# Rights reporting podcast – episode 5 – The right to habilitation and rehabilitation services and programmes

**Speaker:** This podcast is supported by the Rights, Equality and Citizenship Program of the European Union.

**Neven Milivojevic:** Welcome to the Rights Reporting podcast. This is a show aiming to improve the rights of blind and partially sighted citizens in Europe. My name is Neven Milivojevic and I will be hosting today's episode and today we will focus on the important rights of access to habilitation and rehabilitation. Habitation is usually referred to as a process aiming at helping people gain certain new skills, abilities and knowledge. While rehabilitation usually refers to regaining skills, abilities or knowledge that may have been lost or compromised as a result of an acquired disability, or maybe also due to a change in your disability or circumstances. The right is clearly stipulated in the United Nations Convention on the Rights of Persons with Disabilities and more specifically in the Article 26. Well, unfortunately, the political visions do not always turn into reality, and we see that the implementation of these rights often are not in place. We will today meet two experts on this topic, one of them from Spain and the other one from Lithuania. And we will hear more about barriers and challenges, but also about possibilities and tools for solutions. But let us first listen to the story of Conchi Blocona, who is instructor of rehabilitation at the Spanish Association ONCE. And she is going to tell us about a woman called Belen.

**Conchi Blocona:** My name is Conchi Blocona, instructor of rehabilitation at ONCE, and also Belén’s. Her case is what I am going to talk about.

Indeed, she is an example of tenacity and struggle to get through the personal and social vicissitudes she had to lived.

Belén is a person who, since she was a child, and due to the severe visual impairment she had, she joined ONCE and went to a regular school but to follow the classes as the rest of her fellows there are some issues to be considered to guarantee her inclusive education is real and effective.

Many of the measures to carry out were:

* She sat in the front row of the class so that she could use in the best way possible her sight rest and follow the classes.
* Graphics, maps, and images had a bigger size.
* Teachers gave oral instructions to promote her inclusion and socialization with all students.

But not always these measures were carried out, so she had to learn how to manage her emotions and feelings of uncertainty and even rejection since she was little. Regarding her family, was integrated by her parents and her older sister. No family member but her had visual impairments. This had forced them to adapt themselves and integrate the visual disability in their lives and environment. Regarding her adult education, she studied physiotherapy in a public university overcoming physical barriers and the barrier of a passive society which allows many of the times the exclusion being part of it. Regarding her job, when she finished her studies she started to work in different clinics and hospital centres. Few years doing so she attended the official exams to work as a physiotherapist. Once she passed them she applied for her place acknowledging she is a person with disability and she is awarded a hospital where she needs to move inside different buildings of the hospital.

The reasonable accommodation needed for this job, bearing in mind the problems she may have, were tackled by ONCE in order to guarantee access to the hospital and consisted of the following measures:

* A written report evaluating the physical barriers of the hospital to eliminate them, such as: mark the stairs, the elevators, the gaps with slopes.
* In addition, to identify visually and with sound the cabin of the elevators as well as having adequate lighting.
* Remove obstacles in the passage area.
* Regarding the reasonable accommodation in the place of work, therapist instruments and devices are adapted due to its lack of accessible design and in addition, it is recommended to elaborate a visual and touchable map of the hospital.

What difficulties has Belén encountered in this concrete job?:

* The continuous modification of work areas within the hospital without having solved the accessibility problems of the environment.
* At the same time, she finds personal limitations because she is excluded by the environment and she fears it won’t include her, being underestimated and overprotected and even rejected because of her disability.
* Barriers, obstacles, stereotypes and misconceptions leading to wrong decisions must be removed. it is necessary to eliminate barriers created many times by the omission of those responsible.
* The barrier created by a passive society which allows this exclusion and that assumes abnormality as normal and the continuous attempt to treat the unequal as equal.

When a worker with a disability lives with professionals who do not have it, although adjustments have to be made, the disability can take a back seat. And that is when talent, ability and skills prevail. Then the disabled worker reaches fullness in his performance and the rest of the workers eliminates the multitude of barriers and prejudices. Disability is normalized.

**Neven Milivojevic:** I would like to welcome our two guests for today's podcast. We have Bárbara Martin Muñoz, who is the second vice president of the European Blind Union. Welcome, Bárbara.

**Bárbara Martín Muñoz:** Thank you. Good morning.

**Neven Milivojevic:** Good morning. And we also have Irma Jokstyté, who is the vice president of the Lithuanian Association for the Blind and Visually Impaired. Most welcome. Irma.

**Irma Jokstyté:** Thank you. Hello, everyone.

**Neven Milivojevic:** So Bárbara, what are your thoughts about Belén’s story? And even though she was successful in many ways, do you recognize the challenges she met? How would you describe the situation in Spain today and what can be done?

**Bárbara Martín Muñoz:** I think Belén's case is one of many examples of perseverance and good attitude towards life, no matter how hard it was. And it really was for her who died, unfortunately, two years ago. She was a white cane user, but had also a guide dog brought from Rochester, which shows her determination for autonomy and mobility. So this means that she needed constant rehabilitation. That meant at the same time, her rehabilitation for life and work. In reality, her perseverance and patience have been the decisive factors in facing complicated situations and overcoming barriers that apparently seemed in some way insurmountable**.** The biggest challenge for her, I would say, was having to demonstrate constantly that she was capable of performing her job because far from being presumed to do so as it is the case for persons without disabilities, in her case, the relevant issues were the impediments to do so, ignoring the essential. Her capacity and ability to do her job as anyone else. I mean with impediments, by the way, those who were alleged by people with unjustifiable prejudices, attitudes and resistance. Regarding the situation in Spain, you were asking? Well, I think Belén was very lucky because she could study and work on what she liked. But unfortunately, this is not the case normally. As you know, in Spain ONCE does a great job and the Spanish disability movement in general is united, strong and very active with the governments at local, regional and national level. But this is not enough. We still need to raise awareness on how habilitation and rehabilitation are crucial to achieve our real equal opportunities in education,at work, when participating in public life. Oh yes, I know you may be wondering, do you really need to do this in the 21st century when the CRPD you mentioned is on board? And unfortunately, the answer is yes and do we must! We have to do it.

**Neven Milivojevic:** Yes. Well, and also, as you say, ONCE is a very strong association and still there is so much to do. So, Irma, how is the situation in Lithuania when it comes to rehabilitation? I mean, how do you try to meet the challenges?

**Irma Jokstyté:** Well, Lithuanian Blind and Visually Impaired People Association is also quite strong in acting, but we are NGO and of course we have our limits and we need bigger support from the state itself because I think we are the only country which provides the rehabilitation services through public procurement. What it means, it means that we do not have any system, any regular system. And every year people make groups, for example, for rehabilitate some participants that lost their vision. But no one knows who is going to give the service this year. So it means the public procurement has to be done. And then they're gone. The organization which is financed will have to find the resources, the specialists, all the necessary tools and so on. So of course, you cannot have a very effective result with this type of organization tools. But Lithuania is doing as much as they can, or maybe we can always do more, but we are trying to make those changes and seeing the experiences of other countries. I hope that we will take the necessary solutions. And actually at the time when the podcast is being recorded, the meetings and debates about how to improve this system should be done. Another very important problem is that we have a huge lack of specialists of teachers, instructors who could provide with professional help and who can consult and do those trainings in the right way. So it means, you know, how will you motivate someone to study rehabilitation? Let's say for blind and visually impaired people when the community is so small, of course, in a small community is much harder to work effectively.

But another problem is that we don't get contacts of the people who need our help, our organization, and we as people who know the situation very well and as having contacts with all the best specialists, we want to help the people, but, you know, they don't find us at the necessary time. So let's say I have a couple of friends who lost their vision. And then, you know, the doctor said to them, okay, no more medical help can be provided to you. Now you can go home and they go home. They are not directed to any organization. And if someone doesn't tell to them or if they aren't active enough or courageous enough to find the information themselves, how blind people live. So then it takes much time for us to find them and to give the necessary tools so that they can recover their lives. Because this necessity to understand populations what it is to get proper rehabilitation, it means to recover your ability to be an equal and effective part of the society. So that's what we are trying to achieve in Lithuania, to have at least a stable system which would function every year, which would be available and would be available in all the parts of the country, because in the cities you have one situation and one access to information, and in the regions the situation is different. So our NGO association is almost covering the whole country. But of course it's sad that we have to do it alone with the small help of the state.

**Neven Milivojevic:** Well, yeah. And of course, this is it is traditionally not as easy task in Lithuania as it has been, maybe in Western Europe developed their rehabilitation systems in the same way, although you do have structures which you are building on. But how is it, for instance, if you look at access to assistive devices and technologies, how would you say that is in Lithuania?

**Irma Jokstyté:** This year, 2022, we had changes in this system. So the access was expanded with new technologies which we could be compensated for our people. It is very nice. Also, some changes occurred in financing the necessary devices and technologies. The problem is that still, you know, for us and for our people, they are still quite expensive. If you can get a white cane with a full compensation, that's fine. But for example, if you want to have a phone, a mobile phone, and to be able to use its functionality for your assistive apps, you will get from the states €200, something like that. For this and the remaining, you have to find yourself. So let's say if I am using an iPhone and if I find only this phone helpful for my situation, I need to, you know, to find this opportunity. So same thing happens with all the devices. Let's say if people cannot use the voice over, so when they need Braille display, they still also have to pay quite much to get the Braille display. And, you know, they usually have to buy that first and only then get the compensation, which is also very disturbing. So we are trying to change the access. The technological access and infrastructure in Lithuania, it's really fine. We are capable in accessing the devices. Maybe still, you know, there is a need of specialists which would be combining mobility with those assistive devices because here now most often people are taught mobility separately from the use of the assistive devices because these instructors that we have, they are very good in teaching mobility techniques of the white cane and teaching the routes and so on. But they don't have this experience in bringing up the assistive devices to those programs. They are taught separately. And again, we need to expand the education.

**Neven Milivojevic:** I see. So now we covered a little about how the situation is, but it's also interesting for us in this podcast to look at the different political frameworks. And I mean, Bárbara, I know that you are actually an expert on the CRPD, the United Nations Convention. What would you say? Is this a useful tool for improving the situation in Europe and in Spain? And how can we use this as a tool?

**Bárbara Martín Muñoz:** Oh, yes, I think it's the best tool we could have because it is the first human rights convention of this century. It is a minimum rights compendium. This means that if there is national legislation that goes further CRPD these can be applied without contravening it. This is rare, but let's be fair, it sometimes occurs. It defines for the very first time what are disabled people in the international framework and this is key. Let me read to you. Who are those? And those are who have long term physical, mental, intellectual or sensory impairments, which interaction with various barriers may restrict their full and effective participation in society on an equal basis. This definition is key and needs to be reminded to avoid paternalistic approaches to disability matters. So CRPD should be interpreted in order to fully maximise the potential of the rights granted from the human rights perspective. It has a monitoring mechanism consisting of a committee that includes people with disabilities, including blind people and partially sighted from around the world. States parties are the CRPD have to report how they are compliant with the Convention. Two years after its entry into forest for them. And every four years afterwards. Civil society, specifically persons with disabilities and the representatives of organizations have an active role in the monitoring or on the monitoring of this Convention and may submit what is called a shadow report. The Optional Protocol, also part of the Convention, but it is voluntary when it has been ratified, enables disabled people, individually or in groups to report directly to the committee if they feel they are rights under the Convention, are not being guaranteed in any specific situation. And this is very relevant because the CRPD since the very beginning was meant to be applied. But unfortunately, not always. People with disabilities as individuals or their representatives or organisations are aware of its potential and what is more important its binding content.

**Neven Milivojevic:** Most interesting. So would you say that the biggest challenge is actually that the implementation from the state side, or would it be as big a challenge that people don't actually report the challenges where they could relate to the CRPD?

**Bárbara Martín Muñoz:** I would say both. I mean, they are very relevant. It's the first time that individuals can acknowledge the Committee that there is something really that is not working at national, regional and local level and also the importance of having persons with disabilities being part of the whole process. And it is key at national level that all public administration are aware of it because if they don't use it, they are not compliant with an obligation they do have. So I would say both together.

**Neven Milivojevic:** Very fair. So another topic we wanted to cover today is actually the one about habilitation, Irma, we know about habilitation also has a crucial role. How do you work with this in Lithuania?

**Irma Jokstyté:** Well, of course, you know, we have the main issue here is that most of the time, we don't have really clearly separated habilitation and rehabilitation processes. I mean, they even do habilitate children, but they still call it rehabilitation. So there's this misunderstanding. And the other issue is that only children who are in the city tend to have proper habilitation or let's say even it's not the habilitation, but they are at least able to attend children garden, which really compensates quite much because if the child has social life, has access to the social life, has ability to take part in some activities. It's very important. While the children who live in smaller towns and they and their parents do not want to bring them to the regular children garden, then they are left to be grown at home and they don't get any way to get some habilitation. And it's crucially important because if sighted children get those main skills at home, how to take care of themselves, how to tidy up the home and so on. So blind children usually are overprotected by their parents, and the habilitation process should include not only the children, but their parents as well.

And it's very again, it's very hard to access people and to react on time, because the biggest problem in Lithuania is statistics and information transparency and transferring the information, you know, that proper institutions would be on time with appropriate help. But it's understandable, you know, when there are so few people, it's really much harder to bring up the changes, you know. And when we come to political and we say hello, please play your part. Then they say, how many of you need that? And we are let's say, 50 children through the country, right who would need habilitation. They will not look at it seriously. But no matter how many, even the one person would be very important to provide with the necessary help. Because if you don't give the habilitation, you don't give the person a bigger part of their life, because it's much harder to train this skill when you are an adult, when you are out of education at some time.

**Neven Milivojevic:** Exactly. But if we if we look at what Bárbara was talking about before, do you feel like that your government listens when you bring up the United Nations Convention and tell them about the duties they signed up to?

**Irma Jokstyté:** Well, we have in Lithuania, we have forum of disability organizations. It is really actively representing the United Nations Convention, UNCRPD. So it really helps a lot. And also we as NGOs do really hard work in accessing ministries and politicians, and we are happy that, you know, they listen to us. They try to at least react to our needs. How successful, it's another question and another topic. But, yeah, we together with other organizations, of course, we can do more because if we go only from the blind people perspective, we don't get the quick reaction. But if we find more partners, which we are doing, then we can see the changes.

**Neven Milivojevic:** Wonderful. Thank you very much Irma. So Bárbara, we are soon in the end of our podcast, but I would like to ask you about how you see the work with habilitation in Spain and if you have any reflections about successful work in relation to that.

**Bárbara Martín Muñoz:** Well, in Spain, we believe that nothing should be taken for granted, and we are well aware that it took a lot of effort and time to get where we are now. So this is why we do assess very positively what ONCE does. ONCEprovides its social services as soon as it learns of the blindness or severe visual impairment of a child by the family. And I know not only to the baby or the child, but also to the parents who will need to learn how to deal with blindness without over protection, for example, through psychological help as many other considerations. We do believe that blind and partially sighted people are regular students, so they go to regular schools. They get the help they need from professionals at ONCE who also provide some guidelines to teachers in order to guarantee the student not only to follow the class, but also play and with other children and receive equal treatment. All of that is done by providing all kind of aids, technical or not, to access to the educational materials and to the students finish their studies in the university. When we refer to work for example ONCE also assists the public administration or private companies to provide the reasonable accommodation to blind and partially sighted workers who may need and referred to a specific optical aids or screen readers, for example. After many years doing this ONCE knows what to do and how and when. Without forgetting that each person is different and may need to adapt the procedure to guarantee the best rehabilitation possible for her or for him.

**Irma Jokstyté:** Sorry, can I ask shortly Bárbara?

**Bárbara Martín Muñoz:** Yes.

**Irma Jokstyté:** But you don't have any issues in accessing information about people who lost their vision. They reach your organisation easily?

**Bárbara Martín Muñoz:** Yeah, we do have a rehabilitation not only for optical, but when referring to access to information, we are very concerned about that. And this provides me the opportunity to mention the Marrakesh Treaty to facilitate access for blind and partially sighted and otherwise print disabled people to print material where ONCE is honoured to share its library with more than 50,000 works in accessible format, braille and audio format. So that not only child but also musical score and other types of literacy, whether it's leisure or for the university researchers and so on, can be shared with other countries that may have not the economic possibility to do it. So we are really concerned about access to information at all terms. Also in the health from the health point of view, when you access to the hospital or if you need to go to a judge and how to do that. Also, we work very hard on that as well.

**Irma Jokstyté:** Right. Exactly.

**Neven Milivojevic:** But Bárbara, do you have an assignment from the state to do this? Because I think the question was related to how you get to know about the visually impaired and blind people.

**Bárbara Martín Muñoz:** Yeah, because we are in the Spain the only organisation that provides services specifically for blind and partially sighted people. So this is something that the state let us do it through because we can handle that because we have our lottery. So with the money we get from selling the lottery, we provide social services. So when someone is born blind in a hospital, normally they tell them that they have to come to ONCE to provide or to see whether if the problem is so severe that they can handle all kind of situations for the person at least when you are a child ONCE provides almost every child some kind of help to make sure that they can handle and they can go to school, as I said before.

**Neven Milivojevic:** Yes. Well, thank you very, very much, both of you, for participating in this podcast. And thank you also for listening to the Rights Reporting podcast. This show is a part of the European PARVIS project, and is led by the European Blind Union, the Swedish Association of the Visually Impaired and the Eye Association Netherlands. And this project is supported by the Rights, Equality and Citizenship Program of the European Union. Do you want to know more about us? You can find contact details in our show notes also. Thank you very much to Emiel Cornelisse, who is our sound master based in Netherlands. The next episode of his podcast will be aired in about two months, so don't forget to subscribe in your podcast app or check on our website. Until then, I wish you all the best.

**Speaker:** This podcast was supported by the Rights, Equality and Citizenship Program of the European Union.

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