

EUROPE'S BLIND SPOT

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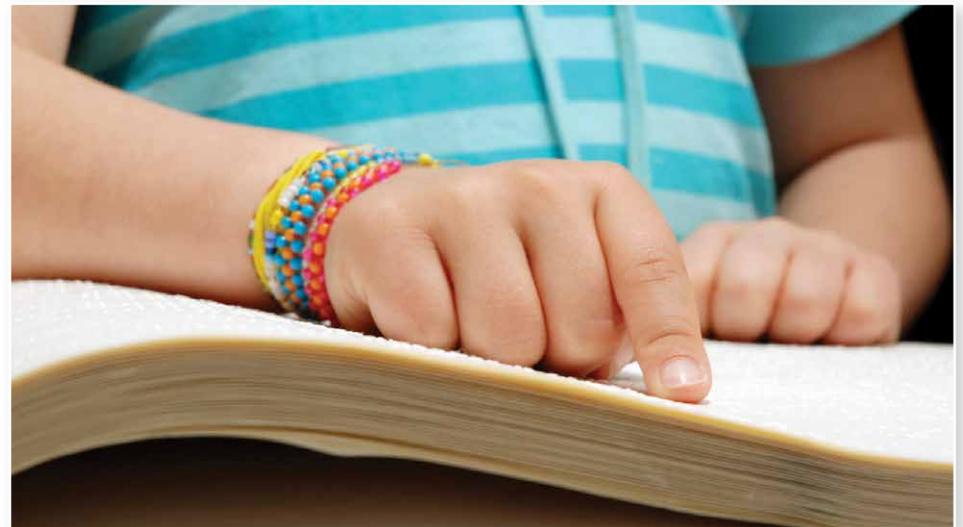
Single EU definition of blindness could help save billions of euros: study

Europe needs a unified definition of blindness to help tackle the condition that costs billions of euros in treatment and loss of economic activity, much of which could be saved, according to a study for the European Forum Against Blindness (EFAB), conducted across six countries.

The definition of blindness remains a key problem, with no clear policy across EU member states, found a study conducted by consultants at Deloitte Access Economics.

In France, blindness is defined depending on whether the sufferer considers him or herself blind, Germany has its own scientific definition whereas Italy and the United Kingdom use official World Health Organization definitions.

The report, 'The cost and burden of eye diseases and preventable blindness', was presented last week (1 October) at a debate in the European parliament designed



to garner responses to the challenge of blindness in Europe. The study included data from France, Germany, Italy, Slovakia, Spain and the UK.

Indirect costs amount to €20 billion in six countries

Across the six countries examined, it found that 123 million workdays are lost every year as a result of eye diseases, which account for healthcare costs of €15 billion on eye diseases and €1.4 billion on blindness itself.

Indirect costs arising from productivity losses and informal care amount to €20 billion for eye diseases and €7.1 billion for blindness, the survey said.

The prevalence of blindness in Europe varied widely between member states, according to the findings, with twice as many people in Italy and Slovakia having lost sight compared to their counterparts in France and UK. It found that between

26,480 and 218,513 individuals are blind in the countries examined, but hundreds of thousands more suffer visual impairment.

"Blindness is the end point, but the number of people with visual impairment is much greater than the 700,000 [blind] in the six EU countries. We think one in every thirty is blind or partially sighted," Professor Sehnaz Karadeniz, the president of the International Diabetes Federation's European region, told Parliament.

Intervention could halve prevalence of blindness

The study found that health interventions - such as appropriate early detection, prevention and treatment options such as screening for cataracts, diabetic retinopathy and glaucoma followed by treatment for these conditions - could halve the numbers suffering blindness and

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save the six states in the range of €1.6 billion to €3 billion each year. But delegates agreed that a clear pan-European definition of blindness would be necessary to implement such money saving policies.

Marian Harkin MEP (Ireland, Greens) told delegates at the debate that Commission support would likely be available for attempts to create a pan-European definition of blindness.

“When you talk about a European standard for visual impairment that should be accessible for European funding because one of the things we try to do is add value, so if you try to coordinate national level information that is the kind of thing that the Commission would look to fund,” she said.

Speakers also addressed the urgency of putting visual impairment higher up the European policy agenda as a result of its connection to the rapidly ageing demographic.

“The real situation is not promising for the future, putting more people at risk for the future with ageing, the diabetes epidemic, and we know that 70% of those who develop obesity also have retinal problems,” according to Joris Kleintjens, a senior research manager with Deloitte, who was one of the report’s authors.

Ageing demographic spells problems for future

Ian Banks, the president of the

European Men’s Health Forum, warned of the impact that rising retirement ages across Europe – especially for women, whose retirement ages are increasingly being tallied with those of men – would have on visual health and productivity.

“This means that there will be many more people working with visual impairment, so we need to plan ahead, not just for treatment but to prevent it, if we want to have a healthy workforce,” he said.

The debate was held as a forerunner event to mark World Sight Day 2013, which takes place this week (10 October), to raise awareness about preventable blindness across Europe, and to support efforts to make blindness a public health priority.

US trumps EU on blind-friendly high-tech consumer products

The EU is trailing behind the US on online accessibility laws that make it easier for the visually impaired to access the internet or use a smartphone.

In the United States, a big part of business has moved online and American companies have a legal obligation to make their websites just as accessible for disabled groups as their brick-and-mortar stores.

These laws are aimed at making life easier for disabled people so that they do not have to rely on wheelchair ramps and self-opening doors to do their grocery shopping, for example.

Still, some companies continue to refuse making their websites more accessible and the National Federation of the Blind



Photo: Balefire/Shutterstock

and the National Association of the Deaf is winning legal victories against them.

The situation of disabled people should improve further when the US Department of Justice issues new regulations on website accessibility later this year, according to the Wall Street Journal.

These could require websites to include spoken descriptions of photos and text boxes for the blind. It could also impose captions and transcriptions of multimedia features for the deaf.

According to the Wall Street Journal,

the costs of making a website accessible to disabled groups vary based on the complexity of the site. It is also much cheaper to build accessibility features into a new site than to retrofit an old one.

No similar EU law

In the EU, there are no common rules yet on online accessibility for public or private websites. Countries are free to determine for example how blind people should be helped to shop on the internet.

María Jesús Varela Méndez of the Spanish National Organisation for the Blind says the US is way ahead of Europe when it comes to online accessibility laws.

“This has been good for the blind and partially sighted because the US is a very big market and since that law entered into force, important companies and manufacturers such as Google, Samsung and Apple have taken into account the characteristics we need to use their smart phones or tablets. Things are improving day by day,” Méndez said.

“In the case of Europe, the situation is completely different because the laws are different in each member state,” Méndez added.

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She explained that while the UK and Spain had adopted helpful legislation for the blind or visually impaired, this was rarely the case across Europe. Member states had sometimes proposed laws that would improve blind people's online access or access to technology, but often failed to complete or implement them.

The spokesperson from the Spanish National Organisation for the Blind said national associations for blind people were on an "impossible mission" and would prefer that the European Blind Union (EBU) press for a common EU law.

"This is the best way to get a better legislation in every country," she stressed, adding that a directive could include cross-border online shopping.

Single market?

Thorkild Olesen, chairman of the Danish Blind Society, said that in many member states, a lot of work had been done to make public authorities' websites accessible for blind people, but that for the most part, private companies could make those decisions on their own.

Instead, the blind and partially sighted help each other find websites that are accessible for them, the chairman said.

"But it would only be natural if the EU as the place which defends free trade across borders that they were first movers and said 'This is how it should be'. That would only be natural for the single market," Olesen stated.

The core elements of the EU disability strategy, which combines anti-discrimination, equal opportunities and active inclusion measures, are reflected in the UN Convention on Rights of Persons with Disabilities.

The rights cover almost all policy fields from justice to transport, from employment to information technology, from social to health policy.

Pressed by EurActiv to provide clarification on the status of the directive, the European Commission declined to comment.

Workplace prejudice keeps blind people out of employment

The statistics show that blind and partially sighted are the disability group with the lowest employment rate but the biggest obstacle for visually impaired jobseekers is not their disability, experts say.

The blind and heavily impaired sighted people have the highest unemployment rate among disabled groups, despite their great desire to be part of the labour market, according to organisations representing the blind.

But workplace prejudice might be even more crippling than disability, a new survey shows.

The survey, conducted by the Danish Blind Society, shows that prejudice is a major reason why so many blind people in Denmark are unemployed. According to the survey, more than one out three Danes is sceptical about having a colleague with sight impairment.

"There is in general a great uncertainty about what blind people can do. One of my favourite examples is about one of my blind friends. In a job interview she was asked whether she needed help to go to the toilet. This is just one of the things that people think we can't do," says Thorkild Olesen, the chairman of the Danish Blind Society.

"Another prejudice is that many think having a blind colleague would mean more work for themselves. They think that a blind person can't completely replace someone who doesn't have problems with their sight. Often it turns out, after having hired a blind person, after a while there aren't any problems at all," Olesen told EurActiv.

12% of the 9,500 members of the Danish Society for the Blind currently have a job. But 70% of those between 18 and 65 receive early retirement benefits. These statistics make the blind the disabled group with the smallest presence in the labour market.

For social workers supporting the integration of the blind, this is blatant injustice, as they can contribute to society in many different capacities, for example as researchers, web editors, physical therapists, book writers, lawyers, doctors and social workers.

Olesen said he experiences prejudices on a daily basis. The most common prejudice is that blind people are on social benefits and therefore represent a burden to society. And if a visually impaired person does work, the assumption is that it is probably in a volunteer job, and that there are never any expectations it might result in anything useful.

"I think it's because people find it difficult to put themselves in the shoes of a blind person. They can't imagine how it is to be blind. They almost believe that life stops if you are blind. It's doesn't, but I think that's why people believe that we're all on benefits and there are no expectations surrounding making it on your own," Olesen said.

Common prejudices

Erwin Denninghaus from the Support Centre for the Blind and Visually Impaired in Germany said that he believed that prejudice against the blind or partially blind was commonplace across the EU.

María Jesús Varela Méndez from the Spanish National Organisation for the Blind studied Business at Santiago University and has a Master's Degree in Marketing. She said she had experienced many prejudices in job interviews.

"Some years ago when I was unemployed, I went to a job interview and one of the first questions was whether I had a driver's license. A driver's license!

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That means that a lot of people don't know what it means to be blind. It's a proof that it's really difficult to go to a job interview because people don't understand our capabilities and in which jobs we can bring good results," Méndez said.

Lars Kjær Hansen, who lost his sight when he was 15 years old, has a degree in International Market Economy and Marketing plus a degree in Coaching and Management. He has worked for Denmark's biggest insurance company, Tryg, for the past five years. He said he still experiences prejudice.

"Even after five years at Tryg, I still meet many people who can't understand that I have the competencies that I have and can work with the things that I work with.

They often think that I just pick up the phones. So you definitely meet prejudice at work if you are blind. And prejudice, lack of knowledge and insecurity play a role both when you apply for a job and when you have the job."

Méndez said she would like Spain to embrace positive discrimination and adopt legislation forcing companies with more than 50 employees to hire a set quota of blind or visually impaired people.

"The EU must interfere on this aspect," she stressed.

Quota system

Such a quota system is already in place in Germany but it has yielded limited results so far.

Every company or factory with more than 20 staff members has to employ at least 5% disabled people. If they fail to do so, employers have to pay an extra tax that will go to a special fund for the disabled.

Denninghaus stressed that in Germany companies do not have to pay for special technical equipment for the blind, unlike in other EU countries. Still, many employers refuse to hire disabled people and prefer to pay the tax, raising doubts about the efficacy of the quota system.

Since all companies work with targets these days, Denninghaus said would like to see job centres do the same, making them disclose statistics about how many blind people they have successfully helped getting on the job market.

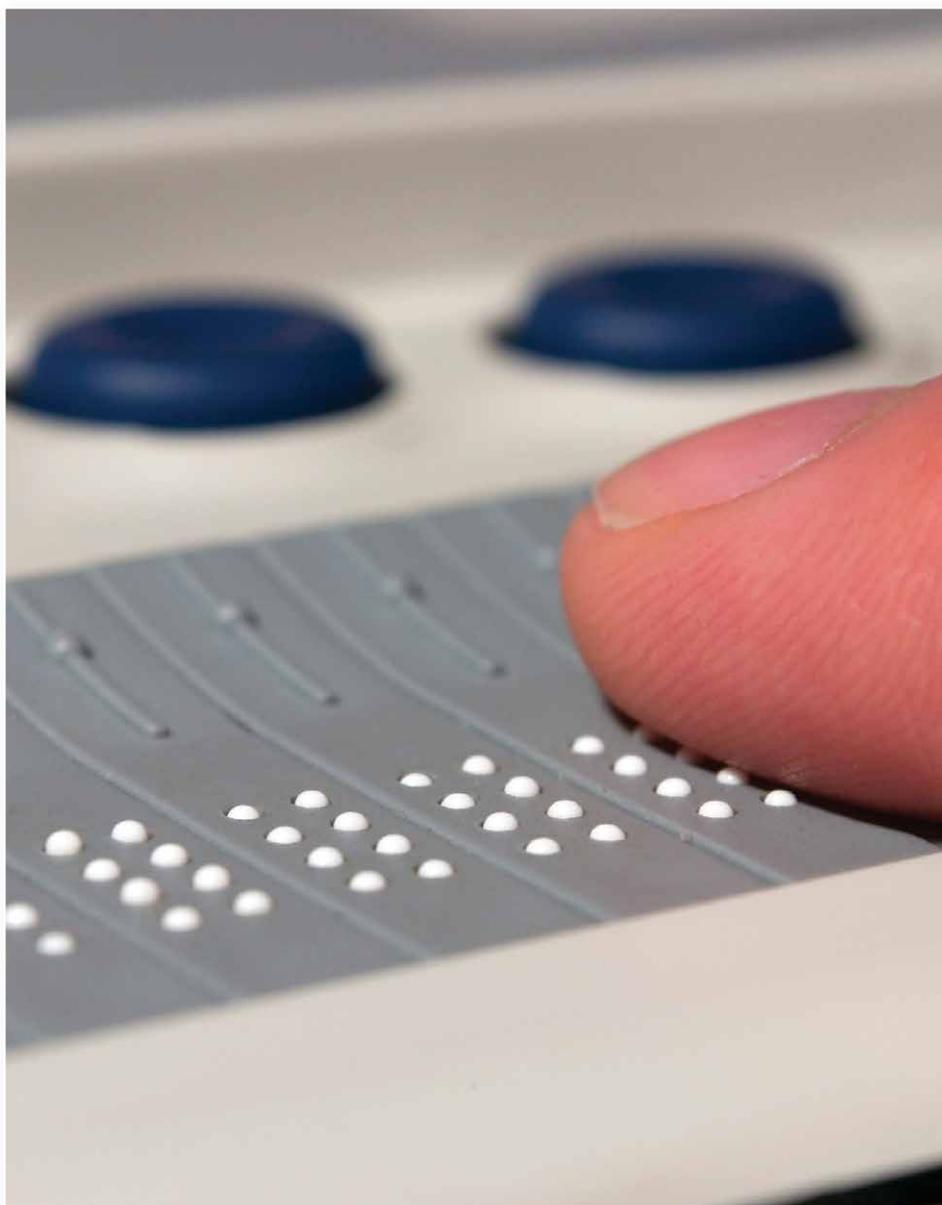
"In industrial countries, it's not possible to get data about the different disabled groups and their participation to the labour market. In Germany, we can just get the sum of all the unemployed within the disabled groups. We don't know what's being done to help them get a job. This is one of our aims; to get the EU, via Eurostat, to get every country to publish these numbers so that we won't have discrimination of disabled people," Denninghaus said.

Solution in sight

Back in Denmark, Olesen said that a good solution would be to gather in one place all the knowledge and expertise on blind and visually impaired people's inclusion in the labour market.

"A national resource centre would make sure that a targeted special counselling for blind children, youngsters and adults regarding education from school to employment is achieved. This would break the negative spiral where fewer and fewer blind people get an education," Olesen said.

The idea would be to pool together all the national expertise in the area, Olesen said. It would make it less bureaucratic for both the visually impaired, employers, colleagues and politicians to find the advice they need, for example in relation to hiring a person with sight impairment.



Professor: Early intervention can prevent many diseases causing blindness

Diseases that can cause blindness, such as diabetes-related complications, can be prevented with better healthcare. The EU should therefore ensure that statistics on blindness in Europe are more uniform so that best practices can be exchanged between member states, says Michael Larsen.



Michael Larsen is professor of Clinical Ophthalmology at Glostrup Hospital and the National Eye Clinic. He spoke to EurActiv's Henriette Jacobsen.

Talking about health and whether our health systems do a good job, I'd like to know which EU countries are front runners and which countries are lacking behind when it comes to treating eye diseases?

Scandinavia, the Benelux countries and the UK are the front runners. East and Southern Europe are lacking behind. However, it's difficult to measure because the approaches when it comes to making statistics are not uniform.

How can the health system prevent eye diseases or a person from becoming blind?

This depends on the causes for the blindness. Primarily diseases such as cataracts and glaucoma can hit the eye and cause blindness. Other things could be the lack of access to glasses and contact lenses, but that is not the biggest problem in Europe. Complications related to diabetes can also lead to blindness. This is more interesting because it's the most common source for blindness among the working force. It's something which for the most part can be prevented and treated.

I'm guessing this is also something that will increase in the future as more people become obese and get diabetes?

Yes, but fortunately the progress in terms of prevention and treatment of blindness moves quicker than the increase in the number of people with diabetes. So even though we are seeing more people with diabetes, there treatment is becoming better which means they are also receiving better treatment for their eye complications related to the diabetes.

Though we have fewer blind people, we still have a high number of blinds and it's an area of great inequality. Complications related to diabetes are more difficult to treat than just giving someone a vaccine. First, you have to make the diagnosis that someone has diabetes. Then you will introduce a lot of medicine which you would have to time and make available in the right doses. This is not necessarily cheap

and many people have too bad contact with their general practitioner.

It becomes what we call a 'poly-pharmacy' as you need a number of different drugs and specialists. It has been proven that this works, but it's not easy to implement this. So only in health systems with excess, this works.

How often do people go to their doctor if they feel they have problems with their eyes compared to problems with other body parts?

They are probably better at going to the ophthalmologist than to other specialists. You feel your eyes, but maybe not so much your kidneys.

So problems with blindness are not related to people waiting too long before they see a specialist?

No. Complications related to diabetes, you usually don't feel before it's too late. So this also requires a pedagogical effort by nurses and doctors to make sure that the patients go to preventative examinations in time. You see very clearly that in those places where they make it easy for people to go to examinations. Things work really well where everything is a stream-lined package solution when it comes to the different specialists.

Which groups in a society should worry about their eyes and becoming blind?

For older people there are a lot of diseases which threaten their sight. Some of these people can't overcome the illness if their treatment is postponed. If we for example talk about glaucoma, it will have consequences for the patient if their treatment comes too late. For cataracts, it doesn't matter that much when you are getting an operation. To operate on people who suffer from cataracts is something doctors usually like. But preventing glaucoma and complications

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related to diabetes... is not related to the same success experience. For cataracts, the patient will already feel the benefit the day after. For glaucoma and diabetes-related complications, you need annual check-ups afterwards and the patient isn't feeling any positive effects immediately. So the doctors don't have the same motivation factor for the patient. They prefer these operations with 'wow' effect.

How many people will be hit by eye diseases?

Usually, 50% of people in rich countries will have to have an operation before they pass away. In many countries, it can be difficult to sell the preventative part. In some places, the area isn't prioritised either for example within their health insurances. For example, if you go to the US... They have big problems with the preventative efforts. This has to do with the fact that people change their health insurance companies all the time, on average around every third or fourth year. This also depends on where they are employed. If you don't know if your

employee will stay with you the next 10 years, you don't help them prevent diseases which could occur within 10 to 15 years.

This is better in Europe because we have a better economy within the healthcare systems. But in Eastern Europe they are still relatively poor and are behind in many of these areas.

Easy access to an optometrist is very important. These are widely used in the UK, but not used at all in France. On the other hand, they have many ophthalmologists progressions in France compared to in the UK.

Looking in the crystal ball, there will be better treatments of the age-related diseases with earlier diagnostics. They will be treated earlier and more effectively. But the biggest revolution for the individual patient will come within the inherited illnesses among children and young people; there'll be gene therapy and electronic devices replacing cells.

So can we in the future expect that some eye diseases will disappear and that blindness will disappear if you aren't born blind, for example?

We could do it already now with the diabetes-related complications. If only we could make sure that diabetes patients would be offered treatment. Then we could avoid that people become blind from having diabetes. Maybe it would still weaken their sight, but in Iceland for example they have many doctors and almost no one becomes blind from diabetes-related complications.

Which initiatives would you like to see from the EU's side regarding prevention and treatment related to eye diseases and blindness?

The first thing the EU should do would be to make sure we have uniform approaches on the statistics in the different countries. We don't know how much blind and visually impaired people are being treated in Europe. For example, in Denmark we only know how many people are blind and how many people become blind per year.

If we for example knew that in Belgium there are only a few blind, then Belgium must do something right that the rest of us do wrong. But these indications we don't know now.

Books without borders give blind new opportunities

A UN Treaty signed by the EU in late June will make it easier for blind and partially sighted people to share audio and Braille books across countries, a move which experts believe could boost the educational level of the disability group.

Groups advocating blind people's rights refer to the signing of the treaty with the UN World Intellectual Property Organization

(Wipo) as "historical".

The treaty, signed in Marrakech on 27 June, enables blind organisations in different countries to share books in accessible formats (braille, large prints and audiobooks), without duplicating production. This was previously prevented by copyright laws.

Currently only 5% of all published books in developed countries and less than 1% in the developing world are accessible to blind and visually impaired people.

"We are extremely pleased that member states have reached an agreement on a very good treaty which will take another step forward in the inclusion of persons who are blind in society," Maryanne Diamond, head of the World Blind Union (WBU) delegation at the Marrakech Treaty talks said in a statement.

"For blind and partially sighted people, access to books is fundamental for our social

integration," Guisepe Terranova from the international relations office of the Italian Union of the Blind and Partially Sighted said in an interview.

"In Italy, our progress towards social integration started due to our rights to culture and education," Terranova added.

It's now "highly desirable", Terranova continued, that the Marrakech Treaty be properly implemented by governments. Without action and implementation, the treaty is only worth the paper its written on, the spokesperson from the Italian Union stated.

Ending book famine for the blind

Thorkild Olesen, chairman of the Danish Blind Society, said that the treaty would have a huge impact on visually

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impaired people's lives in his country.

"It means that it would be easier for us to get hold of the books they have in English, German or French-speaking countries. We are good at these kinds of languages so it would mean a lot. It would mean a lot for our education because there are an extreme amount of books in the world and now we don't have to make them ourselves, so it would be a lot of help for people who want a job and people taking an education," Olesen said.

The treaty is especially important because it would make it easier for young people to obtain non-fictional books in other languages, which are often necessary for university students to have read.

"There's a huge demand for these kinds of books," Olesen said. "Instead of having to re-publish an English book in Denmark and pay for that to be made, we'll be able to get it faster and easier by asking them in the UK where they have already loaded it, if we could get it. We would save some resources and it would make things faster."

María Jesús Varela Méndez, who represents the Spanish National Organisation for the Blind, said the treaty would be most useful for small and poorer countries in the EU, but less relevant for bigger countries such as Spain, the UK and France, which are already able to translate books more easily. Nevertheless, the treaty would have a significant impact on blind people's educational level, she said.

"I think that it will be an important step because I think that it will be possible to save some money while improving and increase opportunities for children and students in general to complete their studies," Méndez said.

Both Méndez, Olesen and Terranova said they knew blind students who had to delay their university studies because they had to have books "specially made".

EU hesitating

According to the British daily *The Guardian*, the EU and the US initially tried to block the signing of the treaty over

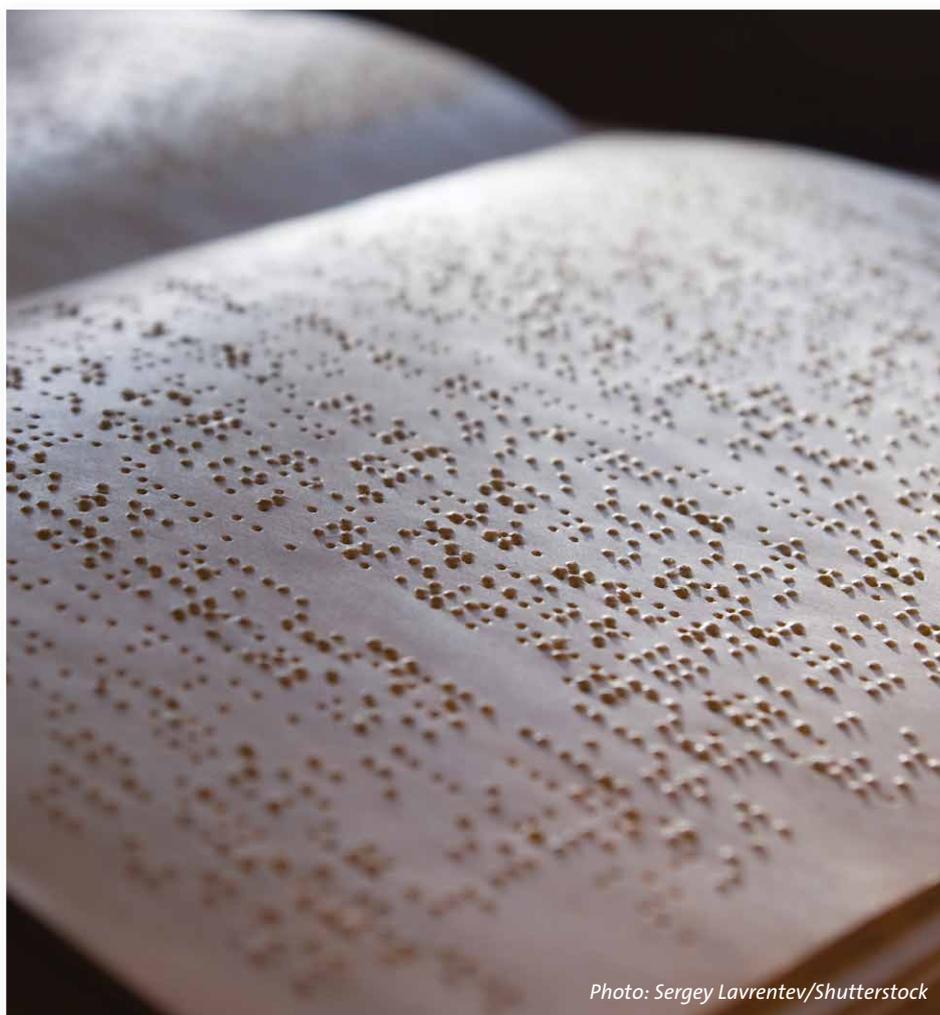


Photo: Sergey Lavrentev/Shutterstock

copyright fears.

Terranova who followed the negotiations closely said the European Commission and EU ministers were initially against the treaty and sided with the European Association of Editors who claimed their copyrights would be breached.

"The Commission also said that work could only be distributed in another country if that work is already commercially available in that country," Terranova said, adding that counter-lobbying by nearly 100 MEPs caused the Commission and EU countries to change their minds.

Olesen added that the European Blind Union, which pushed for the signing of the treaty, had good cooperation with the European Parliament.

The MEPs "did what they could" to get it through, Olesen said, adding that several petitions in Parliament backed the treaty.

"This was of great significance. It was not because the Commission or the Council were happy about this [that the treaty was

signed], but they were eventually pressured to support it," the Danish Society chairman said.

"It's a bit strange because one would think that they support free movement of all kinds of goods and products and these books are products. I don't understand why they were hesitating," he added.

Carmel Dunne, press officer at the Commission for the internal market and services, told EurActiv that was unfamiliar with the EU executive's role in the Marrakech Treaty, but referred to a statement by Commissioner Michel Barnier:

"Our collective effort has made it possible to adopt a new international treaty that means that finally, the visually impaired and print-disabled community will be able to have access to the same books as other people. For too long, this community has been denied the access to knowledge and culture they are entitled to in exactly the same way as everyone else," Barnier said.

South and east left behind as EU eyecare improves

Citizens of Central and Eastern Europe are three times as likely to suffer from blindness or severe visual impairment than the rest of Europe, where the risk has been falling gradually, new data reveals.

In the most successful countries, less than 3% of people over 50 suffer partial or complete sight loss.

However, advances in preventing and treating sight loss are sometimes impeded by inefficient organisation of care and poor access to medication, according to the 2013 Euro Vision Scorecard, published by the Swedish company Health Consumer Powerhouse (HCP).

The HCP compared vision care in 15 European countries: Austria, Belgium, Denmark, France, Germany, Hungary, Italy, Lithuania, the Netherlands, Poland, Slovakia, Spain, Sweden, Switzerland and the UK.

HCP President Johan Hjertqvist said that there would be no overall increase in blindness or visual impairment in Europe despite an ageing population.

But there is much room left for improvement as disparities between countries remain wide.

Michael Larsen, a professor of Clinical Ophthalmology at Glostrup Hospital and National Eye Clinic in Denmark, told EurActiv in an interview that the eye diseases that primarily hit Europeans are cataracts and glaucoma and these can cause blindness.

Complications related to diabetes can lead to blindness and is the most common source of blindness among the workforce. But these complications can for the most part be prevented and treated, he said.

Great gaps

Cataract surgery is available without delay in countries that excel at combating visual impairment, such as Denmark, France, the Netherlands, Sweden and Switzerland, the HCP says.

Patients also tend to have easy access to modern pharmaceutical treatment and waiting times to get an appointment with an eye specialist are reasonable. However, coverage of screening for diabetic eye complications still varies considerably, from 30% to 90%.

By contrast, the situation is much poorer in Southern and Eastern Europe. "The registration of impaired citizens is sporadic, there are no quality registries supporting development of efficient treatments and access to modern medicines is limited," the EVS report said.

Not a money problem

The EVS report adds that improving eye care is not primarily a question of money, but rather an issue of reporting, registration and follow-up.

A major step forward would be to agree a more consistent definition of blindness and sight impairment, the EVS stressed, noting wide variations from country to country.

Larsen said the EU should ensure a uniform approach to statistics in the different countries as no one currently can tell with precision how many blind or visually impaired people are being treated in Europe. Therefore, member states still can't exchange best practices, the professor said.

The EVS recommends building national registries for eye care in each EU country and having a uniform European definition of what blind and visually impaired means.

Furthermore, Larsen recommends the yearly screening of a minimum of 80% of diabetic patients in every country. Cataract surgery should also be made available for all Europeans on demand and more modern eye care medication should be made available to many more Europeans, the EVS said.



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For information on EurActiv Special Reports...

Contact us

Delia Nicolaescu

events@euractiv.com

tel. +32(0)2 788 36 72

Ross Melzer

publicaffairs@euractiv.com

tel. +32(0)2 226 58 17

Other relevant contacts:

Rick Zednik

ceo@euractiv.com

tel. +32(0)2 226 58 12

Frédéric Simon

executiveeditor@euractiv.com

tel. +32(0)2 788 36 78