

## UNHCR/ILI cooperation fall 2021

I want firstly to thank the UNHCR Representation for the Nordic and Baltic Countries for the support that the Independent Living Institute (ILI) in Stockholm received during the fall of 2021 to empower disabled refugees in Sweden which made the events regarding this report possible. ILI was able to widen the network for the project [Article 19 as a tool](#) financed by the Swedish Inheritance Fund and that of [Disabled Refugees Welcome](#) that was a project financed by the Inheritance fund until the end of 2020. Five workshops were carried out with the goal of strengthening disabled refugees in their integration process. The CRPD is one of the main tools for ILIs operation and that of the project *Article 19 as a tool*. Through the CRPD ILI profiles self-determination and participation, upon which the workshop meetings were based.

A total of five events were prepared and successfully carried out for training and empowerment of the 45 refugees who took part in the different events. The languages used in the various events were Swedish, English, Amharic, Tigrinya, Arabic and Persian. Here is a list of the events that were held with the number of participants:

- [26/10 - Disabled Women - Proud Mothers](#) – 6 persons
- [27/10 - Self-determination and the CRPD](#) – 6 persons
- [15/11 - Culture and the concept of disability](#) – 10 persons
- [19/11 - Swedish disability movement – why do we need each other and Covid?](#) – 4 persons
- [27-28/11 Arabic network meeting](#) – 19 persons

### **Hindering factors for participation in meetings**

These are times of Covid, Delta and Omnicron and of course this made a difference on attendance for the meetings. People were sick, afraid to go out and were not vaccinated against Corona. Another hinder occurred for the meeting on Covid and the Civil Society which was a problem with the Paratransport. Transport was stopped this day. All of these factors meant that fewer people than planned came to the meetings. Only one of the persons concerns accesses personal assistance but there was not enough time for the planning needed when the paratransport was stopped.

Even in general the Paratransport has had problems due to Corona, there is now a lack of drivers. As the service decreased during the pandemic drivers went on to find other jobs. This means that people are not accessing vehicles and/or waiting hours to be picked up and then missed a meeting or came home late which is straining. People are saying they are less keen to travel these days due to the insecurity of the service, even when the travel is only within Stockholm's city limits.

### **Meeting results**

Results of the meetings varied depending on the workshop and the topics addressed. Common for all the events was the appreciation of new information. To carry out a successful integration process requires knowledge on the systems of the receiving country, its laws, its expectations and the benefits allowing for a disabled person to function. Many people lack empowerment and are too shy to express self-determination having been treated as someone without value in their country. There can be a need for adjustments of expectations when finding out the culture that is guiding Sweden. Disability can mean that someone is eligible for support, mostly once having a residential permit and the support varies depending on the needs of the person. Support is not the same for everyone having a certain diagnose but varies on the personal situation. It is essential to learn that one must know the rights and then apply for them. It is also important to know that Sweden is undergoing a time of cutbacks which mean benefits are more restrictive. This is the same for Swedish citizens and for the newcomers even though some of the participants feel that they alone are discriminated against due to being a migrant.

### **Workshop - Disabled Women - Proud Mothers**

The first workshop was on the 26th of October with the title: Disabled Women – Proud Mothers. Issues touched upon were prejudice, discrimination, gratitude and views of disability using personal stories. For example, views of disability where one's own children want to hide you away when you become a wheelchair user!

It was pointed out how the issue of women with disabilities is often a forgotten issue. Women meet lesser expectations and have low self-esteem. One of the advantages of being a woman who is proud will be that of having proud children. It will open doors to education, employment, stronger social networks and allow for successful integration. Therefore, the focus of the workshop was on the empowerment of women.

Who are you and what has happened since the last woman's workshop? There was a workshop a year ago that some of the women had attended. The subject that then became in focus was how DRW had helped these women to become proud of their disabilities.

*One person told a story from when she was in her home country. I did not consider myself as a person with a disability. I did not tick the box for disability when registering for my classes. So, I was put on the third floor without an elevator and an inaccessible toilet. I just had problems with my legs, I was not disabled so I did not tick that box. With the DRW project I started to believe in myself and saw that I could be proud that I was disabled which I am. Now I proudly present myself as a person with a disability!*

One person told how a member of the DRW team had met her in the shops. This person stopped by her seeing that the lady had a brace on her leg. *The DRW team member who was in a hurry, sputtered out the question - are you disabled? I wanted to say no, but had to tell the truth, as I was then caught off guard. I had never been asked this question! Then I joined DRW and have changed a lot.*

The other person was met at the airport in Ethiopia. She had not booked assistance at the airport and a DRW team member who happened to be traveling on the same flight wondered why? She had not accepted herself as a person with a disability. She realized that she was hiding her disability and fighting which was straining her legs.

Independent Living profiles the rights of persons with disability. We are not sick. We can be if we have Covid or a flu. We can have conditions which are degeneration for bodily functions which will affect our needs. As disabled people we may have needs but we are not sick. Disability arises from the inaccessible society.

Expectations of women with disabilities was discussed and how they affect what we do or do not do. Have we been hidden away? Have we had the same dreams to study, to have jobs, to have families, to live normal lives? What are our expectations of ourselves?

Expectations lead to the afternoon session on the role of women and their participation. Expectations can depend on the country in which we live and what is considered as normal. One prejudice we have met - *I am an African man - I do not work in the kitchen!* In Sweden we divide the tasks, men and women cook, wash the dishes and mop the floors. Views of physical exercise and training can be different. Some women said that in my country we do not train as in Sweden. Who fixes the furniture? Who drives home after the party?

How do we see ourselves as women?

*One participant: I look after the house, is it clean? Is there food? I do not think about the bills and the car. That is the man's job. I do not think about changing the TV, it is big and not my responsibility. But as a single mother? Then, I have to do all these things.*

*I am active in the church and in the choir.*

*I am a coordinator. I want to hang out with friends.*

The roles of DRW team members who are active women was used to awaken comparison.

One person said that SFI or Swedish for immigrants is important. *I would like to work in tourism or sales. Maybe in a reception.*

What are our dreams? This question was asked. Responses were: *to be independent. To take care of myself. To make decorations and ornaments. To have a gift shop! Maybe to be a silver smith. To be a politician.*

*To study administration for an office job. To be active in a church and helping people in need.*

What are the challenges?

These were found to be social norms, personal expectations, financial situations, access to knowledge;

- How are we seen as people?
- How are we seen with our sexuality? There was a loss of sexuality with the accident. People with disability were seen as not having a sex.
- Other problems talked about:
- Before people were placed in institutions.
- Behavior of relatives (to partner).
- Financial issues and being dependent on someone; Do not want to be dependent on someone.
- Access to employment;
- Access to information and on how the society works;
- Being on the waiting list for supported employment.
- Abuse (when being measured for health equipment) or by partners;
- Being victims of rape and incest; Force (peer pressure not to tell on someone);
- Over protection by parents;
- Not being able to defend one's self;
- Lack of Freedom, being suffocated intellectually;
- No expectation to have a family, be married, work etc.
- People crying when seeing me - mother, friends, family members = Pity!
- I went from a position of pity to someone who could solve everything - I did not want to become a superhero, just me.... I did not want to be seen as a super cripp;
- When I did not hide my arm any longer – People said - Now you are healed! This was due to DRW!
- Something falls - they think it is me...

#### What helped?

- Meeting others like me. Raising self-confidence. Seeing others with disability helped me to see disability as normal.
- Empowerment through peer support;
- Access to knowledge;
- Right information at right time;
- Proper technical aids;
- Translation;
- Inspiration (speakers);
- Training on LSS and other services;
- Municipality says apply, but only with the trainings did I learn what I could and could not have that I belonged to SoL and not LSS;
- Info and tips!

Legislation was gone through at the different levels: UN, EU and Swedish national legislation:

<https://www.jamstalldhetsmyndigheten.se/mans-vald-mot-kvinnor/sexuella-trakasserier/lagar-och-regler>

<https://www.equalitylaw.eu/legal-developments/16-law/46-european-legislation>

Right to vote: 100 years since woman received the right to vote in Sweden. 2021

List of relevant legislation:

**International:**

- UN Human Rights Convention
- UN Convention on the rights of women
- UN Convention on persons with disability
- EU directive on equality

**Swedish:**

- Discrimination legislation
- Employment legislation
- School laws
- Swedish Penal Code (Brottsbalken)

**Key terms** from this workshop were: Empowerment, discrimination, prejudice, rights, expectation, self-confidence, self-esteem, self-denial, accessibility, identity, Disabled not sick!, Proud, Strong, Visible; family, education, employment, shame, guilt and equality. Behavior, segregation, sterilization, over protection, medical care, institutions, power, abuse, abortion of babies with downsyndrom, pity, super crip, lack of freedom, difference between handicap and disabled.

**Workshop - Self-determination and the CRPD**

The purpose of the workshop was to examine what self-determination is and why it is an important topic for persons with disability and included in the CRPD. The mechanisms behind self-determination are important to understand for empowerment. Models of disability were gone through and are important to understand to be able to grasp the reasons why we experience what we do as disabled people.

**What does self-determination mean for you?**

Some of the answers were:

Kicking a habit takes self-determination.

When there is nobody deciding on me except myself. When I take my own responsibility.

Instead of others deciding for me, I have to decide for myself in all things.

An example from yesterday's discussion: It is impossible for you to start a family. You will not marry.

When we choose what we want and when we govern and administer our lives.

Interviews were conducted in pairs on exclusion and participation. Then each person told the story of the other person from their pair:



Participant - A could participate at home but not be outside of the home. No possibility to work. No chance to do anything. At home the parents provided everything. Now in Sweden she feels sad as she has no social competence.

Participant B - had a lot of responsibility at an early age. She took care of her siblings. The father to the half-sister died and this meant more responsibility. After the funeral she gained her disability due to health reasons and due to the stress. A sister then took over. Participant B went back to work in the business but her sister did not think she could any longer. This was exclusion.

Participant C - not much regret as she is a strong person. But she has a group of friends who meet for religion activities. But when there is a trip she is excluded from going with them.

Participant D - as a child as the only girl at home with three younger brothers, she was the additional mother. When she was to move to Sweden and was new here, she had a lot to do to get integrated. The husband came after she was here. She had to do everything herself, pay bills etc. When her husband came she had still the role to take charge. She did not want to socialize and did not know why. But then in some religious services she got the energy to start to be social.

Participant E - Back home after being in the hospital, exclusion in a ski trip, not included to come with the family.

Participant D - Got cancer as a teenager and then was seen as being sick by the family and friends even if she herself had gone on to be involved in a disability organisation. She did have a sister who was sick, but it was she herself with one leg who was considered sick. There was a funeral of her sister and when a friend of the family came she was convinced it was the girl missing one leg who had died as she was "sick" not the sister with the stomach problems who was whole.

Children say to mother when going shopping - you can stay in the car. (at the age of having shame for the parent).

Family attitudes can often be the hardest.

Answers to what is exclusion:

Being considered a patient;

Needing care and not expected or asked to come with the group;

Being kept at home for safety;

Kept from working in the family business - expectation was that as someone with paralysis due to health reasons could not do this work;

Too sick to travel with friends;

Being considered as weak.

Excluded by expectations: By others or by ourselves: shame, depression, will not manage.

Fear due to epilepsi, something might happen that cannot be handled.

Being hidden due to shame: disability is a curse or punishment.

**Models of disability** were discussed including the charity model, the medical model, the social model and the human rights model. Stereotyping as a phenomena was also discussed.

The human rights model became important with the CRPD and legislation that followed seeing disabled people as rights barer.

### **Understanding of disability**

Who are we? We women with disabilities? Who would we want to be?

I am a person with a disability and want to be myself.

I am not sick, I am a person with a disability. In Ethiopia I am considered sick. I live my life as others. And I want to be myself.

I want to be myself and show others that I can.

I am someone with a disability that has rights. I get angry if a bus comes that has steps. I am glad when people boycott events if not everyone can attend. Even in Sweden we cannot take this for granted. The press conferences for Covid were used as an example where in the beginning there was no translation for deaf people. There is an example of a Slovakien intern who had to stay at a hotel that considered itself accessible but there were no windows in the room and she could not access the restaurant. This inaccessibility shows why we fight through the movement. There is a new political stand saying that disabled migrants will not access any services until they are Swedish. There are also several parties saying no more immigrants. Rights come and rights go. So we need to follow the politics and try to influence them to be democratic and to allow for participation of all.

Participation was discussed with the CRPD as a basis. It will depend on who we believe we are and how we get our voice heard on what I want to do.

Who are we as disabled people?

What is self-determination?

Independent Living (IL) was explained as it considers self-determination as a pillar in its work and has pushed for self-determination to be included in Article 19 of the CRPD. The IL movement started in the 60s in the USA. Leaders who wanted to go to school with their friends but whom could not, mobilized to make a difference and to be able to attend school. The story of Judith Heumann was told and how she mobilized friends in New York to change legislation.

### **Independent Living (IL):**

A philosophy, a movement, a way to live.

Self-determination is a basic principle for IL.

Not sick - do not need professionals we speak for ourselves.

We are care packages - we can lead our movement and administrate our services.

Control of services

Right to Participation

CRPD was discussed.

Article 19 was gone through.

There is existing legislation but there are still hinders for which we need to have lobby for change.

Self-determination and the knowledge that we have rights helps us not to accept the treatment of being victims.

Examples of cases were gone through from DRW showing importance of support. There was one case of a person who had an accident where the municipality wanted to put the young man in a home for the elderly. Through support from DRW a flat was found until the municipality or proposed a flat. This kept the man out of the home for the elderly.

Then there is the case where the municipality wanted to take the baby from a mother who had asked for support. DRW helped her to fight against the municipality and keep her baby.

There was another case of a girl lying in a bed and not accessing the Paratransport. This was wrong so DRW supported a volunteer supporting the girl in acquiring the permit to the special transport.

Are we living lives with self-determination?

**Tips on what to do for support was discussed:**

To do an IL plan for future integration.

Where were we when we came to Sweden?

What has happened since then?

What do we still need in order to continue our process of integration?

**Things people want to do:**

A swimming excursion to be planned; One participant wants to swim!

A walk with women from the community.

Teach people to play backgammon.

The group all made decisions to come to Sweden. Now how to live in this country is the agenda. How to become integrated? What was the view of Sweden before coming and once here?

**Evaluation round:** What did we learn from today and what would we like to learn more about? What should have been done differently?

Interesting day, good to reevaluate ourselves and what is going on and what could be in the future.

Learned a lot. The fight is not over. We still have to fight for our rights.

Good chance for me to come to this course. I have been here many years and I have change and now accept my disability.

Through the story of IL I realized we need to fight and stand up for our rights.

Some people have been fighting for 30 years and will most probably fight until they roll into the grave.

I like the social model and not the medical model. The paradigm shift from putting blame on me to blaming society.

New knowledge leads to self-confidence!

### **Workshop - Culture and the concept of disability**

After the agenda for the meeting was presented, people were asked to present themselves to one another. Here are some of the quotes:

*Never heard of disability as a right; First time to hear of this was from DRW (Disabled Refugees Welcome).*

*I have been quite shy and want to know how people who are disabled become people who are sure of themselves with much self-confidence.*

*I know a bit about the law, but it is not practiced on the ground.*

*I was depressed as I was excluded and did not know about rights and had a difficult time.*

*I did not know anything about legislation in my country.*

A short introduction was given on the concept of disability and how cultures see disability in different ways. Legislation develops differently from one country to the next. We do though have a common denominator with the CRPD as most of our countries have signed and ratified the convention. The implementation then varies from one country to another.

During the meeting the concept of disability was discussed and how attitudes vary from our countries. The role of shame and guilt was introduced and how the role again is different depending on our cultures and religions. But shame is common across the globe when it comes to the view of disability. The group could see that there are many shared experiences of being isolated, being discriminated and having a lack of expectations on who they are to be as a disabled person. Stereotypes and expectations were discussed. It was emphasized that our own expectations on who we want to be are important. We want to have friends, to have relationships, get an education, get a job. We want to access our rights. We need to reflect who we are and want to be to decide who we want to be so that we can be strong when dealing with people who do not see us as equals.

### **Workshop – Covid as well as the Swedish disability movement – why do we need each other?**

A discussion on covid was carried out and how it has hindered participation. People know of people who do not want to be vaccinated. What to believe? ILI members tried to explain that with the vaccination life will be more free. That those who are not vaccinated are at more risk.

The meeting on the Swedish disability movement was used to present information on interesting organisations and that which they offer their members. Some persons from the group shared their experience on why they found it important to be a part of the Civil Society. This being mainly that our voice is stronger if we are united. One person who did not know so much on this area expressed interest to become a member of one of the organisations so ILI will help with the contact.

### Arabic network meeting

This meeting gathered people who speak Arabic and Persian. These people came from different areas in Sweden, from Malmö to Gothenburg to Stockholm. An introduction was given on the concept of disability, self-determination and full participation for disabled refugees according to the CRPD.

The meeting was visited by a project leader from DHR who is herself an Arabic speaker and has a family member with a disability. She spoke of the family's experience of migration and getting the support they need for her brother to have full participation and self-determination. She also spoke about a project DHR will be carrying out called Sekundart – that will be training persons to support others in the same situation of needing support.

This introduction was appreciated and opened a river of questions and comments on what people found they were struggling with in order to progress in their integration process. Questions were asked to understand the Swedish system.

How to apply for different things – what is the responsibility between Försäkringskassan (Swedish Insurance Agency) and the municipality?

What services does BoSSe provide?

A young girl who is blind wondered why she could not choose the person who came through the guide service? She accesses the guide service with hours given to be able to participate in society. But she is unhappy with the system as she is herself not allowed to choose who would accompany her to do things. There is an unknown person who arrives from the service. She then does not use this service. She knows that people who have personal assistance can choose and wonders why she cannot?

There were questions on understanding the services and on being assisted in applying for services.

One person even asked if there were any service assisting people to take their lives? This question shows that people are giving up. It expresses the helplessness felt when feeling excluded and isolated.

### Conclusion

ILI is thankful to UNHCR for the possibility of carrying out these meetings. The meetings again showed the situation of disabled refugees and the extent of support needed. The workshops have given more knowledge on the situation and the opportunity to have contacts and offer people support with their questions and needs.