

Keynote of the Youth Advisory Board for the Tyrolean Monitoring Committee

Conference „Child. Right.Medicine“

24th September 2020, University of Innsbruck

Thank you very much for allowing us to speak here today. We are young people with disabilities who are members of the Youth Advisory Board for the Tyrol Monitoring Committee. Today there are only a few of us but actually we are much more. On the photo there are 10 of us at a public meeting of the Tyrolean Monitoring Committee where we all also said something. It is very important to us that we can have our say. It is a human right that we can have our say.



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What is the Tyrolean Monitoring Committee?

What is the Youth Advisory Committee for the Tyrolean Monitoring Committee?

The Tyrolean Monitoring Committee monitors the implementation of the UN Convention on the Rights of Persons with Disabilities in Tyrol. As you can see on the second photo, there are only adults with and without disabilities in the Monitoring Committee.



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But the UN Convention states that children with disabilities must have a say in everything that affects them. They must receive good support for this. That's why the Tyrolean Monitoring Committee launched a pilot project a few years ago. It was tried out if a group of children and young people with disabilities could have a good say in the monitoring committee. This worked very well and everyone wanted to continue.

From this group of young people, the Youth Advisory Board has emerged. The Youth Advisory Board for the Tyrolean Monitoring Committee has been in existence since February 2019. We meet once a month at the Tivoli Youth Center in Innsbruck. The youth center is accessible for people in wheelchairs: there is a lift and a wheelchair accessible toilet. During the breaks we can super chill in the youth center.

At the meetings we talk about human rights for children and for adults with disabilities. We think a lot: alone, in groups or all together. We talk about our experience. And we think about what needs to change. Human rights may not only be written on paper, they must also be implemented.

These issues are particularly important to us:

- We want to work and we want to get a good education for work.
- Family, friendship, love and sexuality are very important to us. Some of us want to have children later, some do not.

- We are often segregated because of our disabilities. Many of us are stared at, laughed at, or called names. That's why equality and accessibility are very important issues for us. Something should change!

Together we considered: What can we do so that children and young people with disabilities are not so often excluded and treated badly? We decided that we wanted to make posters. First, we collected ideas. From these ideas we made draft posters. We discussed a lot about these proposals. It was difficult to find good photos to go with our ideas. That's why we took our own photos with a photographer. The posters are now ready. They will be hung up in schools and other places all over Tyrol.



For this conference, some of us filled out a questionnaire.

These were the questions:

- What experiences have you had with doctors?
- What experiences did you have in the hospital?
- What experiences did your parents have with doctors when you were very young?
- How do the doctors talk to you? Do they listen to you? Do they explain everything well?
- What do doctors think about boys and girls with disabilities?

After filling in the form, we talked about our experiences.

These are the results of our discussion based on our personal experience:

Almost all of us have had a lot of experience with doctors and in hospitals. As babies and small children we had many medical examinations. Some of us have even been in hospital for long periods. A few of us have already had major surgery. Some take medication, almost all of us take regular therapies.

Doctors probably have a lot of work to do with us.

We have had good, but also bad and sometimes very bad experiences with doctors. They are often friendly, but also sometimes rude and impatient. They don't always take us seriously and sometimes don't believe us. Even when we are in pain. It can happen that they say: "We can't find anything, you imagine that you are in pain." Then we feel very bad.

Many of us often don't understand what doctors are saying. Most of the time there is no time for us to ask questions. That makes us angry. Our parents or carers then have to explain everything to us.

People talk about us again and again, but not with us, even though we are there. Then we feel like a number, but not a person.

Doctors sometimes see too little the whole girl or the whole boy. For example, they only see the part of the body that needs surgery, but they don't see the rest of the child who owns the part of the body.

Perhaps doctors think too little about the special situation of children with disabilities.

This is what we want from doctors:

Doctors should talk to us. They should not talk about us. They should take us seriously and listen to us.

Doctors should not use difficult words. They should use plain language. Then we can understand them. And we can ask questions.

Doctors should take enough time for us. Children with disabilities sometimes need more time.

Doctors should be better prepared for children with disabilities.

Then we can live well and become independent.

This is important to us: Having your say is a human right!

Thank you for your attention!