



1.1.1. 4th European Parliament of Persons with Disabilities

Wednesday 6 December 2017
European Parliament hemicycle (Brussels)

STATEMENTS BY DELEGATES DURING PLENARY DEBATES

Plenary Debate 1: we want to vote! Towards accessible European elections 2019 and a full participation in political and public life for persons with disabilities

Speaker	Organisation
Pirkko Mahlamäki	Finnish Disability Forum
Thorkild Olesen	Disabled Peoples Organisations Denmark
Maria Pino Lopez	Plena inclusion movement (Spain, member of CERMI)
Bobeldijk Marcel	EFHOH (European Federation of Hard of Hearing People)
MEP Miriam Dalli, Malta	
Pascale RIBES	Association des Paralyses de France (French National disability Council member)
Danny Canal	EUDY (European Union of the Deaf Youth)
Giulio Nardone	Italian Disability Forum
MEP Brando Benifei	
Anna Hildingsson	The Swedish Disability Rights Federation/Swedish Association for Persons with Intellectual Disability
MEP Jana Zitnanska	
Dovilė Juodkaitė	President of Lithuanian disability forum
Mr. Julien POSTIAUX	Belgian Disability Forum asbl (BDF)
MEP Luigi Morgano	
MEP Lara Comi	



EUROPEAN
DISABILITY
FORUM



Mr. Rudolf Volejník	vice-president of SONS (Unified Organization of the Blind and Visually Impaired of the Czech Republic)
Vera Bonvalot	(BIF-Portugal)
Oswald Föllerer	Self-advocacy-centre Austria (member of Inclusion Europe)
Branislav Mamojka	Slovak Disability Council
Mr Libicki	Member of the Senate (Poland)
MEP Kozłowska-Rajewicz	Poland
Tupilusi Tudorel	CNDR - Romanian National Disability Council
Aneta Świercz	Towarzystwo Pomocy Głuchoniewidomym

Pirkko Mahlamäki, Finnish Disability Forum puheenvuoro Suomen Vammaisfoorumin puolesta 6.12.2017

Täysimääräisesti saavutettavat ja esteettömät Euroopan parlamentin vaalit 2019

Euroopan poliittisten johtajien, yhteistyössä vammaisliikkeen kanssa, on varmistettava, että vammaiset henkilöt voivat täysimääräisesti nauttia äänioikeudestaan ja oikeudesta asettua ehdokkaaksi Euroopan parlamentin vaalissa. Nämä ovat ensimmäiset Eurooppa vaalit sen jälkeen kuin Euroopan unioni liittyi vammaisyleissopimukseen, siis historiallinen tilaisuus mahdollistaa osallisuus ja osallistuminen vammaisille EU-kansalaisille yhdenvertaisesti muiden kanssa, kuten vammaisyleissopimuksen 29 artikla edellyttää.

Muutoksia tarvitaan erityisesti, jotta jäsenmaiden lainsäädäntöä saataisiin tarkemmin vammaisyleissopimuksen 12 artiklan sekä vammaisten henkilöiden oikeuksien komitean yleiskommentin no 1 kanssa yhdenmukaiseksi.

Äänestyspaikkojen esteettömyys laajassa merkityksessä eri tavoin vammaisille henkilöille on turvattava, samoin kuin se, että äänestämisen prosessi on esteetön ja äänestäjän helposti ymmärrettävä.



Esteettömyys koskee myös vaalikampanjaa, vaalitulaisuuksia ja materiaaleja; vaaliväittelyjä ja verkkosivustoja: kaiken vaaliin liittyvän tulee olla esteetöntä ja inklusiivista.

Tulee varmistaa, että kaikki vammaiset henkilöt, mukaan lukien laitoksissa asuvat, voivat käyttää äänioikeuttaan itsenäisesti.

Tänään itsenäisen Suomen 100-vuotissyntymäpäivänä ja muistaen että maani naiset saivat täyden äänioikeuden jo 111 vuotta sitten, haluamme korostaa nuorisovaalien merkitystä, myös nuorten tulee voida osallistua päätöksentekoon.

Maria Pino, Plena inclusion movement (Spain, member of CERMI)

Señores y señoras diputadas

Representantes de los movimientos sociales y Organizaciones de la discapacidad

Me llamo María Pino

Tengo 51 años y vengo desde Castilla La Mancha en España

Mis hermanas promovieron mi incapacitaron hace doce años.

Recuerdo que me llevaron a un juez

Tuve que hablar con un médico forense

Me metieron en una sala

Y me dejaron sola.

Nadie me explicó para qué era aquello.

El juez me dijo todo lo que me quitaban.

Yo solo movía la cabeza diciendo No, no.

Salí corriendo y llorando.

Me sentí impotente.

En el año 2010 cogió mi tutela una fundación tutelar de Plena inclusión

Hice un curso sobre los derechos de la Convención

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Y me di cuenta de lo que estaba pasando.

El año pasado escribí una carta a mi tutor
pidiendo que se revisase mi sentencia.

Ya he pasado por el médico forense
y tengo pendiente hablar con el juez.

Quiero una curatela,
porque quiero mi derecho al voto
y solo necesito ayuda

para los temas económicos

Cuando yo vivía con mis padres, podía votar

Y votaba a quien yo quería

¿por qué no puedo seguir haciéndolo?

Señores y señoras diputadas

Aprovecho esta oportunidad para decirles

Que estoy en un grupo de trabajo de

Plena inclusión y la Asociación Española de Fundaciones tutelares

buscando soluciones para que podamos tomar decisiones

con los apoyos adecuados.

Y quiero pedirles que nos escuchen

Que somos ciudadanos igual que ustedes

no somos bichos raros.

Ayuden a que las personas con discapacidad intelectual

o del desarrollo podamos votar!!

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En España todavía hay 100.000 personas

que no pueden votar por estar incapacitadas por un juez.

Muchas de ellas son personas con discapacidad intelectual.

Plena inclusión, entidad que representa a las personas con discapacidad

intelectual o del desarrollo en España

y el resto de entidades del CERMI



estamos luchando para que esta situación cambie.

El pasado mes de noviembre
el Congreso de los Diputados de España
ha decidido por unanimidad cambiar la Ley electoral
para asegurar el derecho al voto
de todas las personas con discapacidad.

Comienza así a cumplir por fin en España

El artículo 29 de la Convención de Naciones Unidas
sobre los derechos de las personas con discapacidad
que habla de nuestro derecho a participar en la vida política y pública.
Ahora esperamos que ese cambio en la Ley electoral se haga pronto
para que no haya ninguna nueva elección
en la que no podamos votar.

Pero aunque logremos ejercer este derecho
los gobiernos deben asegurar no sólo que votemos,
sino que lo hagamos en igualdad de condiciones

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que el resto de los ciudadanos.

Y es que ni el proceso de votación

ni la información electoral

son accesibles para las personas con dificultades de comprensión

En concreto falta asegurar la comprensión de:

- Los espacios de los colegios electorales.
- Los programas políticos.
- La información sobre cómo votar y las diferentes modalidades.
- La información más básica sobre el sistema parlamentario.

Todo ello afecta a nuestro acceso,

Nada más señorías, muchas gracias.



Danny Canal, EUDY Vice President

The society often forgets the Deaf people's existence because they are not visible enough compared to the blind people, the people using a wheelchair, etc. Moreover, Deaf people have own needs and hopes compared to the other disabled people: access to information and communication. Therefore, the accessibility to the Deaf people is often forgotten.

Access to information and strengthen the youth political participation.

The deaf people must be provided the possibilities to be involved in the elections in their home city. There are two important processes before the election: Firstly, we support young people to participate in the elections at age of 16. It's a way to strengthen their political participation such as giving a good possibility to debate about political issues provided by a teacher or a role model who uses a sign language in a direct way. Secondly, it's important to give them full information about the process of an election and any general promotion with subtitles and a national sign language.

As we all know the fact: young people are often excluded from the society, which means automatically an exclusion from the elections. The deaf and disabled young people are then excluded from excluded. How can we decide about their human rights without them? Now it's the time to give them this opportunity, with the aim to deliver the higher voting result of which the European Union wants to reach.

Marcel Bobeldijk, President of EFHOH

I am Marcel Bobeldijk - President of the European Federation of Hard of Hearing People.

The President of the European Parliament spoke about European Freedom in charters. For that, I thank him! I urge him as the host of this Chamber, to apply Accessibility in charters and to ensure that all events such as these are accessible, from the very first second, to the hearing impaired and all those present. Not like today, which was missing the speech to text support in the very beginning and later had speech to text support that was of very poor quality.



EUROPEAN DISABILITY FORUM



I would like to draw your attention to the 52 million citizens of the European Union with a hearing loss. That is 52 million European citizens who want to use their democratic right to vote.

It is absolutely essential that the elections are accessible to people with hearing loss people at municipal, provincial, national and of course European level.

This starts with the subtitling of all promotional and information films in which citizens are called to vote.

All meetings of all political parties, irrespective of its political color, and all election meetings must be accessible through the presence of a hearing loop system, speech to text support, and sign language.

It goes without saying that all TV programs about the elections are provided with subtitles regardless of whether the program is broadcasted by the public service broadcaster or by one of the commercial broadcasters.

I also call on the candidates of all political parties to take part in party and election meetings only if they are accessible. If they are not accessible, we believe that candidates must take political responsibility for the relevant elections. They must demand that the organization of the relevant party and / or election meeting be made accessible.

This also applies to the appearance of candidates on TV programs, of course, only in the TV programs that are provided with subtitles.

On the election day itself, the polling station must also be accessible to people with a hearing loss by means of a hearing loop at the registration table. In addition, it is desirable that the members of the electoral committee and staff know how to communicate with people with a hearing loss.

In short, as EFHOH, we advocate a fully accessible election. Let us hope that the European Commission and the European Parliament set a good example in the forthcoming elections. So that we as European citizens can be proud of a Europe that is accessible to everyone during elections.

Thank you for your attention.

Vera Bonvalot, Brain Injured Disability European Federation

My name is Vera Bonvalot. I am here on behalf of European Disability Forum, also on behalf of Brain Injured Disability European Federation. Brain injured are people that suffered a brain injury during their adult lifetime and were transformed in a new person having some disability. Mainly an invisible disability like unable to concentrate , no short term memory, inadequate behaviours...

These are people that found out there are two different worlds.



One, was the world they used to live in. A world where they felt freedom in being participants in the society.

The other world is the one they have to live in after the brain injury, It is the world of most of people with disability live in.

A world where education, jobs, free movement, exist but they cannot reach them or understand it, or communicate on it. Are not accessible

In fact, people with severe neurologic damage in countries like my own one: Portugal, the only possibility they have is to stay at home, with no active role in society, no longer free to go wherever they want, , no right to vote any longer etc.

In 2017 I see a European Union that speaks of value, human rights, innovation, but does not make decisions which include all citizens like the ones with disability,(physical and hidden/invisible disability)

This is not a problem of mentality nor money. It`s a lack of political willing.

Some of you, will get old and most probably will have some kind of disability,a brain damage, hard of hearing , what ever.

Do not wait until that day - Deal with all kinds of disability now. Take disability as a priority to be respected in ALL your decisions and work.

Make us live in one only world

MAKE Europe a place for all citizens.

Thank you

Dovilė Juodkaitė, President of the Lithuanian disability forum

Ačiū už galimybę pasisakyti šio svarbaus renginio metu Lietuvos neįgaliųjų forumo vardu Lietuvoje asmenys su negalia patiria teisines, organizacines, aplinkos ir požiūrio kliūtis siekdami realizuoti savo teisę dalyvauti politiniame gyvenime.

2016 m. spalio mėn. vykusių Seimo rinkimų metu net 60 procentų balsavimo apylinkių nebuvo pritaikytos žmonėms su judėjimo negalia.



Taip pat rinkimų metu

- informacija apie rinkimų procesą bei rinkimų medžiaga nebuvo pritaikyta skirtingų negalių asmenims
- informacija lengvai suprantama kalba buvo parengta itin nekokybiška. Ją rengiant nebuvo konsultuotasi su neįgaliųjų organizacijomis.
- aklieji negalėjo savarankiškai dalyvauti rinkimuose
- Lietuvoje egzistuojanti galimybė balsuoti namuose neatitinka įtraukaus, visuotinio dalyvavimo ir asmenų su negalia lygių galimybių principo.

Asmenys su proto ir psichosocialine negalia yra diskriminuojami apribojant jų teisę dalyvauti politiniame gyvenime pripažįstant juos teisiškai neveiksniais.

Lietuvos Konstitucija ir rinkimų įstatymai draudžia neveiksniais asmenims dalyvauti rinkimuose. Šias Konstitucines ir įstatymines nuotatas kritikavo JT Neįgaliųjų teisių komitetas Lietuvai pateiktose bendrosiose išvadose bei rekomendacijose.

Neveiksniais pripažinti asmenys yra išbraukiami iš rinkėjų sąrašų.

Šiuo metu Lietuvos teismai gali pripažinti asmenis su psichikos sutrikimais teisiškai neveiksniais tam tikrose gyvenimo srityse. Tačiau neretai neveiksnumas jiems yra nustatomas visose gyvenimo srityse, arba konkrečiai nurodoma, kad asmuo pripažįstamas neveiksnium balsavimo teisių, rinkiminių teisių, politinių teisių srityse. Toks neveiksnumo pripažinimas yra paremtas neįgalių asmenų gebėjimų vertinimu, vadovaujantis dažniausiai medicininiais kriterijais, gydytojų išvadomis.

Tai prieštarauja JT neįgaliųjų teisių Konvencijai.

Tai panaikina šių žmonių kaip teisių subjektų statusą bei tiesiogiai pažeidžia jų kaip piliečių teises dalyvauti politiniame šalies gyvenime.



Konvencijos 12 ir 29 str. įtvirtina visų žmonių su negalia, nepaisant negalios pobūdžio ar didelių pagalbos poreikių, teisę į lygybę prieš įstatymą ir teisę dalyvauti politiniame gyvenime. Būtent šios teisės yra ir turi būti jų kaip pilnateisių savo šalies piliečių autonomijos, savarankiško sprendimų priėmimo, įsitraukimo ir dalyvavimo visuomenėje pagrindas.

Todėl ES ir visos šalys privalo užtikrinti visiems žmonėms su negalia universalias ir fundamentalias teises į teisinį veiksnumą bei politinį dalyvavimą. Būtinose tikslinėse švietimo ir mokymų priemonėse ir programose, kad politikai, specialistai ir visa visuomenė remtųsi pagarba, žmogiškuoju orumu bei žmogaus teisėmis grįstu požiūriu į asmenis su negalia ir jų neatimamas ir besąlygines teises būti savo šalies piliečiais, prisidėti prie savo valstybių demokratinių procesų, dalyvauti visuomenėje ir praturtinti ją savo įvairove.

Ačiū už dėmesį

EN

Thank you for the possibility to make an intervention in this extraordinary event – European parliament of persons with disabilities on behalf of the Lithuanian disability forum

In Lithuania people with disabilities face both legal, organisational, infrastructure, attitudinal barriers in realising their right to political participation.

During the Parliament elections in 2016 even 60 percent of polling stations were not accessible to persons with mobility problems (wheelchair users, elderly). Yet not all "accessible" stations are accessible in reality.

There was also:

- No information about election procedures and elections materials in the different formats for different persons with disabilities
- Preparation of Easy read material of very low quality, not compliant with EtR requirements, without consulting with DPOs;
- No possibility for blind persons to participate in elections independently
- Possibility to vote at home is considered not inclusive, not compliant with equal opportunities for persons with disabilities

Persons with intellectual and psychosocial disabilities are discriminated against since their right to vote is restricted due to their legal incapacitation procedures.



Both Lithuanian Constitution and electoral laws prohibit persons declared as legal incapable to participate in the elections. Those provisions were critically assessed by the UN CRPD committee in Concluding observations for Lithuania.

Persons declared as incapable are eliminated from the lists of voters.

Currently courts can declare persons due to their mental disorders as legal incapable in particular areas of life. Nevertheless, quite often courts declare person as incapable in all areas of life, or particularly indicate that he is incapable to vote, participate in elections or realize political rights. Such declaration of incapacity is being done after assessment of the person's capacity based mainly on the medical criteria upon the doctors' conclusions.

Such assessment is contradictory to the CRPD provisions.

Legal incapacitation eliminates legal status of the person and directly infringe his right to participate in political life.

Articles 12 and 29 of CRPD establish that all persons with disabilities, despite the form of disability or support needs, have the right to equality before the law and the right to political participation. These rights are central to realization of full citizenship, autonomy, independent decision making, are the basis for involvement and participation in the society.

Thus EU and all states must guarantee and secure universal and inalienable rights to legal capacity and political participation to all persons with disabilities. Targeted programs and measures are needed for awareness raising within society and capacity building of politics, specialists seeking for attitudinal changes towards persons with disabilities. Those should be based on respect, dignity, unconditional realization of rights of persons with disabilities to be full citizens, to contribute to democratic processes in their countries, to participate in the society and to enrich its diversity.

Thank you for your attention.

Anna Hildingsson
The Swedish Disability Rights Federation/Swedish Association for Persons with Intellectual Disability

Hello!

My name is Anna Hildingsson and I come from Sweden.

My organisation, FUB, is a national organisation for children, adolescents and adults with intellectual disability.

I am chairman of the FUB section for members with intellectual disability.

It's called "Inre Ringen".

In 1989, people with intellectual disability were granted the right to vote in Sweden.

At last we became real citizens! Because it must be so, right?

In the same country, there cannot be two kinds of citizens -

those who have the right to vote

and those who do NOT have the right to vote, because of a disability.



EUROPEAN DISABILITY FORUM



BUT, it is not enough that voting rights are simply written in the text of the law.

That is only the first step!

In the years after 1989, almost no people with intellectual disability voted.

But then the requirement came for the political parties sitting in Sweden's parliament AND ALL authorities MUST have information in easy-to-read.

Only then did people with intellectual disability begin to vote in increasing numbers.

And this is really important because our daily lives are VERY much affected by political decisions!

Prior to the 2014 election, FUB participated in an educational course where people with intellectual disability were given the opportunity to learn about how society works.

80 percent of those who had taken the course voted on election day!

In other words - KNOWLEDGE IS POWER!

I really hope that NO EU citizen will be denied their right to vote.

This is a human right!

But keep in mind that the right to vote AND access to easy-to-read information go together.

Because as we say in Sweden: What's necessary for some is good for everyone!

Thank you!

Branislav Mamojka

Slovak Disability Council

Vážený pán predsedajúci, vážené dámy a páni,

Efektívny dialóg medzi reprezentatívnymi organizáciami osôb so zdravotným postihnutím a kompetentnými inštitúciami je dôležitý pre úspešnú implementáciu Dohovoru o právach osôb so zdravotným postihnutím, Agendy 2030 pre udržateľný rozvoj, pre tvorbu Stratégie zdravotného postihnutia 2020 – 2030 a pre tvorbu európskej a národnej legislatívy vrátane tej, ktorá má zaručiť uplatňovanie práva účasti osôb so zdravotným postihnutím na voľbách a ich prístupnosť.

Tento dialóg mal významný vplyv aj na výsledné znenie smernice EÚ 2016/2102 o prístupnosti webových sídiel a mobilných aplikácií verejného sektora. Je to jedinečný nástroj na podporu inklúzie ľudí so zdravotným postihnutím v oblasti informovanosti a kvalifikovaného rozhodovania, čo je špeciálne dôležité aj pre účasť na voľbách. Práve však v tomto smere má smernica zásadné nedostatky.

Smernica sa nevzťahuje na webové sídla kandidujúcich politických strán a nezávislých kandidátov a to ani v ich častiach priamo súvisiacich s voľbami ako sú volebné programy a charakteristiky kandidátov.

Nevzťahuje sa na obsah webových sídiel a mobilných aplikácií „tretích strán, ktorý nefinancoval ani nevytvoril subjekt verejného sektora a ani sa nenachádza pod jeho kontrolou“. Nevzťahuje sa tak ani na univerzity a súkromné školy, ktoré majú zásadný vplyv na rozvoj schopností občanov pre zodpovednú účasť na voľbách. Dnes však prakticky už nie

je možné študovať na týchto školách bez každodennej intenzívnej komunikácie prostredníctvom ich webových sídiel. Študenti sú tak diskriminovaní na základe svojho zdravotného postihnutia.

Prekvapujúce je, že smernica len „nabáda“ inštitúcie únie, aby smernicu rešpektovali, ako sa uvádza v odseku (35) jej preambuly: „Hoci sa táto smernica nevzťahuje na webové sídla a mobilné aplikácie inštitúcií Únie, tieto inštitúcie sú nabádané, aby plnili požiadavky na prístupnosť stanovené v tejto smernici“. Informácie na nich zverejňované majú však zásadný vplyv na formovanie politického názoru občanov a „nabádanie“ nie je dostatočným spôsobom presadzovania ich prístupnosti.

Som presvedčený, že dôslednejšie využívanie dialógu medzi reprezentatívnymi organizáciami osôb so zdravotným postihnutím a kompetentnými inštitúciami mohlo zmierniť a možno aj odstrániť uvedené nedostatky. Preto vyzývam poslancov Európskeho parlamentu a kompetentné inštitúcie, aby vytvárali podmienky pre takýto dialóg a systematicky ho využívali ako prevenciu vzniku uvedených a podobných medzier a nedostatkov legislatívy.

Branislav Mamojka

Národná rada občanov so zdravotným postihnutím v SR

4. Európsky parlament osôb so zdravotným postihnutím

EN

Dear Mr. President, ladies and gentlemen,

An effective dialogue between representative organisations of people with disabilities and competent institutions is very important for the successful implementation of the UN CRPD, 2030 Agenda for Sustainable Development and for European and national legislation drafting including laws ensuring an active part of people with disabilities in elections and accessible elections as well.

This dialogue has had a significant impact on the final wording of the EU Directive 2016/2102 on the accessibility of the websites and mobile applications of public sector bodies. The directive is a unique tool for the support of inclusion of people with disabilities in the area of awareness and qualified decision making, which is especially important for their active part in elections. Nevertheless, the directive has some shortcomings especially in this regard.

It does not apply to websites of the candidate political parties or independent candidates, even in their parts directly connected to elections, such as parties' manifestos or characteristics of the candidates.

It does not apply to the content of websites and mobile applications, such as „third-party content that is neither funded nor developed by, nor under the control of, the public sector body concerned“. This means it does not apply neither to universities, nor private schools having a significant impact on the development of citizens' ability to responsibly take



part in elections. At present it is almost not possible to study at these schools without an intensive communication via their websites on daily basis. Thus, students are discriminated on the basis of their disability.

It is surprising that the directive only encourages European union institutions to comply with it, as stated in the paragraph (35) of its preamble: „Although this Directive does not apply to the websites and mobile applications of Union institutions, those institutions are encouraged to comply with the accessibility requirements set out in this Directive.“ However, the information published on these websites have significant influence on forming of the political position of citizens and sheer „encouragement“ is not an adequate tool of their accessibility enforcement.

I believe that more consistent use of the dialogue between representative organisations of people with disabilities and competent institutions could mitigate or even remove the shortcomings mentioned and other shortcoming as well. That is why I call the MEPs and competent institutions to create conditions for the dialogue and use it systematically as a means of prevention in case of emergence of the mentioned and similar gaps and shortcomings.

Branislav Mamojka
Slovak Disability Council
4th European Parliament of People with Disabilities

Aneta Swiercz

Association for the Welfare of the Deafblind

I am a deafblind person (completely blind, hard-of-hearing). In my opinion it is very important that people with different disabilities can vote. It is very important to provide access to information for the blind, e.g. through the availability of Braille or for the deaf - through the availability of materials in the appropriate written formandsign language. But it is also very important to make elections available for the deafblind persons, i.e. people having simultaneous problems with vision and hearing. A deafblind person, in order to be able to participate in elections, in addition to adjustments for the blind and for the deaf, needs also a guide-interpreter, that is a properly trained person who helps her/him reach a certain place and communicate with the environment, e.g. touch a special alphabet to the palm. Therefore, for the elections to be accessible for the deafblind persons, the state must also provide them with access to guide-interpreter services.

Plenary Debate 2: Human Rights for All: towards a European Disability Strategy 2020-2030 and inclusive EU budget

John Dolan	Disability Federation of Ireland
Sławomir Besowski	Centrum praw osób niepełnosprawnych
Vasileios Koutsianos	NATIONAL CONFEDERATION OF DISABLED PEOPLE IN GREECE (NCDP)
Dr. Markku Jokinen	European Union of the Deaf President
MEP Rosa Estaras	
Zara Todd	ENIL / UK
MEP Indrek Tarand	
Stephanie Wooley	ENUSP
Pietro Cirrincione	Autism-Europe
Nerea Cuervo	CERMI (Spain)
Erzsébet Földesi	Hungarian National Council of Associations of Persons with Disabilities (FESZT)
Matthieu Chatelin	French National Council – EDF Youth Committee
Massimo Ellul	Secretary General, MFOPD (Malta)
MEP Krzysztof Hetman	
Joachim Seuling	Deutscher Schwerhörigenbund (German association hearing impaired)
Valmar Ammer	Estonian Spina Bifida and Hydrocephalus Association
Peter Vanhoutte	EDbU
Giampiero Griffo	Italian Disability Forum
Gerard Ellis	Disability Federation of Ireland



Remarks by Senator John Dolan, Leader of the Disability Federation of Ireland

delegation at the European Parliament for People with Disability, Brussels, 6th Dec 2017

I am honoured to lead our strong Irish delegation of people with disabilities.

Almost 300,000 people with disabilities were murdered by the Nazi regime because they saw such people as, and I quote,

“Life not worthy of living”

It is a chilling fact that the T4 programme of extermination was easily put in place.

In December 1948 the newly established UN lunched the Universal Declaration of Human Rights. It took the position that people have these rights simply because they are human beings.

Six decades later the UN brought us the Convention on the Rights of Persons with Disabilities. (UN CRPD)

The CRPD is an acknowledgement that the UN and the States who signed it, including Ireland, had not sufficiently treated people with disabilities, over those six decades, as

- holders of rights
- as people with inherent dignity
- as being people who can flourish and participate.

The UN CRPD is part of the legal framework of the EU. The European Disability Strategy is a crucial tool to advance inclusion.

Making Declarations is not the same as delivery. Weighing a pig does not increase it's weight.

The EU is the most precious regional democratic entity in this troubled world.

The EU and it's member states must lead - if you do not lead you are deliberately leaving us behind to wither in the margins.



We know the EU can act with determination, strength and resolve. Let's see these applied to the 80 million citizens with disabilities and their families.

John Dolan, 6th December 2017

**Sławomir Besowski, President, Disabled Peoples' Human Rights Center Foundation
Poland**

Witam państwa serdecznie i bardzo chciałbym podziękować wszystkim tym osobom, dzięki którym tu się znalazłem - a swoją wypowiedź dedykować wszystkim tym, którzy zostali w domach pomocy społecznej, w czterech ścianach, pod opieką opiekunów, rodziców i innych osób, które nie do końca spełniają oczekiwania osób niepełnosprawnych. Chciałbym podziękować również wszystkim państwu w prezydium - łącznie z panią przewodniczącą i pozostałymi osobami pilotującymi dzisiejszą sesję. A w szczególności pani Marian Harkin, która w pewnym sensie dokonała wprowadzenia do mojego wystąpienia, oraz panu Mauro D'Attis. Dlaczego? Otóż pani Marian Harkin wspomniała o tym, że zatrudniła osobę niepełnosprawną i dopiero wtedy zorientowała się, co to znaczy być osobą niepełnosprawną i co jest tak naprawdę istotne żeby taka osoba w ogóle mogła myśleć o tym, że znajdzie się w zatrudnieniu, w procesie pracy. Okazało się, że Bruksela jest miastem niedostępnym - jest gorzej dostosowana - To jest mój komentarz, niż Warszawa. Zapraszam państwa następnym razem do Warszawy. Tam będzie znacznie lepiej niż tutaj - to po pierwsze, a druga rzecz to jest taka, że rzeczywiście udało nam się, żeby być tak bardziej przy konkretach, coś osiągnąć - to znaczy mamy Europejski Act o Dostępności. No tak, ale jeżeli popatrzymy na artykuł 19 konwencji CRPD, a potem na wydany 28 sierpnia tegoż roku komentarz generalny do artykułu 19, opracowany przez CRPD - to widzimy że osiągnięciem konwencji jednak jest coś więcej -- to jest Niezależne Życie, artykuł 19 Niezależne Życie. W tymże komentarzu znaczącą część zajmuje kwestia Asystencji Osobistej. Była już wcześniej o tym mowa. Bez asystencji



osobistej ani moi koledzy z Domów Pomocy Społecznej, ani ci którzy są pod kontrolą rodzin, ani nawet takie osoby, które są gotowe się zatrudnić - nigdy się nie zatrudnią. Musicie państwo przyjąć, że Niezależne Życie to jest podstawowe prawo człowieka i musi być realizowane. Na to muszą być budżety. To musi być kontrolowane. Strategia wymaga ewaluacji - częstej ewaluacji. Muszą być określone wskaźniki, które nie tylko będą określały poziom życia i jakby zabezpieczenia socjalnego osób niepełnosprawnych - nie będą się odnosiły do pomocy społecznej - ale do wsparcia, które gwarantuje realizację podstawowych praw osobom niepełnosprawnym - a prawo do Niezależnego Życia takim jest. Na koniec chciałbym jeszcze (oklaski) Przepraszam, jeszcze chwilę wytrzymajcie państwo do oklasków - Chciałbym tylko zacytować takie zdanie z wykładu pani dr Moniki Zimy Parjaszewskiej, która jest przewodniczącą Polskiego Stowarzyszenia Osób z Niepełnosprawnością Intelektualną, która na koniec swojego wykładu zadała pytanie: "Czy jesteście gotowi na konwencję?".

Dziękuję

Markku Jokinen, President of EUD

From the Deaf and sign language perspective, the future EU Disability Strategy (EDS) should take concluding observations and recommendations of the CRPD Committee into account. As CRPD Committee recommended, EDS should ensure:

1. Freedom of expression and opinion, and access to information

- The EU should monitor the compliance on a regular basis and EU should report to us citizens on how Member States comply with these CRPD committee obligations in Web accessibility directive

- Elements not included (Parliament dropped off) in the European Accessibility Act must be objectives of the 2030 strategy.

- AVMS directive: the current draft AVMS Directive obliges Member States to ensure that their broadcasters increase the accessibility of media content, but without creating concrete EU level obligations. Therefore, countries can move at their own speed and are able to only do very little and potentially continue excluding deaf people from accessing audio-visual media, without breaching their obligations under the AVMS Directive.

- The EU must take the necessary measures to monitor the implementation of this future legislation in order to be in line with the concluding observations and include the topic as a



priority in the Disability Strategy and aim at addressing current lacks in future legislative revisions.

2. Participation in political and public life

- It is crucial to take the deaf perspective into account before and during the election period and make it fully accessible for the deaf voters through sign language or captions.
- The European Parliament itself and its Committee meetings must become fully accessible for deaf persons for them to be able to make an informed choice during the elections.
- Activities of political parties, media, campaign materials, electoral programmes must be interpreted in national sign languages and be in sign languages to be accessible for deaf persons.

To sum up:

- Accessibility needs to be viewed as a holistic issue, including the review of existing and future EU legislation with regards to its compliance with the strategy rather than an individualised exercise
- European Disability Strategy itself needs to be accessible (sign language and braille versions)

Zara Todd (UK), Director of ENIL

How many people question their rights as European citizens?

Despite the existence of the UNCRPD I imagine within the last year every disabled person in this room has had their rights questioned.

We need to ensure that all disabled people have the support they need to access all that their countries and Europe has to offer. Part of this is ensuring access measures such as personal assistance and sign language interpretation is budgeted in every part of European budget not just those directly related to disability.

We also need to ensure that European structural funds are used to support the inclusion of all disabled people to be full and active citizens in their communities where we can have choice and control over our lives. European structural funding must be used to support universal design to mainstream infrastructure to make Europe more accessible for all. We want inclusion in our communities is automatic and not a fight.



Stephanie Wooley, ENUSP

ENUSP – the European Network of Users, Ex-Users and Survivors of Psychiatry – representing persons with psychosocial disabilities – calls on the EU to implement the recommendations given to the Union by the UN CRPD Committee:

- To ratify the Optional Protocol to the Convention,
- To review and harmonize EU legislation with the UN CRPD,
- To create a strategy of implementation of the Convention across all EU institutions, with a relevant budget, time frame and with the real involvement of organizations representing persons with disabilities, including psychosocial disabilities,
- To establish a monitoring body to track the implementation of the UN Convention, involving organizations representing persons with disabilities, including psychosocial disabilities,
- To create a framework for meaningful consultation among different bodies in the European Union and persons with disabilities, which need appropriate financial support from you for this purpose. In order to be meaningful, this framework must involve face-to-face meetings and focus groups with representatives of DPOs, rather than dissemination of questionnaires or calls for submissions.

The historic Helsinki conference in January 2005, the EU Pact, Joint Action, the Framework and now the Compass data base of good practices for Mental Health and Well-being are good initiatives but have not done enough to ensure the respect of the rights of persons with psychosocial disabilities in our Member States. Discriminatory mental health legislation still allows for forced hospitalization and treatment measures, including in the community and for years on end, based on an actual or perceived psychosocial disability.

In addition, restrictions on legal capacity still apply widely throughout the EU, violating our right to equality.

These very serious human rights violations as pointed out by the CRPD Committee and UN Special Rapporteurs must be considered a priority by the EU and adequately addressed in strategy and urgent future action. We are counting on you.

Pietro Cirrincione Autism-Europe aisbl vice-president

Buon pomeriggio,
prima richiesta:

Il riconoscimento della condizione di disabilità è il punto di partenza per il rispetto dei nostri diritti, ma il processo di riconoscimento è inutilmente stressante e doloroso, e diverso nei paesi europei: in alcuni dalla diagnosi si passa facilmente alla certificazione di disabilità, ai benefici economici e servizi, in altri paesi, soprattutto per alcune disabilità come lo spettro dell'autismo, questo passaggio è difficile, faticoso, stressante e dipendente dalla commissione che ti deve valutare. Per di più spesso deve essere ripetuto nel corso della nostra vita.

Chiedo che i nostri diritti siano riconosciuti facilmente e indipendentemente da dove siamo nati.



Seconda richiesta:

La ricerca sulla sperimentazione di farmaci per lo spettro dell'autismo si sta espandendo, con investimenti di denaro e risorse, però lo studio dei problemi etici, legati sia alla sperimentazione in sé sia all'accettabilità di un intervento farmacologico a lungo termine, non sono ancora sviluppati, e non c'è il coinvolgimento diretto delle persone nello spettro autistico e dei familiari nella valutazione etica. Ciò potrebbe causare abusi medici, non solo per gli effetti collaterali dei farmaci, ma anche per l'ottenimento del consenso, che dovrebbe essere realmente informato e consapevole.

Chiedo che in ogni paese le persone nello spettro autistico siano consultate costantemente su questi aspetti.

Grazie

EN

Good afternoon,
my first claim:

The recognition of the condition of disability is the starting point for the respect of our rights, but the recognition process is unnecessarily stressful and painful, and different in European countries: in some countries it's easy to go from diagnosis to the certification of disability, to economic benefits and services, in other countries, especially for some disabilities such as the autism spectrum, this transition is difficult, tiring, stressful and dependent on the commission that should evaluate us. Moreover, it must often be repeated in the course of our life.

I ask that our rights are recognized easily and regardless of where we are born.

My second claim:

Research on experimentation of medicines for the autism spectrum is going to expand, by investments of money and resources, but the study of ethical issues, linked both to experimentation itself and to the acceptability of long-term pharmacological intervention, are not yet developed, there isn't the direct involvement of people on the autism spectrum and their families in the ethical evaluation. This could cause medical abuse, not only for the side effects of drugs, but also for obtaining consent, which should be really informed and aware.

I ask that in every country people on the autism spectrum are constantly consulted on these topics.

Thank you

Intervention of Dr. Massimo J Ellul, Secretary General, MFOPD (Malta)

Thank you Madam Chairman,

Those of you who know me also know that I am quite skeptical of the tons of presentation papers, working documents and lovely words and promises coming out from institutions such as these, both on a national and European level.



So, where are we now in 2017 with regards a strategy for persons with disability? Undoubtedly, much progress has been registered and European civil society has been at the forefront of initiatives aimed at ensuring that the voice of persons with disability is heard and is loud and clear.

But still in 2017, we are today discussing a plenary session whose title in itself states that we are working 'towards an inclusive EU budget.' The terminology used already underlines the fact that since we are merely 'aiming' towards inclusivity, we are still in a position of an **exclusive** EU budget to date.

Just this morning, we all heard a number of speakers, most notably an EPP MEP, which based their speeches with an 'us' and 'them' terminology. The MEP speaker in question, in a speech which lasted less than two minutes, incredibly used this terminology a shocking twelve times: 'we' meaning us normal EU citizens and 'you', probably denoting persons with disabilities within the EU.

Imagine that this speech was given in a forum related to gender equality where 'we' would be used twelve times to describe males, for example and 'you' would be used twelve times to describe females. Or a minority and integration related forum where 'we' would be used to project 'normal' Europeans and 'you' would be used to project colored persons, for example.

So it is this 'us' and 'them' mentality which should be initially targeted if we are to win this battle. It is all well and good that, somewhere, in a corner, European institutions have Committees or Working Groups responsible for the rights of persons with disabilities. But then decisions – social, economic, infrastructural, cultural etc – are taken by bureaucrats and politicians who really do not care or understand disability issues, even though their speeches try to project the opposite.

We heard this morning, yet again, that there are still in 2017 persons with disabilities who are not allowed to vote and choose their representatives in a free, informed and unshackled manner like their fellow citizens within the EU jurisdictions. But that is not all. We still have EU countries whose state and national buildings and venues themselves do not allow disabled citizens inside them. Yesterday, we congratulated and awarded a number of EU cities who are mostly accessible to persons with disability. But all of us know that there are hundreds of cities, towns and villages throughout the EU countries which cannot even dream of being nominated for such a city accessibility award.

So our institutions, be they local, national or within the EU structures themselves, are fundamentally at fault for not being fully proficient in taking off the mantra of a minority grouping, where persons with disability – the whole 80 million of them throughout the EU – are segmented in 'boxes' with other vulnerable groups.

Therefore, my final comment is this: Just like decades ago, when gender equality was still something of a dream, society – and EU states in particular – created positive discrimination



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initiatives which gave women a needed boost in a male dominated society. Isn't it time that our EU institutions properly and practically brainstorm the methods which can be introduced for a general positive discrimination policy in favor of persons with disabilities?

My speech today should not be seen as merely criticism of the institutions. With nearly 80 million persons with disability throughout Europe it is indeed shameful that we, the disability movement in the EU, are not able to elect more representatives and ensure that more officials are sent to the EU structures who are themselves persons with disabilities. We have the numbers, but we don't have the leaders. Do not think that this is an impossible task. Just some moments earlier, my dear friend Senator John Dolan from Ireland mentioned World War Two and Nazi deliberate atrocities against persons with disabilities. Just keep in mind that this city itself, indeed the country we are presently in, was itself liberated from Nazi tyranny by an army whose commander-in-chief was himself handicapped.

This is what ***Nothing About Us Without Us*** should mean.

Thank you.

Joachim Seuling

Stellungnahme für den deutschen Schwerhörigenbund anlässlich des 4. Sitzung des Parlaments der Menschen mit Beeinträchtigungen in Brüssel am 6. Dezember 2017, 2. Plenardebatte, Thema „Menschenrechte für alle: Auf dem Weg zur Europäischen Behindertenstrategie 2020-2030 und einem Inklusiven Haushalt“

Meine sehr geehrte Damen und Herren,

gestatten Sie mir eine Anmerkung bevor ich zu meiner Stellungnahme zum Thema der zweiten Debatte komme. Ich hoffe, dass die Menschen mit Hörbeeinträchtigung bei der Strategie 2020-2030 und ihrer Umsetzung nicht ebenso vergessen werden, wie bei dieser Sitzung.

Die Untertitel für Hörbeeinträchtigte sind sehr unbefriedigend. Im Gegensatz zur internationalen Gebärdensprache, gibt es bis heute aber keine internationale Schriftsprache. Sowohl technisch als auch inhaltlich ist die hier angebotene Schriftdolmetschung nicht geeignet, der Diskussion im Plenum folgen zu können.

Weiterhin möchte ich Ihren Blick auf die Mittagspause lenken. Immer wieder höre ich, diese Pausen sind wichtig für Gespräche, zum Kennenlernen und um sich zu vernetzen.

Akustisch war die Mittagspause in den dafür vorgesehenen Räumen eine Katastrophe. In den engen und lauten Räumen bedeutet es für Menschen mit Hörbeeinträchtigung



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Höchstleistung zu erbringen, um überhaupt Gespräche führen zu können. Damit werden Menschen mit Hörbeeinträchtigung bei der Sitzung des Europäischen Parlaments der Menschen mit Beeinträchtigung diskriminiert.

Warum betone ich dies so?

Rahmenbedingungen wie heute sind die Ursache dafür, dass Hörbeeinträchtigte Veranstaltungen wie diese meiden und sich isolieren.

Nach eigener Einschätzung haben rund 52 Millionen Menschen in Europa eine Hörbeeinträchtigung! Wahrscheinlich sind es in Wirklichkeit sogar noch viel mehr Menschen davon betroffen. Nur 73 Prozent davon suchen ärztlichen Rat und nur jeder zweite davon wird an Spezialisten überwiesen.

Hörverluste können die Ursache für soziale Isolation und Depressionen sein, häufig sind **sie** die Ursache für Schäden der geistigen und körperlichen Gesundheit älterer Menschen.

Hörverluste und deren Folgeschäden sind ein großes Problem für die Gesundheit der Bürger Europas und drohen, gewaltige Belastungen für die Gesundheits- und Sozialsysteme zu verursachen, wenn sie nicht behandelt werden.

Innovative Medizintechnik wie Hörgeräte und Hörimplantate können die Belastung mindern. Schon mit einer guten Raumakustik sowie aktueller Hörtechnik kann die Teilhabe vieler Menschen am gesellschaftlichen Leben ermöglicht werden, die sich sonst in Isolation zurückziehen. Europäische Entscheidungsträger sind daher aufgerufen tätig zu werden,

- das Bewusstsein für diese Situation zu schärfen
- wirksame Präventionsmethoden zu untersuchen,
- den Zugang zu diesen Technologien zu erleichtern und die Versorgung zu verbessern

Die Europäische Kommission und der Rat können:

- Die Führung zu übernehmen und sicherstellen, dass der Zugang zu professioneller Hörversorgung einschließlich Diagnose, Rehabilitation, Service und Wartung ein Recht für alle Bürgerinnen und Bürger Europas ist,
- In Zusammenarbeit und unter Führung auf diesem Gebiet tätiger Experten soll eine europaweite Strategie zum Umgang mit Hörverlusten zu entwickelt werden, mit einer Fokussierung auf gleiche Rechte für Alle, Prävention und



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Rehabilitation und dem Ziel, den Alltag für schwerhörige Menschen zu erleichtern;

Die Mitgliedstaaten sollen:

- Effektive Strategien für die Prävention und frühzeitige Identifizierung von Hörbeeinträchtigungen in ihre Gesundheitssysteme integrieren;
- Der Zugang zur Versorgung mit Hilfsmitteln wie Hörgeräten, Cochlea-Implantaten und andere Hilfsgeräten ist zu fördern;
- Altersgrenzen für Maßnahmen zur Teilhabe oder Versorgung mit Hilfsmitteln sind aufzuheben, die ältere Menschen darin hindern, ihre Rechte gemäß der UN-Behindertenrechtskonvention (CRPD) wahrzunehmen;
- Effektive Maßnahmen zu ergreifen, um den Zugang aller Menschen zu öffentlichen Einrichtungen, öffentlich zugänglichen Gebäuden und audiovisuellen Medienangeboten sicherzustellen;
- Ausbildung und Anerkennung für die mit Hörverlusten befassten Berufe in allen Mitgliedsländern zu gewährleisten.

Lassen Sie mich eine abschließende Bemerkung machen, es reicht nicht aus, Rechte zu haben, es muss auch Konsequenzen haben, wenn diese Rechte verletzt oder verweigert werden.

Anmerkung:

Weiterführende Informationen zu den Forderungen der Organisationen der Menschen mit Hörbeeinträchtigungen wurden im November 2017 über die Plattform Health First Europa im Manifest zu Hörverlust und Behinderung veröffentlicht.

<http://healthfirsteurope.eu/topic/hearing-loss-and-disability/>

Valmar Ammer

Estonia Association of Spina Bifida and Hydrocephalus



Dear Members of the European Parliament and delegates from all around Europe. My name is Valmar and I come from the Estonian Society of Patients with Spina Bifida and Hydrocephalus.

I will speak a little bit about the capacity of advocacy organizations in Estonia, which is also a concern in Europe.

The biggest problem is that advocacy organizations are weak in Estonia. They are not really able to stand up for their target audience.

If we look at, for example, the Estonian Taxpayers Association - they have membership fees that enable them to represent their members, hire necessary personnel and so on; they do not have to curry favour with anyone and they provide strong positions and statements. If necessary, they can help taxpayers in court, they organize strong, expensive and high level trainings for their members.

Now, let's look at organizations for people with disabilities. They do not have the resources to hire an attorney or a lawyer for their members. They can't afford a salaried lawyer who could draw up competent standpoints and responses to patients' problems. Volunteers have to work besides their daily job. There is no fund available to cover legal expenses, even if in the event of a positive court ruling, it will be returned to the other party. Even the state will not take DPOs seriously as their partner.

I think that until DPOs are able to hire strong lawyers and lobbyists, the state will not take them seriously. They get some money to barely exist and do advocacy work besides their daily jobs and they are not considered important, because the target group does not go to court for their problems, etc.

Payment to specialists for their time is simply uncommon in Estonia. And if you do not do this for free, nothing will change for advocacy groups. This is the practice for involvement today!



4th European Parliament of Persons with Disabilities

Contribution by Mr. Gerry Ellis

Disability Federation of Ireland

December 6th, 2017

I am speaking today on the subject of access to technology. However, much of what I say can be easily adapted to other aspects of society SUCH AS transport, education, the built environment etc.

Technology does not have to be complicated or sophisticated to be effective. Being blind, I can raise the glass at the front of my tactile watch and feel the hands to tell the time. I have a simple piece of plastic with the word "Taxi" printed on it to attract the attention of taxi drivers. An excellent use of modern technology to provide a simple and cheap solution to wheelchair users in the developing world is the Leveraged Freedom Chair.

However, we as persons with disabilities must take cognisance of the importance of developing and future technologies. We are doing so partially by engaging with those who are developing them. For instance, I was part of a group that met Google last week in relation to Artificial Intelligence and part of a different group that met W3C yesterday in relation to Augmented and Virtual Reality.

Other examples of areas of quickly developing technology where many persons with disabilities are engaging include:

- wearable technologies
- Machine learning.
- Driverless cars
- New light-weight materials such as graphene
- 3D printing

We are working towards ensuring that our needs are reflected in the key concepts of bias and fairness to avoid the kind of barriers that exist in other areas of society being perpetuated and further compounded in these new technologies. Persons with disabilities not only want, but need, to share the Potential benefits of these and other new technologies to guarantee access to current and future opportunities in education, work, leisure and all aspects of society.

Plenary Debate 3: the EU in the world: leading by example on Sustainable Development and the Rights of Persons with Disabilities

Michael Kalmár	European Dyslexia Association President
Martin Gec	Slovenian national council
Luk Zelderloo	EASPD
MEP Helga Stevens	
Sotiris Xiouros	Cyprus Confederation of Organizations of the Disabled
Herbert Pichler	Österreichischer Behindertenrat - Austrian Disability Council
Zsuzsanna Szilvasy	Autism Europe
Karina Chupina	International Federation of Hard Of Hearing Young People
Anna Woźniak Szymańska	POLISH ASSOCIATION OF THE BLIND, President of the Main Board
Chris Roberts	Alzheimer Europe
Simon Klein	Stammingsförbundet (Swedish Stuttering Association)
Mirela Bukovac	International Federation Spina Bifida and Hydrocephalus, Youth Group
Karolina Celinska	DHR - Swedish Federation of people with mobility impairments
Abia Akram	CEO of the Pakistani National Forum of Women with Disabilities/ Asia Pacific Women with Disabilities United
Francisco Aedo	CERMI (Spain)

Michael Kalmár, chairman of the European Dyslexia Association

My name is Michael Kalmár – I am the chairman of the European Dyslexia Association.

I speak for the European citizens affected with an invisible disability, dyslexia. Dyslexia is the most widespread specific learning difference, making the acquiring and using of reading, spelling and writing skills and other communication-related abilities difficult.

The group of persons with dyslexia and co-occurring disabilities encompasses between 10 to 15 percent of the population.



The abilities of reading and writing are important prerequisites in our scripture orientated society for individual cultural, social and economic development and success. Persons with dyslexia therefore, are navigating through life in a largely non-‘dyslexia’ friendly world. Often they are challenged with failure in school, training and employment. General communication impairments and social segregation are common threats, with well-known consequences in the lives of those affected, their family members and society. Millions of children, adolescents and adults with dyslexia across Europe have the right to maximise their personal opportunities. Therefore we ask the European Institutions to work with the EDA to make early identification of dyslexia across Europe the norm and to make lifelong appropriate support and equal opportunity a reality.

Sotiris Xiouros, Cyprus Confederation of Organizations of the Disabled

Dear Mr. President
Exceptional guests
Dear colleagues

At first let me express our sincere thanks for giving us the opportunity to address this short intervention to the 4th Parliament of Persons with Disabilities on behalf of the Cyprus Confederation of Organizations of Persons with Disabilities (CCOD).

Today we would like to place emphasis on the main and very crucial challenge for persons with disabilities in our country being the implementation of the International Classification of Functioning, Disability and Health (ICF), as the disability assessment tool for designing and implementing most disability policies. We strongly believe that it is not based on the human rights model to disability and is unsuitable for the inclusion and respect of rights of persons with disabilities in all aspects of life.

The disability and functionality assessment system is used for the assessment of applicants for the most important financial benefits on which the right to adequate standard of living and social protection depend. As a result, the limitation of the rights of persons with disabilities and the exclusion of many of them from the welfare system of the state has been immense and continues to grow even as we speak.

Unfortunately, these persons who, with the help of technology or the support of their families are in a position to perform some activities are subjected to important cuts in their benefits or are deprived of the personal assistance, support and even 24 hour care they need all together. This is a rather real and humiliating situation we cannot tolerate.



For the above reasons we would like to stress the need for measures to be taken by our country, with the contribution of the EU as a member entity of the CRPD, to revisit the ICF-based procedure of assessment and replace it with a more suitable tool that does not violate the CRPD and reflects the human rights approach for all persons with disabilities.

Anna Wozniak Szymanska
President of The Main Board of the Polish Association of the Blind

Dear Sirs,

1. I appeal to Members of the European Parliament to prepare directives concerning - "European standards for the rehabilitation of persons with various disabilities".

Substantiation

Directives are the most effective instrument that enforce changes in the policies of the European Union Member States. At present, the standards of rehabilitation in individual member states are very diverse, which results in failure to provide professional support and the lack of various forms of assistance for people with disabilities. Rehabilitation experts know good practices and methodologies of the rehabilitation process. This knowledge and experience should be used to create a friendly law for people with disabilities. In my opinion, as a long-term practice, we will not be able to improve the professional activity rate as well as social or political activity if people with disabilities do not receive rehabilitation assistance in the fastest time possible for them. Help that will satisfy their needs depending on their age, sex, degree of disability, place of residence, economic situation, their abilities and skills and the use of their potential.

2. I appeal to Members of the European Parliament to prepare directive concerning the creation of a European support system for people over 25 years with relegated disabilities who depend on their families and for those families.

Substantiation

In the Polish education system, up to the age of 25, there is a possibility of appropriate interactions within the framework of compulsory schooling. However, after the age of 25, these people and their families are left alone and there are no systemic solutions for adults who require constant care and their families.

Family support is a guarantee of adequate quality of life for dependent people. This is a condition for the implementation of art. 19 of the United Nations Organization Convention on the Rights of Persons with Disabilities. To my knowledge many EU countries have the same serious problem.

Anna Wozniak Szymanska
President of The Main Board of the Polish Association of the Blind



President of the Coalition for People with Disabilities
Member of the commission for cooperation with the European Union - European Blind Union

Chris Roberts, on behalf of Alzheimer Europe

My name is Chris Roberts, I was diagnosed with mixed dementia, Alzheimers and vascular five years ago, I represent the European Working Group of PwD, which has been established since 2012.

Dementia 'IS a disability',

it is covered by, disability discrimination legislation.

And at a domestic level, that means the Equality Act,

At an international level, the equivalent is the Convention on the Rights of Persons with Disabilities

(the CRPD).

Both these laws talk about reasonable adaptations and adjustments, that can be made to ensure that people with dementia and other disabilities, are included and not excluded, 'doing with and not for'

We need to make sure that the public services that do exist, are more enabling to help reduce the anxiety and agitation, that people affected by dementia, feel on a daily basis, and not to forget their families that are also affected.

A quarter of people in hospitals and prisons have a form of dementia:
what are we doing to make their experience easier ?

And yet despite dementia being recognised as a disability, good practice is not widespread or fully promoted as the law dictates,

any training and awareness that does exist to try and improve this is very weak, tokenistic and inconsistent.



People affected by dementia still face numerous challenges in realising their rights and encounter continual stigma and prejudice.

There still remains a total lack of understanding about the dementias, as well as multiple discriminations on so many grounds, including age and gender, compounded with bad care, abuse and, mostly non-existent services.

The legislation which is there to protect and uphold our rights has been poor, variable, and in some European countries, has been trampled on, or even worse, not considered at all.!

People affected by dementia are not receiving the protection that these laws are supposed to provide.

Dementia is mostly, until the late stages, a hidden or invisible illness.

So perceptions of this illness and what the person requires often prevails over the person's actual needs, which can vary hugely depending on the type of dementia, the environment, the country they reside in, their age, and the support around them (or lack of!)

Furthermore, the 'social model of disability' which should be applied to dementia, is continually overridden by the 'medical model'.

This must change!

And finally,



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I would like to say thank you to all of you that have stayed to listen and have “not left us behind”!

‘Nothing about us without all of us’

Karina Chupina

International Federation of Hard of Hearing Young People (IFHOHYP)

Dear Members of Parliament, dear leaders of the disability movement,

Hard of hearing people have an **invisible disability** and are **often forgotten** in policy discussions.

In hard of hearing youth community, there are young people relying on oral speech, late-deafened, hearing aid and cochlear implant users, youth with Usher Syndrome, youth who are bilingual and use signs in addition to spoken language.

For many of us, one of the biggest challenges is the **access to hearing aids** and **assistive listening technologies** that are a **door to our education and employment**.

(And as we could see here, today, from the lack of quality speech-to-text, accessibility standards are not being followed in the European Parliament...)

You can't get a job without a good hearing aid. And you can't get a suitable hearing aid without a job to pay for it. It is a vicious circle.

You can get a cheaper hearing aid provided free of charge that does not fit your profound hearing loss – and you won't understand what people say. As a result, you will get a low qualification job despite hard-earned education degrees. Sometimes, you have to pay thousands euros more to get a hearing aid that suits your needs.

But lots of hard of hearing young people are unemployed. They don't have the privilege of health benefits that cover cost of hearing aids and assistive technologies, even if partially. The reality is that at job interviews, youth with hearing loss find it hard to compete not only with non-disabled people, but also with other people with disabilities. Difficulties with speech, pronunciation, articulation, mastering voice, intonating and understanding speech **increase their social isolation** and deprive them of the **biggest value in their lives – the luxury of communication**. Because of this, hearing loss is stigmatised and people with hearing loss can be more discriminated on the background of visible disabilities.

All of us understand how important is a high quality wheelchair for a wheelchair user. At the same time, even professionals may often not know what hearing loss means, the impact it has and what assistive technologies are required for inclusion.



Why then do we need all the EU achievements in early rehabilitation, science and technology? What for?

We need to have a **right to choose** devices that work for us. We need **effective reimbursement systems** recognising **social**, and not only medical factors in the lives of young people. As hearing loss is increasing in all age groups¹ in Europe, we demand our right to be heard and visible.

We call the European Commission:

1. To put hearing loss **on the political agenda** and incorporate it in **population surveys** in Europe – for the statistics to serve as a basis for development of evidence-informed policies to improve quality of hearing care
2. To develop **effective state-funded reimbursement systems** for assistive listening technologies and hearing devices, based on person-centered approach, ensuring freedom of choice and cost not being a barrier for hard of hearing people, especially in the age of transition
3. To increase awareness of hearing loss as a **cause of social isolation and depression**
4. Following the UN CRPD Art 25 (b), to implement the professional **hearing care standards** (EN-15927) (early diagnosis, rehabilitation, service and maintenance)
5. **To conduct research on hearing loss** (including research on prevention and rehabilitation) – for better understanding of its **social and economic impact**² and improving quality of life for people with hearing loss
6. To globally promote examples of **accessible Erasmus Plus youth projects** and Council of Europe study sessions organised **by, with and for young people with disabilities** – and invest in making EU Youth programmes' **accessible for all youth with disabilities**
7. To provide a guaranteed and accessible place for **youth with disabilities in policy making** that concerns them, in the European Commission, SDG and the UN CRPD processes – including underrepresented hard of hearing and deafblind young people
8. Finally, we call the European Union to be the LEADER in the provision of **quality speech-to-text, subtitling and induction loops' accessibility**.

Thank you.

¹ Hearing loss due to recreational exposure to loud sounds. A Review. WHO, 2015. ISBN 978 92 4 150851 3

² As an example, underemployment in people with hearing loss in the UK was 33,5 bln Euros in 2013. The Real Cost of Adult Hearing Loss. The Ear Foundation, 2014.



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Simon Klein, chairman of Stamningförbundet, the Swedish Stuttering Association

My name is Simon Klein and I'm the chairman of Stamningförbundet, the Swedish Stuttering Association.

I wish to highlight the responsibilities of the EU and national governments to raise awareness on disabilities and combat prejudice, as stated in article 8 of the CRPD. When I was younger, my stutter was much more severe than it is today. It affected my oral participation in the classroom, and it often kept me silent in social settings. I knew that my speech was likely to fail me and leave me open to humiliation and prejudice. The adults around me didn't know enough about stuttering to help me. Last month, the Swedish government decided that special education teachers need to learn about neuropsychiatric disabilities such as ADHD. This is a good first step, but it is not enough. All teachers need to have an awareness and understanding of all disabilities that they encounter! I used to doubt that I would ever be able to have a job where I had to speak, and thought that my chances of finding a life partner were very small. I feared that people would not understand why my speech was different, and judge me for it. After getting involved in the stuttering and disability community, I have learned that my experiences are not uncommon. A lack of public awareness and understanding of disabilities can lead to direct and indirect exclusion from society. Children and youths with any form of disability have the human right to a quality education that understands, and adapts to, their disability. Persons with a disability have the human right to live in a society that is aware of, and accepts, their disability, in all aspects of life. If no one is to be left behind in the implementation of the sustainable development goals, awareness-raising, education and lessened prejudice concerning all forms of disability is needed! Thank you very much!

Video: https://www.youtube.com/watch?v=fB_w3tZp7tQ

Mirela Bukovac

Youth Group, International Federation for Spina Bifida and Hydrocephalus

Dear all, my name is Mirela and I'm from Croatian association for Spina Bifida „Aurora“ and I'm a member of IF Youth Group for SBH.

I want to talk about the situation of young people with disabilities on the labour market. In Croatia, 68% of young people with disabilities have primary or no education, 29% of young



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people with disabilities have secondary education, and there are only 3% with higher education level. Among all employees, people with disabilities make less than 1%. Despite the fact that our government adopted laws to improve labor market situation by introducing a quota of 1 person with disabilities per 20 employees, the situation hasn't changed for the better.

To avoid this, we should raise awareness of employers so that they see people with disabilities through their abilities. We need to show good examples of employment in the media. We need to showcase success of the companies who hired people with disabilities and practise inclusive hiring processes. There should be win-win, pro-business or pro-employer stories that get a lot of publicity. A story of a successful employer proud of hiring people with disabilities will inspire more employers to welcome workers with disabilities.

So we ask the EU to promote inclusive and sustainable economic growth through increasing diversity, upgrading technologies and innovation, so that people with disabilities can have an opportunity for a decent job.

Karolina Celinska, DHR - Swedish Federation of people with mobility impairments

Ledamöter av parlamentet, mina meddelegater och vänner!

Tack för möjligheten att tala inför er idag.

Jag skulle vilja ta tillfället i akt att särskilt lyfta två frågor som jag känner starkt inför och som jag upplever behöver extra uppmärksamhet.

Först vill jag lyfta full delaktighet och inkludering. En nyckel för att uppnå det är Universell utformning. EU måste bli bättre på att planera, bygga och skapa utifrån den mänskliga mångfalden. Än idag skapas miljöer som utestänger. Tillgänglighet och användbarhet ifrågasätts fortfarande med argument som "men nog räcker det väl med att vissa bostäder, vissa lokaler, vissa aktiviteter är tillgängliga". Nej, det räcker inte! Varför ska människor med funktionsnedsättning nöja sig med mindre? Med Universell utformning kan inkludering och delaktighet bli mer än tjustiga viljeyttringar, det kan vara en verklighet!

Den andra frågan jag vill uppmärksamma är Rättigheterna för flickor och kvinnor med funktionsnedsättning!

I ljuset av #meetoo-kampanjen är det av största vikt att vi flickor och kvinnor förstår och vet att vår kropp är vår egen och att andra endast får ta del av den, när vi själva tillåter det.

Med andra ord samtycke!

Flickor med funktionsnedsättning får sin kropp från tidig ålder utsatt för undersökningar, tester, övningar, anpassningar allt som en del i att leva med funktionsnedsättning. Olika professioner som möter flickor har ett oerhört ansvar att skapa trygghet och ge flickor en bra



självbild. Flickor och unga kvinnor med funktionsnedsättning måste ges tillgång till utbildning i sexuell och reproduktiv hälsa. Först när vi kvinnor med funktionsnedsättning känner egenmakt, vet att vår kropp är vår egen och att samtycke är vår rätt. Först då kan vi få jämställdhet! EU ska vara ett föredöme för flickors och kvinnors rätt!
Tack!

Francisco Aedo, CERMI

Buenos días, señores y señoras, miembros del Parlamento Europeo y representantes del Movimiento Asociativo de la Discapacidad de toda Europa

Me llamo Francisco, tengo 20 años y soy sordo profundo. Utilizo un Implante coclear que me permite acceder a la audición, a la información y a la comunicación.

En el 2019 será la primera vez que pueda votar en unas Elecciones al Parlamento Europeo y estoy deseando poder participar en ellas y así contribuir a lograr una Europa más democrática en la que la voz de todos los ciudadanos sea escuchada.

No obstante, para poder ejercer mi derecho al voto, necesito previamente haber podido acceder a toda la información y así poder, con todo el conocimiento, elegir al partido al que quiero votar.

Para mí, persona sorda que comunico en lengua oral, es imprescindible que toda la información relativa a las elecciones en televisión esté subtitulada. Sé que el anuncio de las instituciones europeas animando a votar en las Elecciones de 2014 europeas no estuvo subtitulado. Lo sé porque la versión en español la subtituló la Confederación Española de Familias de Personas Sordas – FIAPAS, la entidad que me representa a mí y a mi familia.

Es indispensable también que los debates entre los candidatos estén subtitulados. Igualmente, deberían ser accesibles los mítines electorales. Las personas sordas que comunicamos en lengua oral necesitamos contar con subtitulado en directo y de bucles magnéticos que permitan que el sonido llegue de una manera clara y limpia a nuestras prótesis auditivas.

Las páginas web de los partidos políticos suelen tener vídeos informativos y materiales audiovisuales en donde explican el programa electoral de cada uno y, en la mayoría de las ocasiones, estos materiales audiovisuales no están subtitulados, por lo que es complicado acceder a esta información.

Además, es necesario que si una persona sorda que comunica en lengua oral y utiliza prótesis auditivas es designada miembro de una mesa electoral, las administraciones públicas le faciliten de manera gratuita un bucle magnético que le permita ejercer este deber ciudadano.

En España eligen por sorteo quienes van a ser las personas que el día de las elecciones están en la mesa electoral comprobando la identidad de cada votante y controlando el proceso



electoral. En el caso de que me toque cumplir este deber ciudadano, quiero poder hacerlo, accediendo a la información y a la comunicación, como todos los demás.

Muchas gracias por darme la oportunidad de dirigirme a ustedes y confío en que adoptarán las medidas necesarias para que todos las personas sordas, como es mi caso, podamos votar en igualdad de condiciones que el resto de ciudadanos europeos.