

March and April 2017



# Europe for Us!

The Newsletter of the European Platform of Self-Advocates



## Inclusion Europe at Equinet Conference



# Introduction

Hello to all self-advocates!

In this edition of “Europe for Us” you will read about many interesting topics.

On page 3 to 5 you will read about the “Equinet” conference on discrimination of people with intellectual disabilities. It took place in Zagreb in Croatia.

On pages 6 to 10 you will read about the first self-advocacy conference held by AKIM Israel. The whole conference was put together by people with intellectual disabilities.

On page 12 you will read an interview with Oswald Föllerer. He is a self-advocate from Austria. Oswald talks about a new law on guardianship in Austria. Guardianship means when a person takes decisions for another person.

On page 14 there is another interview. Helen and Darren Clark both have a learning disability. They got married in 2014.

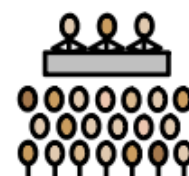
We are always trying to improve “Europe for Us” and would love to hear from you.

What do you think about this issue of “Europe for Us”?  
What would you like to read about in the next issues?

Please send your ideas to [s.el-amrani@inclusion-europe.org](mailto:s.el-amrani@inclusion-europe.org)

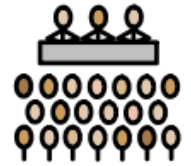


**Editor**  
Soufiane El-Amrani



# Equinet conference

In March, an organisation called Equinet organised a conference.  
A conference is a big meeting.



The conference took place in Zagreb in Croatia.  
Equinet stands for the European Network of Equality Bodies.  
Equality Bodies are offices where people work  
who know about discrimination.

Equality Bodies can receive complaints about discrimination.  
They also try to make people stop discriminating against other people.  
The word discrimination means treating a person worse,  
for example because they have a disability.

The conference was about discrimination against  
people with intellectual disabilities.  
Three people from Inclusion Europe participated at this conference:

- **Soufiane El Amrani.**  
He is the easy-to-read editor of Inclusion Europe.
- **Maureen Piggot.** She is the president of Inclusion Europe.
- **Senada Halilčević.** She is the vice-president of  
Inclusion Europe and the chair of EPSA,  
the European Platform of Self-Advocates.

## **Soufiane's presentation**

Soufiane did a workshop about using easy-to-read tools to talk about under-reporting.

Under-reporting means that people who experience discrimination often do not tell anyone.

They also do not tell the police or someone else who could help them. Then the police might think that the problem is small.

Easy-to-read can help people in different ways, for example:

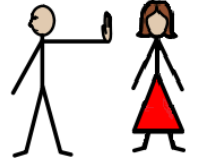
- 1) Helping people understand more about discrimination.
- 2) Helping people understand more about abuse.

Abuse is when someone treats you badly.

This can be that the person shouts at you.

This can also be that the person hurts you or is violent in another way.

- 3) Helping people when they want to tell police or someone else that they were discriminated against or that someone abused them.



## **Maureen's presentation**

Maureen made another presentation.

Her presentation was about the different types of discrimination that women and girls with an intellectual disability experience.

They often experience more discrimination than men or boys.



One problem is that people often do not listen to what women with intellectual disabilities are saying, just because they are women.

Often, they cannot take their own decisions.

And someone else makes the decisions for them.

## Senada's presentation

Senada made another presentation.

The presentation was about the discrimination of persons with intellectual disabilities.

Senada is the chair of EPSA, the European Platform of Self-Advocates.

She is also the vice-president of Inclusion Europe.

Senada talked about different ways of discrimination.

Some examples are:

- **Children with intellectual disabilities are not always allowed to study in the same schools as the rest of the children.**



It is important to give the same opportunities and the same education to children with intellectual disabilities.

- **People with intellectual disabilities need to be more free and be included in society.**

Also they need to be able to live independently and in their own homes.

- **Lack of easy-to-read information.**

There is not enough information in easy-to-read.

People with intellectual disabilities need more easy-to-read information to know what is happening.



You can find all the presentations and more information here: <http://bit.ly/2oah365>

# First Self-Advocacy conference held by AKIM Israel

AKIM Israel is an organisation for people with intellectual disabilities in Israel. AKIM Israel is a member of Inclusion Europe.



Self-advocates from AKIM Israel held their first meeting in January. Around 70 people came to the conference. The whole conference was put together by people with intellectual disabilities. During the conference they shared their own experiences with everyone who was there.



Also different people shared their own life experiences. They were:

- **Ada and Motti** – They are a married and independent couple running a shared household.
- **Rami and Regina** – Members of the Holon advocates' group. Holon is a city in Israel.
- **Irit** – a young girl with Down syndrome who shared her story about her trip with her sister to India.

Inclusion Europe wants to wish all the best to the new self-advocacy group.



# Interview with Oswald Föllerer

In Austria there has been a lot of criticism about the law on guardianship.

Guardianship allows some people to make life choices for others. The person who makes choices for you is your guardian. Your guardian can decide things for you, like where you live. Sometimes, people under guardianship are not allowed to vote, get married, or take care of their kids.

Now there will be a new law.

We talked with Oswald Föllerer.

He is a self-advocate from Austria.

He is co-founder of the Centre for Self-Advocacy in Vienna.

Vienna is the capital of Austria.

The Centre for Self-Advocacy is a member of EPSA since beginning of 2016.

Oswald Föllerer was part of the working group that worked on the new law.



## **1. Why has there been so much criticism of the Austrian law on guardianship?**

Many guardianships were carried out by lawyers. These lawyers often do not have enough time for the people they take decisions for. Often, the lawyers cannot be reached easily. There were examples where guardians were doing a bad job.

For example the guardians did not give enough money to the people they take decisions for.

Some guardians also managed badly the things that these people owned.

Sometimes the guardians sold their things.

## **2. How does the law influence your everyday life?**

When a person is under guardianship, then he or she often cannot decide freely to marry or to move in with his or her partner.

Many people are also told that they should not have children or they are persuaded to have themselves sterilised.

Sterilising means when a doctor does something to a person so this person cannot have children anymore.

Sterilising someone against their own will is against their human rights.



### **3. How will the law be changed?**

With the new law

people with intellectual disabilities

will be able to decide.

They also will be listened to when deciding who will be their guardian.

Another change is for the guardianship.

It will only last 3 years and after this time it is over.

Then the guardianship can be renewed.

Or it is possible to look for other types of support

for the person with an intellectual disability.

### **4. What was it like working in the inclusive working group which proposed changes to the law?**

The working group met during 3 years and a half.

The working group was made up of

- Lawyers
- Doctors
- People working for the state
- Professionals
- People with intellectual disabilities or psychological illnesses.

It was often difficult to work in the working group,

because there were many difficult words.

After we told them, they used more texts in easy-to-read.

Taking part in the working group was exciting.

There were many ideas how to make things better.

We also took ideas from other countries.

# Interview with Darren and Helen Clark

Helen and Darren Clark both have a learning disability.

They got to know each other at a party organised by Mencap.

Mencap is a member of Inclusion Europe.

They married after 3 years, in 2014.



Here is an interview with them  
about their marriage and their life together.



**Please tell us when and how you met.**

**Darren:** We met at a Mencap Party. It was love at first sight.

**Helen:** This was around 7 and a half years ago.

**What do you like about each other?**

**Helen:** Darren and I have the same hobby. We both like music.

Darren is a happy and chatty person when he wants to be.

I feel a sparkle when I see Darren.

**Darren:** When I first met Helen she had a beautiful dress on.

**Helen:** I had this dress on yesterday!

**She smiles and her eyes light up.**

**Darren:** Helen can sing too. She has a lovely voice.

Helen is cute like a teddy bear. Very warm.

I want to be with Helen, she is my first love.



**You got married in 2014.**

**Do you want to tell us who made the proposal?**

**Darren:** I asked Helen to marry me on my birthday.

**Helen:** Darren proposed to me in a Mencap day center where we usually do activities.

Darren had a ring with him.



He got down on one knee and asked me to marry him.

I said no first but then I said “what the hell” and finally said yes.

**What was the best thing about getting married?**

**Darren:** The party and the free food!

To get married for us means that it doesn't matter what disability you have. You can get married.

We have lovely wedding photos.

**Helen:** My parents and I paid for the wedding.

I was going to wear jeans and T-shirt but in the end I wore a beautiful dress.

I had 14 bridesmaids.

**How is it to live together?**

**What do you enjoy most and what is difficult living together?**

**Darren:** Helen is cute and funny to live with.

I can chat to her and she will listen to me. I like her cooking.

I don't like it when Helen listens to loud music and

I can't hear the TV anymore.

Helen likes to do arts.

But when she does her arts

I always find paper and glitter everywhere.



**Helen:** I don't listen to him, I just pretend.

It goes in one ear and out the other.

**She smiles.**

If I can't do something Darren will help me and support me.

I have problems with my mobility

and now I am struggling sometimes.

Sometimes I can't do things with Darren.

Sometimes we argue about cleaning

as he can be lazy if he stays in bed all day.

**How would your life be without each other?**

**Helen:** I would struggle without Darren.

I wouldn't be able to do many things as he supports me a lot.

**Darren:** I would miss her so much I wouldn't be able to manage.

**Do you have the intention to have children?**



**Helen:** No thank you.

**Darren:** Maybe one day.

## Short-News

### Mélanie can do it.

Mélanie Ségard has completed her wish of presenting the weather on TV.

Mélanie has Down syndrome.

She did a campaign on Facebook and 200,000 people supported her. The campaign “Melanie can do it” was made by Inclusion Europe’s French member UNAPEI.

You can watch the video here: <http://bit.ly/2nkM2xd>



### European Accessibility Act.

On 6 March, Inclusion Europe took part in a demonstration in front of the European Parliament.

The demonstration was organised by the European Disability Forum. People demonstrated for a strong Accessibility Act in Europe.

The Accessibility Act is a proposed law that improves the accessibility for people with disabilities in Europe.



### Able to include.

The Able to Include project is a project to make new technologies accessible for people with intellectual disabilities.

An example is a tool that makes it simpler to send and receive e-mails.

Another example is a tool that make easier to use Facebook.

You can read the newsletter here: <http://bit.ly/2oUj1oi>



## Test summary

You have read a lot of important things today.

Maybe you would like to let others know.

Explain to your friends what you have learned:

What was the Equinet conference about?

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Which members of Inclusion Europe gave a presentation at Equinet conference?

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What are children with intellectual disabilities not always allowed to do?

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# Summary

## “Equinet” Conference

From the 9 to 10 of March Equinet organised a conference. The conference was about discrimination against people with intellectual disabilities.

Discrimination happens in different areas, for example:

- **Education of children.**
- **The lack of easy-to-read information.**
- **People often do not listen to women and girls with intellectual disabilities.**

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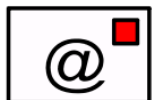
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