be distributed to special resource classes,” says Carina Pettersson.

Another direct result of the project in Nepal is that the country now officially classifies autism as a disability. There was no such classification before this partnership began.

On the other side of the globe, in Nicaragua, the Swedish National Association for Persons with Intellectual Disability (FUB) is involved in running a project within the framework of MyRight. Sven-Arne Persson from FUB in Östersund explains that the partnership began following a journey to Nicaragua many years ago, when FUB came into contact with a local department of the Los Pipitos organisation in the small town of La Dalia in Northern Nicaragua. Los Pipitos is a nationwide parents’ organisation for persons with various disabilities.

“At that time, in 2009, they only had six members in La Dalia. Since then, the local organisation has grown rapidly and it now has around

one hundred members looking after many children and young people with various kinds of disabilities,” says Sven-Arne Persson.

He believes that it is important that the group has grown.

“They have organised themselves and started to have access to their own lives. Parents tell us how children and young people who used to hide themselves away are now out and about together. This is the major benefit, that they no longer need to feel ashamed.”

Since 2012, FUB has also been running a project with Los Pipitos’ national organisation aimed at young adults with disabilities. The purpose of the project is to support them to be more independent and have better opportunities in the labour market. A similar project has also been under way in Bolivia for the last couple of years.

Sven-Arne Persson, who has extensive experience of working as a teacher at a special needs upper secondary school in Östersund, has managed to make no fewer than 19 trips to Nicaragua.

The trend towards a more inclusive society is making progress in the country he has taken to his heart. But he points out at the same time that there is still a great deal of work to be done when it comes to people with intellectual disabilities. This group does not as yet have its own organisation in Nicaragua.

“Knowledge of children and young people with intellectual disabilities is still poor, and it’s the group that has the lowest status among persons with disabilities,” says Sven-Arne Persson.

He believes that the partnership between FUB and Los Pipitos has been enormously beneficial – for both parties.

“It’s important that we come into close contact, that parents meet and share experiences. Another thing is the pleasure – that we all make new contacts and work together.”

For his own part, Sven-Arne Persson has learned a lot down the years.

“It’s our partners who own the projects. But for me, these years have been one enormous journey, my life has changed completely,” he says.

MyRight's member organisations also have projects closer to Sweden. The Swedish Association of the Visually Impaired (SRF), Stockholm and Gotland County district, is involved in a programme in Bosnia and Herzegovina. The programme started in 1998. This was just a couple of years after the end of the conflict in the country. As in all wars, the conflict in Bosnia and Herzegovina resulted in many people suffering life-long disabilities. The lack of rehabilitation and inclusion in society hit those who had been injured during the conflict in the same way as others who live with disabilities.

SRF's partner organisation in Sarajevo is called Udruženje slijepih Kantona Sarajevo and works on behalf of persons with visual impairment. Initially the partnership was mainly about humanitarian initiatives, explains Hamaddah Mansour from SRF Stockholm-Gotland, who himself has a visual impairment. At that time the most difficult challenge was working with society's views of persons with disabilities and their rights.

"Many weren't able to get out, they had no help in going to school. There was no help from their families, and not from society either. Politicians had no vision of how they should include people with disabilities," explains Hamaddah Mansour.

Collaboration then was based on strengthening Udruženje slijepih Kantona Sarajevo as an organisation and their lobbying work aimed at both society at large and decision-makers in the Sarajevo region, or canton, as the various regions are known in Bosnia and Herzegovina. The organisation is now strong and has achieved success in its lobbying work aimed at local politicians and media.

"They've achieved a lot in Sarajevo based on their conditions. Now, for example, there are schools for persons with visual impairments in the city and local regulations regarding accessibility. But it's not like that in other cantons," says Hamaddah Mansour.

He points out that the authorities in the various cantons in the country have a lot of power over local development. The fact that the

situation for persons with disabilities has been improved in the capital is one of the reasons why many in that group dream of moving to Sarajevo. But SRF and its partner organisation have instead set themselves the goal of moving this development to other parts of the country too. The partnership has been focusing on this since 2015.

"Society and politicians don't think about persons with disabilities, there are no plans. So you have to work very hard to encourage local authorities and society to have plans and visions to be more inclusive," says Hamaddah Mansour.

The new project is based on supporting the local organisation in establishing the development seen in Sarajevo in other cantons too – by such means as lobbying aimed at local politicians and the dissemination of information via the media. Initially it was SRF alone that supported the organisation. Now they have several other forms of financing, including a state subsidy.

Hamaddah Mansour also says that SRF has acquired plenty of new knowledge and experiences through this partnership. He points to how good Udruženje slijepih Kantona Sarajevo has been at reaching out to the general public and decision-makers.

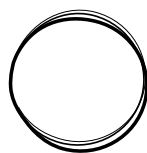
"Despite a difficult situation, they've been good at working with the media, doing really well in creating personal contacts," he says.

At the same time he feels that there is still much work to be done to increase knowledge of persons with disabilities in Bosnia and Herzegovina compared with in Sweden.

"In many families there's still a negative attitude towards disabilities. They need to keep working there to increase knowledge and awareness. And there's also a lot left to do politically. Bosnia and Herzegovina is still not easily accessible for persons with disabilities, on public transport for example," says Hamaddah Mansour.

He makes the point that SRF will never be able to help a partner organisation to solve all of its problems.

"What we can do is to help the organisation to become strong enough to stand on its own feet."



ACCOUNTS FROM SRI LANKA, RWANDA AND TANZANIA

– HOW THREE PEOPLE ESCAPED FROM CLOSED SPACES

In the following chapter we will meet Sameera Sandaruwan, Sada Igikundiro and Nindi Mtumwa Shafii. They come from three different countries and are all of different ages. But they share similar experiences – how difficult it can be to live with disabilities in impoverished environments. And all three bear witness to the crucial role that the right support can play. Thanks to MyRight's local partner organisations, they have managed to break out of the isolation that their disabilities had created.



SRI LANKA

Inhabitants: 22 million.

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

Population: Sri Lanka is most densely populated in the south-eastern parts of the country, where the major city of Colombo is also situated. 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.

Health: The average life expectancy is 76. In the list of countries where maternal mortality

is highest, Sri Lanka is in 118th place out of 184 countries that were compared.

Economy: Sri Lanka has seen strong economic growth since the 26-year-long conflict in the country ended 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.

PROJECT FOR SELF-RELIANCE IN SRI LANKA:

The Organization for a Society without Physical Disability (DHR) is running a project in partnership with the national Sri Lankan Foundation of Rehabilitation of the Disabled (SLFRD) and the local Wellassa Organization of Persons with Disability (WOPD). The partnership is taking place in Monaragala, one of the poorest districts in the country. The purpose is to strengthen the local organisations, conduct lobbying work and strive to ensure that persons with disabilities have greater opportunities for education and self-reliance.

Sameera Sandaruwan with his wife Indika Hennayaka Mudiyansele and their daughter Theekshana Thathsarani.



VOCATIONAL TRAINING GAVE SAMEERA BACK HIS ZEST FOR LIFE

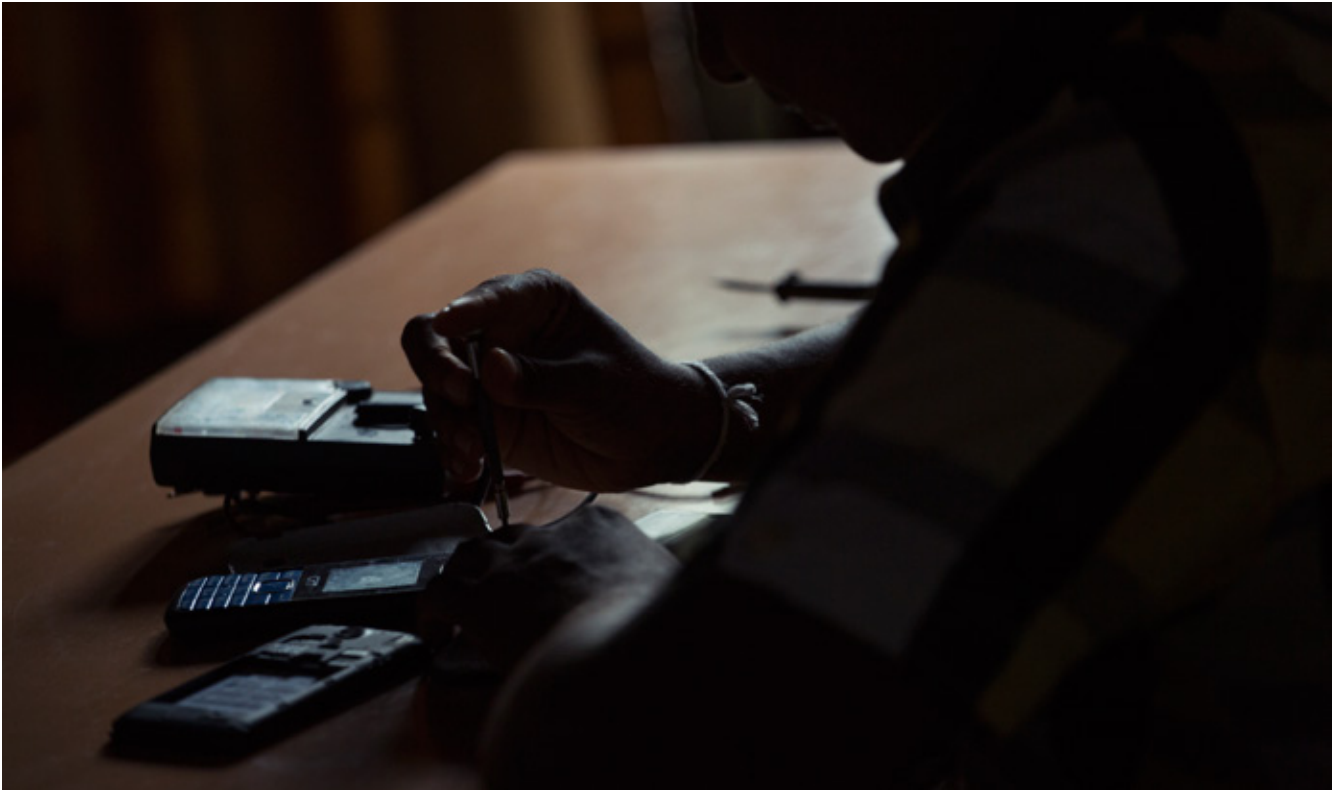
Sameera Sandaruwan was only twelve years old when an accidental fall resulted in him being paralysed from the waist down. Alongside the personal disaster, the incident also represented a major challenge for Sameera's already poor family, as his father was forced to stay home from work to take care of his son. Sameera completely lost his zest for life and for many years felt like a major burden on the family. Today the situation is totally different.

Sameera remembers the date well, although virtually nothing of the actual fall from the tree and the time immediately thereafter. It was 16 May 2001 when an aunt asked him to climb up a tree to collect a jackfruit for her. So Sameera did this, even though his mother had warned him not to climb the tall trees.

"When I came home from the hospital I couldn't even move from side to side in the bed. Then I just lay there for several years," he explains.

Sri Lanka is currently considered a middle-income country in the lower class. Despite strong economic growth since the end of the civil war, many of the country's inhabitants live close to the poverty line. For families with low incomes, an accident resulting in disability can be a financial disaster. In Sameera's case, his father was forced to give up his job to take care of his son.

"During that period I just wanted to die. I was totally dependent on my parents and I'd become a burden for them, even though no one said that was the case. I tried to commit suicide several times by taking poison. The accident created so



many problems in the family, who were already poor. We became totally dependent on my mother's income, which meant we became even poorer."

In connection with our interview, Sameera is paying a visit to Colombo with his wife and children. He looks younger than his 30 years as he sits in his wheelchair in MyRight's office. He answers all the questions quickly, precisely and with a soft voice. A short while ago he was sitting silently, looking with affection at his little daughter as she lay sleeping between two office chairs in the room next door. The girl is his first-born, only nine months old and as sweet as anything.

He has also brought with him the awards he was presented with by the Chamber of Commerce in Monaragala. One is a certificate stating that Sameera has been named one of the most prominent entrepreneurs in the province. The other is a statuette, still wrapped in plastic, from the same Chamber of Commerce. Both the awards can usually be found in Sameera's small repair workshop for mobile phones and other

electronic equipment that he now runs in his home village.

Monaragala is one of the poorest districts in Sri Lanka, and before the accident both of Sameera's parents worked as day labourers to provide for their five children. It would be four years after the accident before life began to look a little brighter for Sameera. Having simply lain in bed at home, he started to read newspapers and write texts and poems.

"I was never very good at school, but I could read and write a little even before the accident. After the fall I was able to practise those skills. Reading, writing and drawing became a way for me to forget my problems," he said.

In time other villagers started to visit Sameera to ask him for help with writing letters. This resulted in him building up a network around him, and as a 16-year-old he also started to make new friends.

"That's when life started to change. I also had access to a wheelchair that a local politician donated to me," explains Sameera.

Sameera now runs his own mobile phone repair workshop.

About ten years ago he also came into contact with the local Wellassa Organization of Persons with Disabilities (WOPD). It was then that life really took off again.

Through the organisation, Sameera was given the opportunity first of all to pursue vocational education, and then a six-month further education course specialising in mobile phone repairs. This course also included a starter package with the equipment needed by a mobile phone repairer – as well as enhanced self-confidence.

“Before then I had no desire to live. But through the vocational training I met a lot of other people with disabilities. That made me understand that I wasn’t alone and made me start to appreciate life more.”

Initially Sameera lived with his sister at home in Monaragala and ran his business from there. Now he lives together with his wife and daughter in their own home in another village in the district, where he also rents premises for his repair workshop.

“Step by step, my finances have improved. Now I can pay all my expenses and provide for my wife and child with my own income. I’m incredibly happy and proud of my current situation. Now I want to live my life to the full.”

Sameera met his wife after the vocational training, when he started to regain his zest for life. But the road to love was a struggle too. Every day he had seen Indika Hennayaka Mudiyansele pass by on the road outside his sister’s house as she walked to work.

“I fell in love with her and did all I could to win her heart, but at first I was rebuffed. But I didn’t give up, I wrote poems to her, sent messages and continued my attempts to make contact,” says Sameera.

Finally he succeeded, and today the couple are happily married. The only shadow over their relationship is the fact that Indika’s parents have remained opposed to the marriage.

“They refused to approve me because of my disability, and they still have no contact with us. They didn’t even come and visit us after we’d had our child,” recounts Sameera.

He believes that there is still much to do in terms of attitudes to persons with disabilities in Sri Lanka. As an example, he describes an incident that happened when he was on his way home from the mobile repair workshop together with his wife.

“A woman came up and stopped us. I thought she was going to ask me about a mobile phone that needed repairing. But instead she opened her bag and wanted to give me a few coins as she thought I was a beggar. That made my wife angry.

“If society doesn’t provide the necessary support, many people with disabilities ultimately have no choice but to beg,” believes Sameera. “With the right support, many can instead become independent and avoid having to beg,” he says.

The need to be independent is an issue that Sameera returns to. Today he believes that that fateful fall from the tree has not after all robbed him of the most important thing in life. And he no longer feels that he is a burden.

“I’ve been able to marry, I have a decent income and I’ve even been able to give a little bit of money to my parents. It’s been really great to be able to support my parents, who are now really happy for me. They told me they lost all hope for me after the accident, but now they’re happy and have no concerns,” says Sameera proudly.



RWANDA

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

Capital: Kigali, about one million inhabitants.

Population: Rwanda is one of the most densely populated countries in Africa. 60 per cent of the population are below the age of 25. 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. The vast majority of the population are Christians.

Health: The average life expectancy is just over 60. In the list of countries where maternal mortality is highest, Rwanda is in 35th place out of 184 countries that were compared.

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.

PROJECT FOR DEAFBLIND PEOPLE IN RWANDA

The Association of the Swedish Deafblind is running a project in Rwanda together with three local partner organisations – Rwanda National Union of the Deaf, Rwanda Union for the Deaf and Rwanda National Association of Deaf Women. There is no single organisation in Rwanda working for the country's deafblind. The partnership was established through MyRight in 2011. Since then, 130 persons living with both disabilities have been identified in Rwanda. Many of them previously had no opportunities to communicate with their relatives and were left with no support whatsoever. In the project, they are working to provide people with deafblindness with an opportunity to communicate with the aid of tactile sign language. Through the project, the organisations have also been working to get information out to the media and spread knowledge to local authorities and citizens.

NEW WAY TO COMMUNICATE HELPED SADA TO BREAK OUT OF HER ISOLATION

17-year-old Sada Igikundiro was born deaf, and at the age of six she also lost her sight. Sada was unable to communicate with the outside world, and her life was transformed into a passive wait at home for another day to pass. But thanks to a project in which deafblind people learn to communicate with the aid of tactile sign language, her life was changed.

"I'm not joking,
I can make
food!" says
Sada Igikundiro.



Sada has
regained her
language
through tactile
sign language.



With its lush greenery and its pleasant climate, Rwanda's orderly capital city of Kigali is reminiscent of a city by the Mediterranean. The car journey to Sada's home village out in the countryside takes about two hours. The excellent asphalt road runs up and down long slopes in this small East African nation that is often called "the land of a thousand hills". Many tourists who come here take the same road from the capital as they make their way out into the country to look for its famous mountain gorillas.

There are notable contrasts as we turn off the main road in the province of Musanze to travel the final stretch to Sada's family. The smooth asphalt gives way to a severely cracked, barely navigable track across red earth, and the driver has major problems taking us over the last few slopes before we reach Sada's house.

Sada's mother Hawa Uzamukunda tells us that she has ten children, but points out that she is usually corrected by Sada when she says this. Only eight of the children are still alive. She works in agriculture and Sada's father usually helps other families with various tasks. Three of the couple's children are still living at home in the small family house.

Sada is in a very good mood today. Because the time has come for her to leave her home village once more and travel to Kigali to attend new training days at the Masaka Resource Centre for the Blind. There she will also be able to meet other deafblind people who, after a long period of isolation, have been given the opportunity to learn how to communicate with the outside world.

"It's really great to travel to Kigali, I enjoy travelling away from home," says Sada, brightening up.

It was worse before, she explains. When Sada's sight disappeared, for many years she had hardly any impressions at all from the outside world. Thanks to the fact that she could see until the age of six, she had been able to learn sign language, but as a deafblind person she was isolated in her home and trapped in her own world. Most of the time she was sitting at home, or lying in her bed.

"It was awful, I was sad and angry. I just sat at

home from morning until evening and could no longer see what was happening around me. I slept far, far too much and felt very alone,” she explains. Fidele Irizabimbuto translates and interprets her words. Fidele is one of few sign language interpreters in Rwanda who can also communicate with deafblind people. This takes place by means of tactile sign language, a form of communication based on those who are speaking using signs that are received by touch and by their hands following one another in movements. Fidele is one of the two interpreters who through the project have trained Sada’s ability to communicate with the aid of tactile sign language.

When Sada and Fidele communicate, their hands move quickly up and down, back and forth, with breaks when Sada laughs or smiles a little sheepishly, like any other young person being asked about her life.

The turnaround came in 2011. This was when Sada’s mother was contacted by a representative of the deafblind project who had heard about her daughter and wanted her to take her along to a meeting in Kigali. At first Hawa was dubious. The family was unsure about whether Sada could cope with it. But after another discussion the first journey was arranged. Much has changed in the family’s life since then.

Through the project, both Sada and Hawa have received regular training in tactile sign language at the Masaka Centre. And even though Hawa says that she is still far from fully trained, she can now communicate with her daughter in a totally different way than before.

“Life has changed a lot. In the past Sada was isolated. Thanks to the training she’s started to move around more and is much happier. In the past Sada didn’t know what was happening around her, but now I can communicate much better with her. If we’re going to buy new fabric for clothes, I can ask her what colour she wants. Then we go together and look, and Sada can feel the material and say what she wants,” explains Hawa.

Within the project they have also focused on emphasising everything that Sada can actually manage, even though she can neither see nor hear. She is now happy to go on walks alone

outside the home.

“In the past I was sad and angry, and used to just sit here at home and do nothing. I wasn’t well and wasn’t used to moving around. Now I go out a lot, and I usually feel my way around. When I first started to go out I became really tired, as my body had become so weak. I stumbled a lot. It still happens now sometimes, but not as often,” explains Sada.

Sada’s life has also changed a lot within the walls of the home.

“I can clean, wash up, peel and chop sweet potatoes and put them in a pan. I’m not joking, I can make food!” says Sada.

In Rwanda it is not unusual for society at large to believe that families with deafblind children are suffering some kind of punishment for their sins. Sada’s mother explains that thanks to the project she has gained a totally different understanding of her daughter’s disability.

“The most important thing is that I’ve learned to accept the situation. In the past it felt shameful to have a child like this. But through the training programme I’ve come to understand that Sada is like any other child,” says Hawa.

Through the project, Hawa and Sada have also had the opportunity to meet other families living in a similar situation.

“In the past I thought that I was the only person in the world to have a deafblind child. But having met other families I’ve realised that this is not so. Through the training I’ve met others with deafblind children who are far behind Sada, and who are in a more difficult situation. We can communicate better than many others, and I’m very happy about that,” says Hawa.

After the interview we travel back towards Kigali in our minibus. When we get there, it has become pitch dark outside and the street where we stop is filled with vehicles and people. Sada quickly jumps out of the front seat, unfolds her white cane, takes her mother’s arm and moves quickly towards the hostel where they will be sleeping. At eight o’clock the next morning, Sada waves goodbye to her mother before starting a new day of training at the Masaka Centre.

TANZANIA

Inhabitants: 52 million

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

Population: Almost one third of the population live in cities. 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 majority of the population are Christians, with a large Muslim minority.

Health: The average life expectancy is 62. In the list of countries where maternal mortality is highest, Tanzania is in 23rd place out of 184 countries that were compared.

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 growth rates are 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.

INITIATIVE FOR PERSONS WITH MENTAL ILLNESS IN TANZANIA

The Tanzanian Users and Survivors of Psychiatry Organization, Tuspo, is an organisation in Tanzania that works for people living with mental illness. The organisation was formed in the country's biggest city, Dar es Salaam, since when local departments have also been set up in six of the country's districts. The organisation now has more than 700 members. Tuspo's purpose is to provide support for its members. The organisation also works

to break down the stigma of mental illness that is particularly common in rural areas of Tanzania. One of the goals is to spread correct information and combat prejudice at a local level. The organisation strives to ensure that its members are included in society by offering occupational training to combat the poverty suffered by many people with mental illness.

Tuspo has for many years been working in partnership with the Swedish National Association for Social and Mental Health (RSMH) within the framework of MyRight.

SUPPORT AND MEDICINES LIFTED NINDI'S "CURSE"

When Nindi Mtumwa Shafii was hit by mental illness, her parents turned to the local witch doctor to break the "curse" that they believed had been placed on her. It ended with them locking Nindi in an empty room.

There is widespread belief in magic and witchcraft in many poor African countries. Inadequate competence and knowledge of mental illness means that it is common to seek explanations in curses and to place one's faith in unscientific cures and treatments. This was something that Nindi, who is now 46 years old, experienced after giving birth to her second child.

Straight after giving birth she found out that her husband had met another woman. A woman with whom Nindi was also expected to share her life – at the home of her parents-in-law. The husband's betrayal caused Nindi to suffer a breakdown, and life in the home of the impoverished parents-in-law was characterised by constant, violent rows.

"Then I decided to move back home to my own parents. But they thought that I'd been bewitched," explains Nindi.

Nindi had started to talk to herself and she



screamed a lot. Her family took her to a local witch doctor, who explained that the cause of her mental problems was that the husband's new woman had placed a curse on her. But the treatments and medication she was given did not help.

During the interview, Nindi sits in the shade under a tree at the pre-school that she runs herself. She explains that it was thanks to the fact that she finally received proper care and support from the Tuspo organisation that she can now provide for herself. Through Nindi's Day Care and Tuition Center, she can provide for herself, her mother and her youngest child, as well as the three children of her late sister, for whom Nindi is now responsible.

The pre-school is in one of the many districts of Dar es Salaam characterised by simple, single-storey concrete buildings. Between the houses are narrow, bumpy gravel roads and among the residential houses are small food shops of the hole-in-the-wall model.

In the morning, the pre-school children gather in an outdoor area with steel mesh walls to sing

and introduce themselves to each other in English. Nindi's voice is clear, her expression direct and her serious manner is interspersed with both laughter and smiles as she walks around answering the children's questions.

Her journey here has been a long one. When she was at her lowest point, the family did not understand that she was in need of care, and when attempts to break the alleged curse did not help they took drastic action.

"The family was ashamed of my screams. So I was locked in an empty room where I had to sit on my own. In there, I thought it would have been better if I was dead. My mother was ashamed of me and so were my older children, as I'd also left my husband."

Locked in the room, Nindi had no opportunities to communicate with any other people. Contact with the family was through a window in the room.

"They used to look in through the window to see if I was still alive. They refused to let me out as they were worried that I'd disappear."

Nindi Mtumwa Shafii has now learned to live with her mental disability with the aid of the correct medication.

Finally, however, Nindi was taken to a hospital, where she was admitted. Healthcare staff said that her problems had probably been triggered by the severe stress to which she had been subjected. At the hospital she was also given a medicine, olanzapine, which she will need to take for the rest of her life.

Suddenly her life started to turn

“My family was absolutely amazed at how much better I was after that. They’d believed that I was bewitched,” says Nindi.

When Nindi was discharged, healthcare staff also advised her to make contact with Tuspo. It was a piece of advice that would prove crucially important.

“If I’d not received the support that I did through Tuspo, it’s not unthinkable that I’d be dead now,” says Nindi.

Since then Nindi herself has been involved in the organisation’s work. Every week she uses some of her time to support people who come to Tuspo asking for help with their mental illness.

Then she tells her own story.

“I tell people who have problems similar to the ones I had that help is available and that you can get better with the aid of medicines.”

It is also thanks to Tuspo that Nindi now has her own business. One of the organisation’s projects gave her the opportunity to attend a one-year child minder course.

“After that, I realised that I didn’t need to look for a job any more, but I could open my own pre-school.”

When Nindi started her pre-school in 2010, it was the first one to open in the area and the number of children registered rose quickly. In time, however, a lot of competitors appeared and there are now fewer children in Nindi’s business. At present there are ten.

“But it still gives me an income and makes it possible for me to pay the rent and other bills, and also to provide food for the family.”

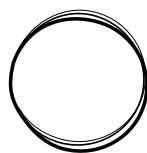
Since Tanzania had a new President in 2015, the application of the laws has changed. For a time it was not certain that Nindi would be able to continue to run her pre-school. She contacted the local authorities to protest and was finally able to talk them around. But the battle took its toll on Nindi’s energy.

The stress made her start to feel her old problems again. The family is totally dependent on the income from the pre-school. She found it difficult to sleep and started talking to herself again. But the situation has stabilised now.

“I’m happy and satisfied that I can now provide for my family, and I’m also proud. But my dream is to be able to build my own house and create a really big pre-school where I can have my family close by, and to have a centre where people with mental illness can come with their children. That would make me even prouder,” says Nindi.

Nindi enjoys running her pre-school, “Nindi’s day care and tuition center”.





MYRIGHT'S RECOMMENDATIONS AND TIPS

– how we can achieve the global sustainable development goal of combating poverty. Recommendations to the government and decision-makers and tips for activists.

15 RECOMMENDATIONS TO THE GOVERNMENT AND OTHER DECISION-MAKERS

- 1] Make clear demands for the inclusion of a disability perspective in international work on sustainable development. Pay attention to the texts about persons with disabilities that are contained in the global sustainable development goals, and conduct a dialogue with all parties about how they should be realised.
- 2] Link the poverty goal in the global development goals to the situation for persons with disabilities. Including persons with disabilities makes “Goal 1: No poverty” possible.
- 3] More nations must take the lead when it comes to the global situation for persons with disabilities. Sweden has a unique role with a strong, well-established disability movement and with the Swedish government that can raise the issue in many contexts.
- 4] Review “Sweden’s Policy Framework for Swedish Development Cooperation and Humanitarian Aid” from a disability perspective.
- 5] Develop work for all. Prioritise the right to provide for oneself and link this to the issues facing persons with disabilities in the workplace. MyRight emphasises that the right to provide for oneself is crucial for a person’s opportunities to live a dignified, independent life.
- 6] Invest more public funds in guaranteeing inclusive, equal opportunity education as well as life-long learning adapted for children and adults with disabilities.
- 7] Extend and change social security systems. According to the ILO, nations must strive to develop social security systems that also include persons who are not included in employment creation measures. Those in extreme poverty, including persons with disabilities and their families, can be reached using the method

of creating a “floor” instead of a “ceiling” in a country’s social protection system.

8] Strive to achieve sustainable financing in order to build up and reinforce national social security systems so that they include persons with disabilities.

9] Work to make sure that those countries that have signed the UN Convention on the Rights of Persons with Disabilities (UNCRPD) make changes in the legal regulations that discriminate against persons with disabilities and restrict their democratic, social and economic rights.

10] Mandate authorities that work on the implementation of UNCRPD and global development to include the disability perspective in development cooperation. For Sweden’s part, this can involve an addition to the undertaking of the Swedish Agency for Participation and Sida.

11] Develop national and international statistics on persons with disabilities in relation to the global sustainable development goals. Allocate resources for this work.

12] Be clear that a nation’s policy for international development cooperation must include

a disability perspective. Allocate resources for this work.

13] Involve civil society organisations for persons with disabilities in development cooperation. This must take place at all levels: implementation, monitoring and evaluation. Civil society organisations must also be involved in those countries where development cooperation is active.

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

15] Mandate Sida to map out and analyse how the authority is working at present with the disability perspective 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 the disability perspective is currently included in work, and to prevent active exclusion.



LISTS OF TIPS FOR ACTIVISTS

8 tips to those active within civil society organisations that work with global development

- 1] Learn more about the global situation for persons with disabilities and the link to the global sustainable development goals, ideally in interaction with several organisations and parties.
- 2] Learn more about the UN Convention on the Rights of Persons with Disabilities (UNCRPD).
- 3] Invite MyRight and those active in its projects in order to acquire greater knowledge and generate a dialogue about ongoing developments for one of the most vulnerable groups in work to combat poverty.
- 4] Spread knowledge of the link between poverty and disability and how different actors can counteract this being permanent.
- 5] Evaluate and analyse how the disability perspective can be included in your organisation.
- 6] Take into account and include persons with disabilities in international development cooperation and in your projects.
- 7] Make your organisation accessible to all, including persons 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 for the rights of persons with disabilities.

7 tips for those active in the disability movement

- 1] Learn more about Agenda 2030 and the global sustainable development goals.
- 2] Learn more about the UN Convention on the Rights of Persons with Disabilities (UNCRPD).
- 3] Learn and draw inspiration from organisations working in other countries with rights for persons with disabilities.
- 4] Evaluate and decide how your organisation can work for rights internationally.
- 5] Collaborate and maintain a dialogue with organisations that work for global development.
- 6] Create your own partnership projects with parties in low- and middle-income countries.
- 7] Support and become a member of MyRight.

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