



EUROPEAN
DISABILITY
FORUM



Nothing about us without us
Report 2016 - 2017

NOTHING ABOUT US WITHOUT US
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Recycled paper has been used

- European Down Syndrome Association (EDSA)
- European Dyslexia Association (EDA)
- European Federation of Hard of Hearing (EFHOH)
- European Federation of Parents of Hearing Impaired Children (FEPEDA)
- European Kidney Patients' Association (CEAPIR)
- European League of Stuttering Associations (ELSA)
- European Network of (ex-) Users and Survivors of Psychiatry (ENUSP)
- European Network on Independent Living (ENIL)
- European Union of the Deaf (EUD)
- Inclusion Europe
- International Federation for Spina Bifida and Hydrocephalus (IF)
- International Federation of Persons with Physical Disability (FIMITIC)
- Retina Europe

11 ordinary members

The ordinary members of EDF are organisations for persons with disabilities that are consistent with EDF's aims and objectives.

- Alzheimer Europe
- Association for Research and Training on Integration in Europe (ARFIE)
- Association Internationale Aphasie (AIA)
- Design for All Europe (EIDD)
- European Association of Service Providers for Persons with Disabilities (EASPD)
- European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA)
- European Guide Dog Federation (EGDF)
- European Multiple Sclerosis Platform (EMSP)
- European Union of Supported Employment (EUSE)
- Mental Health Europe (MHE)
- Social Firms Europe (CEFEC)

4 observer members

Observer members of EDF are national organisations of persons with disabilities from countries in Europe outside the European Union.

- Albanian National Council of Disabled People (ANCDP)
- Confederation of the Disabled in Turkey (CDT)
- National Council of Disability Organisations of FYROM (NSIOM)
- National Organisation of Persons with Disabilities of Serbia (NOOIS)

29 associate members

The associate members of EDF are non-profit organisations or companies that are committed to promoting EDF's aims.

Associazione Nazionale Mutilati e Invalidi Civili (ANMIC) • Austrian Association in Support of the Blind and Visually Impaired • CBM EU Liaison Office • Coalition for Independent Living (CIL) • Confederation of Family Organisations in the European Union (COFACE) • Dachverband der Steirischen Behindertenhilfe (DSBH) • Ente Nazionale per la protezione e l'assistenza dei Sordi (ENS) • European Academy of Yuste Foundation • European Dysmelia Reference Information Center (EDRIC) • European Federation of Hereditary Ataxia (EURO-ATAXIA) • European Ostomy Association (EOA) • European Polio Union (EPU) • European Union of the Deaf Youth (EUDY) • EUROPSY Rehabilitation • Flemish civil rights organisation for persons with disabilities (GRIP) • Fundación ONCE • Housing Options Scotland (HOS) • Inclusion Scotland • International Federation of Hard of Hearing Young People (IFHOHYP) • Kosovo Disability Forum (KDF) - joined EDF in 2017 • Light for the World (joined EDF in 2016) • National Commission of Persons with Disability (KNPD) • Remploy (joined EDF in 2016) • Saint Lazarus Foundation (joined EDF in 2016) • San Marino Paralympic Committee • Union of Disabled People in Bulgaria (UDPB) • Union of Disabled People Organisations' of Azerbaijan (UDPO) - joined EDF in 2017 • Vittime Italiane Talidomide (VITA) •

A word from the president



2016 and 2017 have been dramatic years for the European Union, and historic years for EDF and 80 million persons with disabilities in Europe. The EU continues to face escalating challenges to its vision: increasing threats of terrorism, over one million refugees and migrants arriving on European shores and the process of losing a member state- the UK. Despite this complicated context EDF saw achievements in many areas of our work: UN CRPD, SDGs, non-discrimination, employment and social services, EU funds, accessibility, standardisation, transport, research and more.

In 2017, EDF adopted its strategic framework which defines our priorities for the coming 4 years, and elected a new Board and executive committee.

We ended 2017 with a historic gathering, the organisation of the 4th European Parliament of Persons with Disabilities - marking 20 years of campaigning for the rights of 80 million persons with disabilities in Europe. With strong support from the President of the Parliament, our allies in the Political Groups and the Disability Intergroup, EDF and its members mobilised persons with disabilities from across the EU for a day of Parliamentary discussions on the rights of persons with disabilities. On that day, we adopted a Manifesto on the European Elections, a Resolution on the next European Disability Strategy and an Emergency Resolution on the European Accessibility Act - these documents will guide our work together in the coming years.

NOTHING ABOUT US WITHOUT US!

Yannis Vardakastanis
EDF President

EMPLOYMENT & SOCIAL POLICIES

The right to employment is enshrined in Article 27 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Access to employment is also a precondition for the economic and social inclusion of persons with disabilities and their families in society.

Unfortunately, more than 53% of persons with disabilities in Europe are unemployed. Women with disabilities, people with disabilities living in institutions and people in need of high level of support are even more likely to be discriminated against and excluded from the labour market. Unemployment is closely linked to poverty and social exclusion.

At the European level, the debate on employment has been boosted by the launch of the European Pillar of Social Rights (the Social Pillar) aiming to promote access to employment, decent working conditions, including work life balance, and social protection.

HIGHLIGHTS IN 2016-2017

EDF met with the President of the European Parliament, Antonio Tajani, to discuss the role that the European Parliament can play in ensuring that all citizens can vote or stand for election in the European Parliament elections of 2019.

During the 4th European Parliament of Persons with disabilities in December 2017, EDF presented its Manifesto on the European elections 2019 to European Parliament leaders, calling for fully accessible and inclusive 2019 elections.

EDF and its members closely worked with the European Economic and Social Committee (EESC) on the right to vote - we provided direct examples of obstacles faced by persons with disabilities via first-hand testimonies, and supported the Committee's efforts to reform the electoral rules governing the European elections. In 2017, the EDF Board held a panel discussion with the rapporteur of the EESC during the EDF Board meeting. We also supported the organisation of a Hearing at the EESC.

EDF initiated cooperation with the Organisation for Democratic Institutions and Human Rights (OSCE/ODIHR), an international organisation promoting Human Rights in the wider Europe, Russia and North America. EDF, through the participation of its Vice-President, Pat Clarke, became a member of the expert group advising the ODIHR on the right to political participation of persons with disabilities. We want to make sure that the OSCE and its participating states consult with and adequately involve persons with disabilities and their organisations in every activity on the right to political participation. EDF contributed to several OSCE documents, including guidelines on political participation and a handbook for election observation teams.

EDF, the ODIHR and the Disability intergroup of the European Parliament organised a thematic meeting with MEPs, organisations of persons with disabilities and experts, on the topic of the involvement of persons with disabilities by political parties.

EDF and its members held a dialogue on the right to vote with the European Commission during the conference for the European Day of Persons with Disabilities 2017.

EASY-TO-READ



This is a summary of this booklet in easy to read.

Easy to read is a way to make information accessible so people with intellectual disabilities and all people can understand it.

The European Disability Forum

The European Disability Forum is an organisation of people with disabilities in Europe.

In short, we call it EDF.

EDF was created by people with disabilities 20 years ago.

EDF works to protect the rights of people with disabilities in Europe.

EDF is the link between people with disabilities and people who make laws and decisions in Europe.

We talk to people who make laws and decisions in Europe about what people with disabilities need to have a good life and same chances as everybody else.

EDF believes that a fair society includes people with disabilities and that people with disabilities should decide about their lives. We believe that nothing should be decided about us without us.

We believe that all people have the right to:

- be treated fairly
- have same chances in life
- make their own choices
- take part in the community and live together

EDF members

EDF has around 100 members from all over Europe.

These members are also organisations of people with disabilities or organisations that want to help people with disabilities.

Some of these organisations represent people with a certain type of disability.

For example, intellectual disability.

On page 50 of this booklet

there is a list of all the organisations that are members of EDF.

EDF members come together and discuss important things for people with disabilities. They also choose the people who can take decisions for EDF. All together they decide how to make things better for people with disabilities in Europe. On page 8 and 9 of this booklet you can see pictures of people who take decisions for EDF.

Also EDF has an office in Brussels. On page 10 of this booklet you can see pictures of people who work at EDF office. You will also find information about how to contact EDF office.

EDF's work

In 2016 and 2017, EDF worked on many different things that are important for people with disabilities.

The UN Convention

The United Nations is a big world organisation that works for peace and a better world.

In short, we call it 'the UN'.

The UN made a document which says what rights people with disabilities have and how countries can protect these rights.

This document is called

'the UN Convention on the Rights of Persons with Disabilities'.

In short, we will call it 'the UN Convention'.

The European Union is a group of 28 countries in Europe.

These countries came together to make things better for their people.

Some years ago, the European Union signed the UN Convention and agreed to do what it says.

This was a very important step.
It means that the European Union agreed to make things better for people with disabilities in Europe.

Almost all countries of the European Union also signed the UN Convention.
They agreed to work hard to make the lives of their people with disabilities better.

Both the European Union and its countries have to present to the UN the work they do to make the UN Convention happen.
They write a report talking about what they do for people with disabilities.
The UN checks this report and tells them what they must do better to protect people with disabilities.

There is still many things that the European Union and its countries must do to make sure that people with disabilities in Europe have good lives and same chances as everybody else.

EDF wants the UN Convention to happen in Europe.
and we think that the European Union can do more for that.
That is why EDF had many meetings with people who make decisions in Europe.
We want to make sure that they respect the UN Convention when they make decisions.
We want them to respect the rights of people with disabilities. We also want the European Union to have a good plan saying what they will do in the next years to make the UN Convention happen in Europe.
We call this plan 'European Disability Strategy'.
We want this plan to respect all the things that the UN Convention says.

Discrimination

People with disabilities are sometimes treated badly or unfairly because of their disability.

This is called discrimination.

Some people with disabilities have bigger risk of being treated badly or unfairly.

For example, women, children, older people or people who live in institutions.

At EDF, we work to stop discrimination of people with disabilities.

We want the European Union to make a law that protects people from all kinds of discrimination.

People may have different abilities, religion, age or views but we are all equal and we should all be treated with respect.

Freedom of movement

In the European Union, people have the right to move, live and work in any country of the European Union.

When they move to another country, they should be able to use products and services exactly as the people who live in this country.

For example, a German person can move to Belgium and live there.

Or a French student can go study at a university in Spain.

We call this right 'freedom of movement'.

Unfortunately, many people with disabilities cannot enjoy this right.

It is often hard for them to travel, study or get a job in another country.

That is because many things are not accessible for them and they cannot use them like other people.

In the last two years, we continued to work to make freedom of movement happen for people with disabilities.

People with disabilities should have same chance as everyone else to move, live and work in any country of the European Union.

To help this happen, EDF asked the European Union to make a 'European Disability Card'

This card could make things easier for people with disabilities when they visit or live in another country of the European Union.

The European Union made this card.

Unfortunately, until now only 8 countries were interested to have this card for their people with disabilities:

- Belgium
- Cyprus
- Estonia
- Finland
- Italy
- Malta
- Romania
- Slovenia

That means that the card can be used by people with disabilities who are traveling only among these countries.

For example, a person with disability from Belgium who moves to Cyprus can use this card.

The card gives to people with disabilities some advantages in culture, sports and other activities.

For example, they may get lower prices

when they buy tickets for museums or for a football match.

Or they may get information that is easy to read and understand.

EDF was happy that the card was made

but we want the card to be used in all countries of the European Union.

We want the European Union to make this happen so that all people with disabilities can use the card when they travel in any country of the European Union.

Also, EDF went to meetings and wrote papers to explain how important freedom of movement is.

We said to people who make decisions in Europe how they can make sure that people with disabilities can enjoy freedom of movement like everyone else.

Accessibility Act

People with disabilities cannot use many things and services in Europe because they are not accessible. For many years, EDF was asking the European Union to make a strong law that will make things and services accessible so all people can use them.

We call this law 'the Accessibility Act'.

Finally some time ago, the European Union published a text saying how this law should be.

If this law happens certain things and services in Europe will become accessible so all people will be able to use them.

For example, cash machines, televisions and ticket machines will become accessible.

That will make it possible for people with disabilities to get money from a cash machine
watch programmes on television
or get a ticket from a ticket machine when they travel like everybody else.

EDF thinks that this law is very important.
We want the European Union to make this law happen.
We had many meetings with people who make decisions in Europe.
We explained to them what people with disabilities think about this law
and how it can make their lives better.
We asked them to make this law stronger
and make more things and services accessible for all people.

Now people who make decisions in Europe are discussing this law.
They will decide if they will make this law happen in Europe
and what things and services will be accessible.

We hope that they will hear what we tell them
and they will make a strong law
that will make things better for people with disabilities in Europe.

Transport

It may be hard for people with disabilities to travel
because transport like planes, boats and trains
are often not accessible to them.
Also they may not get the support they need
or information may be difficult for them to understand.

EDF thinks that people with disabilities should have the same chance
to travel when they want like everyone else.
For this to happen, transport like planes, boats and trains in Europe
must be accessible for all people.
This way people with disabilities will be able to use them
without problems.

If transport is not accessible
people with disabilities will not be able to use it
to go to their work or to visit their family and friends.
They will be left out.

We work to make sure that people who take decisions in Europe understand this and make all transport accessible for all people.

We often work together with other organisations who also think that transport should be accessible for all people. For example, lately we worked together with two world organisations and we made a very useful paper.

The paper says how people who work in buses, trains and metros could help people with disabilities.

For example, it says how the driver of a bus can help a person in a wheelchair to get in the bus and have a safe trip.

Economic crisis

In recent years, there is an economic crisis in Europe.

That means that countries in Europe have problems with money.

They have less money than before.

Many people in Europe don't have enough money to have a good life.

It may be hard for them to find a job.

Things are even harder for people with disabilities.

Some countries in Europe give little or no support to them.

Often people with disabilities do not have enough money to have a good life.

Without money and without a job, they may be left out of the community.

EDF asks countries in Europe to protect people with disabilities from the economic crisis.

We ask them to help people with disabilities to have a good life and same chances as everyone else.

Using European money

The European Union gives money to its countries.

This money is called 'Funds'.

The countries should spend this money to make schools, streets and other things that make the lives of people better.

This money is very important for people with disabilities too.

It can be used to make things accessible for them

and help them to be part of the community like everybody else.

For example, countries can use this money to build accessible schools so students with disabilities can go to school together with other students.

Or they can make streets, metros and buildings accessible

so people with disabilities could go around and be part of the community like everybody else.

The European Union should give this money only to countries who work to make sure that all people can take part in the community and have same chances in life.

Countries should spend part of this money

to help people with disabilities and other people who need support.

EDF checks how countries use this money.

We check if they use it for the good of all people

and if they use it to do good things for people with disabilities too.

EDF doesn't want countries to spend

the money they receive from the European Union

on things that make people with disabilities be left out.

For example, we don't want countries to spend this money

to build institutions where people with disabilities

live away from the community.

Instead, countries should spend this money

to help people with disabilities be part of the community

like everyone else.

Work

Having a job and making your own money helps to be independent and make your own choices.

Some people find it hard to get a job because they have a disability. There are too many people with disabilities in Europe who do not have a job.

Without a job, they may not have enough money to buy the things they need and have a good life. They may be left out of the community.

For some people with disabilities, it is even harder to get a job. For example, women with disabilities or people with disabilities who live in institutions.

EDF wants people with disabilities to have same chances to get a job as everyone else

EDF believes that the European Union should work to make it easier for people with disabilities to get a job and have a good life.

EDF talked to people who make laws and decisions in Europe about the problems that make it hard for people with disabilities to get a job.

For example, buses and metros are often not accessible for them so they cannot use them to go to work.

Or some people do not want to work with them because they have a disability.

That is unfair.

We want people who make laws and decisions in Europe to help people with disabilities have same chances to find a job and be part of the community like everyone else.

The right to vote

Every five years there are European elections.
That means that people in Europe vote and choose
who will make decisions and laws in Europe.
The next European elections will be in 2019.

It is very important to be able to vote.
It means that your voice counts.
It is also important to be able to stand for elections.
That means that people can vote and choose you
to make decisions and laws in Europe.

People with disabilities in Europe often have problems
when they try to vote or stand for elections.
Sometimes it is difficult for them to go to the place
in which they can vote.

For example, if the building has stairs
people in wheelchairs will not be able to get there to vote.
Also people with intellectual disabilities
may not get information that is easy to read and understand
so they may not know how to vote.
Often people with disabilities are not allowed to vote
or stand for elections because they have a disability.

EDF thinks that all people should have the right to vote
and choose the people who will make decisions and laws in Europe.
People with disabilities have the right to vote too
and their disability should not be a problem for that.

EDF met many people who make laws and decisions in Europe.
We told them it is unfair to not vote only because you have a disability.
We asked them to make sure that all people with disabilities
can vote in the next European elections.

The European Parliament

The European Parliament is a place where people make laws and decisions about important things in Europe. These decisions are also about people with disabilities. They can make their lives better.

EDF works close with the people of the European Parliament. We tell them what people with disabilities need to be able to take part in the community like everyone else. We tell them how they can make things better for them.

We also make sure that they do not forget people with disabilities when they make decisions and laws. In all the decisions they make they should always respect the rights of people with disabilities and work to make their lives better.

In December 2017 we made a very big meeting at the European Parliament. Around 800 people with disabilities from different countries in Europe came to this meeting. We talked with the people from the European Parliament about our rights. We told the people of the European Parliament how they can make sure that people with disabilities in Europe have same chances in life like everyone else. We asked them to make things better for all people with disabilities in Europe.

Sustainable Development Goals

Some years ago, countries came together and made an agreement that they will work to make the world better. They set some goals to make this happen.

We call these goals 'the Sustainable Development Goals'. They have to make these goals happen by 2030.

For example, they agreed to protect people who are poor and make things better for them.

They also agreed to try to make peace in the world and to protect the planet.

Countries in Europe also agreed to make these goals happen.

These goals concern people with disabilities too.

When countries in Europe work to make these goals happen they should always keep in mind people with disabilities and the UN Convention (read more on page 13).

They should make sure that no one is left behind.

Both the Sustainable Development Goals and the UN Convention are very important for people with disabilities.

If they happen, all people with disabilities will have better lives and same chances as everyone else.

EDF met people who make decisions in Europe and asked them to remember people with disabilities

when they work to make the Sustainable Development Goals happen.

They should use the Sustainable Development Goals to make things better for people with disabilities too.

They should leave no one behind.

Technology

Most people in Europe use technology every day for many things.

For example, they may use:

- computers at their work
- mobiles to talk with their friends and family
- the internet to look for things

Technology can be very useful for people with disabilities too. If technology is accessible, they can also use it as everyone else. For example, it can help them to learn new things, work or stay in contact with their friends. It can help them to take part in the community like everyone else.

EDF thinks that technology should be accessible for all and that everyone should be able to use it.

In the last years, EDF was asking the European Union to make websites accessible for all people.

In 2016, the European Union made a law that says that public websites in Europe should be accessible.

For example, the website of your hospital or the website of the community you live at will be accessible and people with disabilities will be able to use them and find the information they need.

This was a great step.

We hope that more websites and technology will become accessible for people with disabilities.

Standards

A standard is a document with rules that explain how something should be made.

Standards are useful to explain to companies how they should do certain things.

If there were no standards, each company would do things differently and that would create problems.

For example, the bank cards we often use to pay our bills or to get money from a cash machine

would have different sizes and forms in every country.

This way, it would be impossible to use them when we travel to another country.

Thanks to standards, the bank cards have the same size and form and we can use them to get money in every country.

Also, in train stations and metros, there are some signs on the floor that blind people can feel with their feet.

This way they know where they should stop at the platform to wait for the train to come and they do not fall in the gap.

There are standards that explain how these signs should be made.

If there were no standards, each train station would use different signs and blind people would be confused or in danger.

EDF often helps people in the European Union who make standards.

We talk to them about the needs of people with disabilities

and we ask them to think of them when they make standards.

Standards should make things better for all people.

Women with disabilities

Often women with disabilities are treated badly or unfairly.

They may also go through 'sterilisation' against their will or without being well informed about it.

'Sterilisation' is a medical operation that makes it impossible for women to become mothers and have kids.

EDF made a document to talk about this.

We want this to stop.

Women with disabilities should have the right to decide if they want to become mothers and have kids.

There are laws that protect women with disabilities.

Countries in Europe should work harder to respect these laws

and protect women with disabilities.
They should make sure that they are treated fairly.

Refugees with disabilities

In the last years, more than 1 million refugees came to Europe. These people had to leave their countries and their homes because it was not safe for them to stay there anymore. Their countries had war and their lives were in danger. Among these people, there are also people with disabilities.

Things are often very hard for refugees with disabilities who arrive in Europe. Often, the places they stay are not accessible for them. For example, showers and toilets may have steps so people in wheelchairs cannot get in. Or refugees with intellectual disabilities may not get information which is easy to read and understand. They can be confused or left out.

Things can be even harder for women, children and older people with disabilities. They may not get the support they need.

EDF talks to people who take decisions in Europe about the rights of refugees with disabilities. We ask them to respect their rights and make sure they are treated fairly. We explain how they can make things better for refugees with disabilities who arrive in Europe.

Young people with disabilities

It is often hard for young people with disabilities to finish school go to the university or find a job.

Many things are not accessible for them and they may be left out. They do not have same chances in life as other young people without disabilities.

EDF works to protect the rights of young people with disabilities. We want their voices to be heard. We want them to have same chances in life like everyone else.

EDF has a group of young people with disabilities. This group meets and discusses important issues about young people with disabilities in Europe. We tell people who make decisions in Europe how they can help young people with disabilities to have same chances and take part in the community like everyone else.

Children with disabilities

Many children with disabilities live in institutions away from their families. They may also be treated badly and be left out. For example, they may not be able to go to school with other children.

EDF works to protect the rights of children with disabilities and make sure their voices are heard.

We often work together with other organisations who try to make things better for children. For example, we work with a world organisation for children called 'Unicef'. We help them to do some important work to protect children from being treated badly.

Children with disabilities and all children have the right to have a good life and be treated well.

Work outside Europe

EDF is part of a world organisation that works for people with disabilities all around the world. This world organisation is called 'International Disability Alliance'. In short, we call it IDA.

EDF and IDA go to important meetings in different parts of the world to talk about the rights of people with disabilities.

For example, in the last two years we went to important meetings in New York. We talked about many important things there. For example, we talked about:

- refugees with disabilities
- women with disabilities
- the Sustainable Development Goals (read more on page 34)

EDF also works with the Council of Europe.

This is an organisation that works to protect the rights of all people.

EDF talks to the Council of Europe about the rights of people with disabilities.

We ask them to help to make the UN Convention (read more on page 13) happen and make things fair for people with disabilities in Europe.

Work with other organisations

EDF often works with other organisations who also want to make the lives of people better.

These organisations can be world organisations or European organisations.

For example, EDF works closely with a European organisation that protects the rights of women.

This organisation is called the 'European Women's Lobby'.

Sometimes we also work with companies who care to help people with disabilities. We organise meetings and other things together to support the rights of people with disabilities.

On page 50 of this booklet, you can see a list of these organisations and companies.

Our money

On page 51 of this booklet, you will see a table with the money we used to do our work.

We got this money from the European Union and other organisations who wanted to help us to do our work.

We spent this money:

- to pay the people who work for us
- to travel for important meetings
- on other things that are important for our work.

More information

If you want to find more information about EDF and our work, you can visit our website at www.edf-feph.org.

You can also send us an email at info@edf-feph.org.



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