



European Economic and Social Committee | Comité économique et social européen

PERIOD **ACTIVITY REPORT** **2020** Permanent Group on **2023** Disability Rights

**DIRECTORATE C. – LEGISLATIVE
WORK**

PRESIDENT: Pietro Barbieri

Introduction

*The activities of the Permanent Group on Disability Rights (PG DIS) during the current mid-term (2020-2023) were influenced by two major crisis: the **COVID-19 pandemic** and the **war in Ukraine**. In the background, the consequences of **climate change** have also become more and more evident. Persons with disabilities (pwd) have been particularly affected by these setbacks and the group carried out activities to discuss and propose recommendations in these fields.*

*In parallel, the adoption of the **EU Disability Strategy 2021-2030** also represented a starting point to analyse the situation related to the rights of pwd in various policy areas and proactively contribute ahead of the adoption of strategic measures.*

*The PG DIS has continued to offer a **platform for debate to civil society organisations**, especially organisations representing pwd (DPOs), by organising public hearings and carrying out fact-finding missions to look more closely at the state of implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).*

The Group also pursued the cooperation with the European Commission and the European Disability Forum in key events like the Conference of State Parties (COSP) to the UNCRD and the European Day of Persons with Disabilities. It has also been involved as observer in the Disability Platform set up by the European Commission at the end of 2021.

Pietro Barbieri

President of the Permanent Group on Disability Rights

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Activities & main findings

Description of activities, key challenges and achievements/results

In the present half term, the group focused its activities on the consequences on pwd of the COVID-19 Pandemic, the Russian war of aggression in Ukraine and climate change.

A hearing was organised to discuss good practices in the prioritization of pwd in the **vaccination rollout** and present recommendations to member states in case of similar events.

As pwd living in institutions and long-term care facilities sadly registered a very high death rate in the early months of the pandemic, an event highlighted the **importance to pursue de-institutionalisation** process and draw attention to the role of families as carers of pwd.

A fact-finding mission on **independent living and support services** for pwd to leave in the community will take place in March 2023.

Another hearing is planned for early 2023 on **access to health and global health** for pwd.

A fact-finding mission to Poland was organised to evaluate the reply given to the refugee crisis due to the conflict in Ukraine and the specific challenges encountered in the reception of **refugees with disabilities**.

The consequences of climate change on pwd and the importance to work on the concept of **climate justice** were debated in another hearing organised by the group.

In parallel to this, the PG DIS carried on with its more traditional activities linked to the monitoring of the implementation of the UNCRPD and the EU Disability Strategy through the review of EU policies and legislation. Hearings and fact-finding missions were organised on **transport accessibility, legal capacity, social services** for pwd, **inclusive education** and the **EU Disability Card**.

As 2022 was the European Year of Youth, the group dedicated a hearing to discuss the **obstacles faced by young people with disabilities in the field of employment**.

The work done by the EESC on disability is highly recognized by **other EU institutions** (EP and EC), and **civil society organisations**, in particular DPOs. The Group works closely with the European Disability Forum, which takes part in all the events since the preparation phase. The reports of the missions are regularly sent to the European Commission Focal Point, to the EP's relevant committees and published online. In addition, the Group is now involved as observer in the European Disability Platform, set up by the Commission in December 2021.

The PG DIS has continued as well **developing synergies** with other EESC structures. The IMI group was involved in the preparation of the mission on refugees with disabilities and the hearing on climate

justice was organised in cooperation with the secretariat of the NAT section. Moreover, disability rights are included in the non-discrimination strand of activities of the group on Fundamental Rights and the Rule of law (FRRL).

Appendix I – List of meetings and events

	As of 29 October 2020	2021	2022	Until 25 April 2023	Total
PG/Observatory meetings	1	3	3	1	8
Fact-finding missions	0	2	2	1	5
Conferences and hearings organized by the PG/Observatory	0	3	3	1	7

Appendix II – Reports of fact-finding missions



Permanent Group on Disability Rights

REPORT

Fact-finding mission to Malta: independent living and community-based living schemes

Date: 20-21 March 2023

Members: Tudorel TUPILUȘI (Gr. III)
Irena PETRAITIENĖ (Gr. II)
Martina ŠIRHALOVÁ (Gr. I)

Observer: Haydn HAMMERSLEY (European Disability Forum)

EESC Secretariat: Valeria ATZORI

Monday 20 March 2023

Meeting with representatives from public authorities

Dr Alistair De Gaetano – Directorate for Disability Issues (MIVC) (National Coordination Mechanism)

Mr De Gaetano presented the bodies currently working on disability in Malta as well as the legislative setting. There are three public authorities working on disability: the Directorate for Disability Issues within the Ministry for Inclusion, the Commission for the Rights of Persons with Disabilities (CRPD), and Aġenzija Support.

The Disability Directorate is the focal point for the CRPD and the National Coordination Mechanism. The Directorate examines all legislative proposals to ensure that they comply with the Convention and that they engage with disabled persons' organisations (DPOs). In addition, a screening of existing legislation has led to reforms such as the UNCRPD Act of 2021, applying the UN Convention to Maltese law; in the same year, the part of the Equal Opportunities Act referring to PWD was amended; in 2023, the Personal Autonomy Bill was adopted and the Protection of Adults in Vulnerability Bill and the Criminal Code were both amended.

The work of the Directorate has recently been focusing on the mental health and empowerment of people with autism, the accessibility of digital platforms, and digital skills for PWD.

Edwina Gouder – Directorate for Disability Issues (MIVC) (National Coordination Mechanism)

Ms Gouder outlined the main elements of the Malta Disability Strategy 2021-2030. The strategy represents a roadmap for the disability sector for the next 10 years. It is based on the principle of "Nothing about us without us" and is accompanied by the Autism Strategy 2021-2023. Objective 10 of the strategy deals with independent living, and Malta has developed six actions to achieve this: addressing gaps in services; strengthening personal assistance schemes and community living schemes; setting up a "Train the practitioner" unit; curtailing abuse; improving coordination among service providers; and de-institutionalisation.

Nicole Borg – Directorate for Disability Issues (MIVC) (National Coordination Mechanism)

Ms Borg presented the work done by the department on deinstitutionalisation. There are still some institutions on the island, but many resources are put into trying to transition to community-based care. For this purpose, a public-private social partnership has been established with NGOs. There are 13 agreements in place offering respite to parents. Most of the budget for carrying out these activities comes from the Ministry, not European funds (EUR 4.2 million). The department also supports the Maltese organisations representing PWD with a multiannual agreement and has increased the funds allocated.

Samantha Pace Gasan – Commissioner for the Rights of Persons with Disabilities

Ms Pace Gasan presented the preliminary findings of the study *Towards Deinstitutionalisation in Malta*. The aim of this study is to collect more data and information on how services for PWD work on a daily basis, as well as to integrate good practices from other countries, gather feedback from various stakeholders, and adopt recommendations. As part of the study, interviews were conducted with PWD living in institutions, including people with mental health problems, PWD living in homes run by NGOs, and members of the National Parents of PWD Society. The first such institution in Malta was Id-Dar tal-Providenza, which opened in 1960. Founded by a priest, its aim was to take children out from caves where their families were hiding them. This institution is still open, but since 2013 they have also started to run smaller group homes. The Deinstitutionalisation (D-I) process was described as fragmented and as being more focused on avoiding putting more people in institutions. As such, it is difficult to quantify its extent.

In 2014, a project was launched to provide support for independent living settings known as "Just Society".

According to the study's results, parents opt to put their children in institutions in response to a sudden emergency like sudden illness, old age, and death, or due to a lack of viable alternatives. People with mental health conditions coming from Mount Carmel Hospital are also often placed in institutions.

PWD living in institutions interviewed in the framework of the study responded that they wanted more choice on aspects of their life, including nutrition and how and with whom they spend their time. They complained about the lack of autonomy and privacy, while relationships with staff and other users were generally indicated as being good.

The study contains several recommendations on completing the transition from institution to independent life in the community, which were outlined by Ms Pace Gasan. These include the need to:

- strengthen social welfare
- carry out a reform of the personal assistance (PA) scheme and promote PA as a career choice
- involve PWD and their organisations
- raise awareness of disability rights
- encourage and support the disability movement
- adopt a preventive approach
- stop opening new institutions
- reskill staff from institutions to enable them to work in day-care centres to promote and support independent living
- focus on transitioning people to independent living, with the appropriate budget
- encourage parents to form a cooperative to act as personal assistants for other PWD
- provide specific training on independent living
- present the report, lobby and advocate
- ensure mainstream services are fully inclusive and accessible

As regards data, the Commissioner explained that, in Malta, there are currently officially 25 000 PWD, but that the number is probably higher as the system for applying for disability status works on a voluntary basis. Currently, around 400 people receive subsidies of EUR 9/hour to pay for a personal assistant.

Oliver Scicluna – CEO – Aġenzija Sapport (national service provider)

Mr Scicluna presented the activities and programmes run by the agency. Aġenzija Sapport is the national agency providing professional and innovative services to enhance the quality of life of persons with disabilities. The agency's vision is to be the leader in guiding the community, promoting "ability" rather than "disability" and replacing care for PWD with support. The services offered by the agency include: assessment and intervention, community services, day services, residential services, respite services, sign language interpretation, and employability services, among other things.

Within the **Assessment and Intervention** team, social workers, physiotherapists, occupational therapists, and speech and language pathologists work with individuals with a disability and their families/guardians to provide support using a multidisciplinary approach.

As for **community services**, their aim is to assist persons with a disability to lead an independent life in the community, while at the same time enhancing the quality of life of both the service user and their family/guardians. The service may encompass interventions aimed at: improving personal care; assistance with learning and participation in housekeeping skills; community participation and social skills; engagement in leisure activities; and the prevention and management of behaviours of concern.

Day Services were assigned to Aġenzija Sapport in 2007 and currently there are thirteen day centres for persons with a disability in Malta and Gozo. The aim is to help persons with a disability continue to develop their potential through different types of activities, and to provide support to their families, so they can continue living within the community, without being socially excluded or institutionalised. The Day Services also aim to enhance each service user's independent living skills, thus empowering them to live as independently as possible, and to enhance the employability skills of each service user to their full potential and enable them to participate as active citizens within the community.

Where a family home environment is not possible or available, the **Residential Services** enable persons with a disability to live as independently as possible in the community. Such residential support is

provided within small and personalised apartments and houses, which may be residences belonging to the agency, the home of the individual with a disability, or at another location acceptable to all parties but located in the area where Aġenzija Support operates. Residents gain skills in community living through individualised support plans.

The **Way to Work Service** assists persons with a disability in strengthening or gaining additional skills for employability. The aim is to complement other services and programmes in the sector in order to ensure that persons with a disability feel more confident about seeking employment and living more independently. The service includes training over a number of weeks on topics such as independent living skills, employability, boundaries in the workplace, hygiene, sexual health and boundaries, use of public transport, and how to present oneself with confidence during an interview.

Matthew Zerafa – CEO – Housing Authority

Mr Zerafa gave a presentation on the activities carried out by this organisation, whose function is to help persons with a disability adapt their homes to make them more accessible. The Housing Authority is also changing its offer to make it fully compliant with Article 19 of the UNCRPD (independent living). The schemes currently available were presented, including: the New Hope scheme (not very popular); the Lift Installation scheme (at least one person in the building with mobility issues, financed by ERDF); the Sensibility scheme (for sensory conditions); and a scheme for PWD (to adapt bathrooms, etc.)

Meeting with representatives from organisations representing PWD:

Marthese Mugliette, President of the Malta Federation of Organisations of Persons with Disability (MFOPD), Venera Micallef, Secretary of the Malta Federation of Organisations of Persons with Disability (MFOPD); Catherine Vassallo, Secretary of the Mental Health Association Malta; Pauliana Said, President of the Voice for Inclusion Gozo Association; Joanna Xerri, President of the Down Syndrome Association; Frank Turchett, President of the Malta Society of the Blind; and Marta Ruth Falzon from the Malta Dyslexia Association.

The organisations representing PWD (DPOs) in Malta that met during our mission felt that DPO involvement and **consultation** needed to be stepped up. Currently, DPOs are systematically consulted by the Ministry of Disability, but not by other ministries. The problem seems to lie in the implementation of Article 33 of the UNCRPD.

As regards the **educational system**, the organisations were of the opinion that the system was not adequately preparing children, especially those with intellectual disabilities, for life and work. Skills for independent living should be taught from a young age. The current system in Malta provides that schools should be inclusive until students are 16 years old, at which stage they can only go to a resource centre until the age of 21. Resource centres are often isolated and do not offer training in skills that are useful to help people enter the labour market. In Gozo, the situation is even worse, as there is no resource centre and young PWD have no choice but to stay at home after the age of 16.

The **employment** rate for PWD in Malta is low, mainly because PWD lack sought-after skills, namely in digitalisation. People with mental health conditions are more affected than those with physical disabilities. There is quota system of 2%; however, many employers prefer to pay a fine instead of employing PWD. The situation on the smaller island of Gozo is even worse. PWD receive a disability allowance, which they do not lose if they find a job; however, if they do not find a job they keep only the allowance and not the minimum income, which is double the disability allowance. This penalises PWD. People with less severe mental health conditions do not receive the disability allowance if they work; they are therefore not incentivised to stay in the labour market.

PWD in Malta do not have equal **access to leisure** activities; there is need for a common social space that is accessible to everybody.

One major problem is the **availability of personal assistants (PAs)**; there is an alarming shortage. The role of PAs is often performed by family members. Their role and their rights also need to be formally recognised. DPOs also pointed out that assistance and services for PWD are very expensive, which is why many families apply to put their children in day-care centres or in institutions like Id-Dar tar-Providenza.

As for **living in the community**, small group houses (up to 10 people) have been opened in the past few years; however, the way PWD live there is no different from life in a big institution, as they lack autonomy and choice. The situation is also difficult for PWD living with their parents as receiving adequate services and assistance is problematic. PA schemes need to be reinforced as they are an essential tool for independent living; however, they must be accompanied by accessible services and infrastructures. This is still not the case in Malta.

In the field of mental health, the medical model of managing disability is still prevalent, while in the case of physical disabilities there has transitioned to a social model.

Day-care centres are managed by Aġenzija Sapport. PWD spend most of the day doing crafts. The centres are mostly full and there are long waiting lists to enter. There are some programmes, such as the one managed by the Maltese Association for Supported Employment, which, after a one-year training course, succeeded in giving employment to 14 people, of which one was in a secretarial position and the rest in supermarkets or in the public sector. However, in general, DPOs felt that the day-care centres are not an optimal solution, as people stay there for too many years without being able to enter the job market. For example, in Sliema, the skills space managed by Aġenzija Sapport, which was intended to teach PWDs skills to help them find employment, has become a day-care centre.

Meeting with service providers

- Martin Micallef, Director; Nadine Camilleri Cassano, Administrator; and Remona Cuschierid, Service Coordinator, Id-Dar tar-Providenza
- Paula Doumanov, Chief Quality Officer at Inspire – the Foundation for Inclusion
- Elena Tanti Burlo', Director of Services and Vice-President of the Equal Partners Foundation

Id-Dar tal-Providenza is a large residential institution run by the Roman Catholic Church, located away from the community in an isolated area, with around 95 residents. It was founded in 1968 by a local priest who received the land as a donation. At the time, the institution welcomed children with disabilities who lived segregated lives at home, some even locked up in a cellar or a cave. The original residents remained over the years and now most of them are 40-60 years old, along with one child with multiple disabilities and a 29-year old. There are also around 20 residents aged 60-80 years old for whom geriatric care is necessary. They all have mental health problems and multiple physical disabilities. They live in shared flats (around 10 people per flat), each of them with carers. Around 300 people, including carers and other staff work in the institution. Residents usually take part in external activities in the morning (work or in day centres) and in the flat in the afternoon. Several recreational activities are organised on a weekly basis.

Changes have been introduced over the years and residents are now encouraged to develop their autonomy. Four small community-based homes for disabled people were opened, thus moving away from the notion of institutionalisation. Such group homes house a maximum of four people living together. However, because of the high cost of services and therapies and the shortage of staff, as well as the good reputation of the institution, Id-Dar tal-Providenza has a long waiting-list of families asking for their children to be admitted. In the care sector, there is high demand and limited availability; workers are mainly migrants, which also poses the issue of the language barrier (Maltese not spoken). A change in the approach to disability, both by families and workers in the care sector, is needed in order to shift from care to support.

D-I was pushed, but without having in place adequate available and accessible community-based schemes and services. The institution is forced to admit new residents as there are not enough group homes available. It was felt that the government should do more.

Inclusion of PWD in schools is not a reality. According to legislation, learning support educators (LSE) are assigned to help students with disabilities. However, difficult cases are often given to newer and less experienced LSEs, who have more difficulties in managing them. Parents sometimes prefer to send their child to a resource centre where they have the impression their child will feel more included. The whole educational system in Malta is very selective from a young age. This should be changed using a synergy-based approach, with a team of people who would support the teacher and monitor the progress of the students with a disability. Each teacher should learn braille, sign language and receive universal training. However, teaching unions are against teachers being given any new tasks.

Tuesday 21 March 2023

Visit to San Andrea School

San Andrea is an independent private school in Malta. In the mid-1980s, a group of parents got together to share views on a common educational situation. They were concerned about the educational future of their young children, as private schooling at the time did not offer enough choice of schools to parents. The solution they settled on was to set up an independent school, financed by the collective effort of the parents. The school seeks to celebrate inclusion and diversity holistically as well as to deal with social, emotional, cognitive, existential and identity-related difficulties from a

mental health perspective. The school teaches the values of sharing and respect for diversity. It currently has 1200 students, of whom around 250 have some type of disability, including mental health conditions. The school offers plenty of activities, such as theatre, pet therapy through a therapy dog and a cat in the science lab and rabbits in the garden, various playgrounds, a swimming pool, and multisensory rooms. In class, children can choose the type of chair they prefer and when they have finished their tasks they can select a book from the ones available and read.

Skills are taught throughout secondary school, from 12 to 16 years of age.

Visit to the Skills Space Centre run by Aġenzija Sapport in Sliema

The centre was opened in 2017 with the aim of promoting inclusion and training disabled people to live independently. The new centre features specially designated areas where people with different abilities receive instruction on basic home living skills, including how to prepare meals and operate appliances such as vacuum cleaners and washing machines. In addition, they can choose other activities such as theatre, baking and crafts. They also volunteer in the community with older people, clean litter from the street and help in animal shelters. Relatives are able to observe and follow the training from behind two-way mirrors, easing fears many families often have when leaving their loved ones in the care of professionals. The centre currently welcomes 40 people aged from 18 to 60 years old. Most of them stay for years, although a minority do find a job.

CONCLUSIONS AND RECOMMENDATIONS

- The involvement of PWD and their organisations in designing, implementing and monitoring each policy and measure needs to be stepped up, especially for those measures which are adopted by ministries other than the Ministry for Inclusion.
- The disability movement should be supported with adequate resources.
- The transition from institutions to independent life in the community should be accompanied by better availability of social services provided IN and BY the community.
- No new institutions should be opened.
- The shortage of professionals working in the care sector and of personal assistants (PA) should be addressed by carrying out a reform of the PA scheme, promoting being a PA as a career choice with adequate salaries and working conditions, and improving working conditions across the whole care sector.
- Parents of children with disabilities could be encouraged and supported to set up a cooperative where they could offer their services as PAs to other families in need.
- The budget allocated to PWD to hire a PA should be increased to cope with increased cost of living.
- Staff currently working in institutions could be employed in day-care centres, provided they receive appropriate training that focuses on promoting and supporting independent living.
- The approach to disability taken both by families and workers needs to shift from care to support.

- Children with disabilities should receive training on living independently from a very young age both in their families and at school.
- Ensure that mainstream services are fully inclusive and accessible.
- The educational system should be adapted and made less competitive; all teachers should be trained in basic braille and sign language and be supported by a team of professionals in order to ensure the inclusion of students with a disability in the class.



Permanent Group on Disability Rights

Report

Mission: Country visit to Italy: European Disability Card

Date: 17 October 2022

Members: Tudorel TUPILUSI (GR III)
Irena PETRAITIENE (GR II)
Jacek Krawczyk (GR I)

Observer: Álvaro COUCEIRO (European Disability Forum)

EESC Secretariat: Valeria ATZORI (valeria.atzori@eesc.europa.eu)

Meeting with representatives from public authorities

Antonio Caponetto and Maia Barbara Miernik, Ministry for Disability

Elena Rendina, Ministry of Labour and Social Policies

Maria Sciarrino, Cesidio Morgani, Maria Grazia Botturi, Alessandra Meucci Nicolina D'occhio,
National Institute for Social Security (INPS)

Silvia Cirillo and Roberto Vannata, Ministry of Culture

Stefano Imperatori, Stefano Arbia, Alessandra Battista, Istituto Poligrafico

- The Italian Disability card project started in 2018 at the initiative of the Italian DPOs FISH and FAND and became a reality in 2021, when the first cards were produced. INPS, which was responsible for recognition of disability status, took over management of the project, while the Istituto Poligrafico materially produced, printed and delivered cards to beneficiaries within 60 days of a request.
- The production was then put on hold because of remarks by the Italian Data Protection Officer; it was relaunched in February 2022. Currently around 70 000 cards had been issued.

- To receive a card, applicants had to request it via the INPS's dedicated webpage, attaching a photo. Citizens with a disability of minimum 67% and citizens with a disability acquired at the work place of minimum 35% were eligible for a card.
- A photo and personal data appeared on the front of the card, while on the back there was a QR code that linked up to the INPS database.
- In a second phase, a chip would be added to the card, linking it with the national ID and for harmonisation at EU level.
- The card had a dual function: it replaced the various paper documents attesting recognition of disability status and it granted access to a number of services for access to culture, sport and transportation.
- Because the provision of services and care was decentralised in Italy, regional and local authorities played a major role in implementing the Disability Card.
- Both public and private entities could offer free access to their facilities after signing an agreement with the Ministry for Disability.
- The INPS had encountered some technical difficulties in providing the card automatically and quickly, such as unsuccessful photo recognition, unsuccessful recognition of certification of disability status prior to 2010, and non-digitised or unsuccessful recognition of disability status resulting from a court ruling.
- The card had been launched at a press conference by the Ministry of Disability, the Director of the INPS and FISH and FAND representatives. A communication campaign on the card would be carried out in the next months to raise awareness about it, both among users and potential service providers. Information was available on the [Ministry](#), [INPS](#) and [FISH](#) websites.
- The card gave free access to public museums; additional agreements had been signed with cultural foundations. Free access to trains and other means of transport was not yet a reality. Local transport was managed by local companies and was subject to different conditions.
- The organisations did not have data indicating in which sector the card had been most used, but they surmised this was in culture and sport; they were working on agreements with sports organisations.
- In Italy, the primary function of the card was simplification; it did not currently replace the mutual recognition of disability status among EU MS, although Italy would support EU action in this direction and currently provided pathways for easier access to mutual recognition.

Meeting with representatives from organisations representing PWD (Persons with Disabilities)

Antonio Cotura, Vice President, Italian Disability Forum (FID)

Vincenzo Falabella, President, Federazione Italiana Superamento dell'Handicap (FISH)

Carlo Calvani on behalf of Rino Pagano, President, Federation National Associations for Disability (FAND)

- The particular feature of the process of implementing the card in Italy was that planning was done by DPOs (FISH and FAND) and not by the relevant ministry, as in other countries. FISH, FID and FAND represented the 4.5 million PWD in Italy.
- Their work had started in 2019 when they launched the idea with a budget of EUR 5 million.
- They had also taken part in the work to prepare the website on which people could request the card. The site was fully accessible and used plain language.

- In Italy, some services were managed by local and regional authorities, so for full implementation of the card it would be necessary to raise awareness about it throughout the country.
- The PWD organisations fully supported the card and its extension to the whole of the EU and saw the potential it had for making the life of PWD easier in the EU. To be successful, the card needed to be advertised and a communication strategy adopted.
- It was now urgent to find more partners that accepted the card, especially in the private sector and in transport. Dialogue had been opened with Italian railways, but action was also needed at local level.
- The budget needed to be increased, as the initial EUR 5 million had been used up. This would be discussed in connection with the next annual budget law.
- In Italy the card replaced paper recognition of disability status, and this contributed to simplification. It did not grant any additional rights.
- The PWD bodies had a website (disabilitycard.it) collecting all the relevant information and they were also available by email and phone (+/- 10 requests a day).
- In a second step, the plan was to add a chip on the card to merge it with the information on the ID card. This would, however, entail higher costs (estimated at EUR 15 million).

Meeting with representatives from trade unions and employers' organisations

Nina Daita, CGIL

Silvia Stefanovich, CISL

Mirella Novelli and Federica Cianchi, UIL

Lucia Scorza, Confindustria

Alessandro Cellucci, UGL

- The main problem in relation to the card so far was that it was not well known and there were not many active agreements in connection with it.
- Its main advantage was that it replaced the mass of papers previously needed for proving disability status. However, this was still the case in shops where PWD benefited from discounts, because shop assistants often did not recognise the card. Another problem was the excessive bureaucracy and multiple procedures in place for ascertaining disability status. The card had the potential to help simplify the procedure.
- Neither the European dimension nor the possibility of using the card in another MS to benefit from the same advantages had been highlighted in Italy.
- Currently the card could be obtained by the INPS or DPOs only. It would be useful to expand the channels of distribution and facilitate access for older people not always familiar with IT, by including other charitable organisations (known as the Patronati).
- Currently the card mainly granted free access to museums: this was also the case previously, but trade unions and employers' organisations felt that it would be more useful to invest money in making museums fully accessible, as many PWD could easily manage to pay for tickets.
- They supported the idea of the card but thought it needed more publicity and its scope broadened to include services that were genuinely useful and necessary for a PWD's life.
- Trade unions regretted not having been involved in the project.
- Employers' organisations also supported the card, but felt it needed to be further developed. They also pointed to the danger of discriminating among PWD, as the % disability required for eligibility varied according to whether the disability was or was not acquired at the workplace.

GENERAL CONCLUSIONS AND RECOMMENDATIONS

- Stakeholders evaluated the card positively and supported its use
- DPOs had launched the process and were heavily involved in all its phases (planning, implementation and distribution).
- Participation of the social partners could have been greater, as this would have helped to broaden knowledge about the card. Social partners and other CSOs should be involved in a structured way, namely through participation in the national observatory on the situation of PWD, discussing further ways to implement the card.
- The main positive effect of the card was the introduction of a single document attesting disability status. It helped to simplify procedures and had potential to facilitate the identification of a single pathway to ascertain disability status.
- Since discrimination could arise from the fact that, in order to have the right to a card, different percentages of disability were required according whether the disability was or was not acquired at the workplace, it was recommended that it be granted to all PWD with 45% disability or higher.
- The possibility of extending use of the card to caregivers should be considered.
- The "European" Dimension of the card was not highlighted; this aspect could be developed through appropriate communication.
- The card was still only known about and used by a small minority. Work was necessary to increase communication about it and launch awareness-raising campaigns about both potential users and potential service providers, especially at regional and local level and in the private sector.
- The budget and resources should be adapted and increased appropriately.
- Other civil society institutions (namely the Patronati) should be included among the stakeholders who could make it easier to obtain the card, as these organisations reached a different public (often not accustomed to using digital services).

Thematic Study Group on Disability Rights Report

Mission: Virtual country visit to Lithuania: Transition to a fully inclusive educational system for people with disabilities

Date: 25 November 2021 and 26 November 2021

Format: Virtual

Members: BARBIERI, Pietro (GR III)
PETRAITIENĖ, Irena (GR II)
JONUŠKA Alfredas, (GR I)

Observer: Maureen Piggot, member of EDF's Executive Committee

Administrator: Valeria ATZORI (valeria.atzori@eesc.europa.eu)

25 November 2021

Meeting with public authorities

Ramūnas Skaudžius, Vice-Minister for Education

In 2020 LT decided to transition to a fully inclusive educational system by 2024. From 2024 on, conditions should be in place to enable all children with disabilities to attend mainstream schools. This does not mean that special schools will be closed. In case of a high degree of disability, they can also be useful. Parents will choose the best solution. The action plan is ready.

Main actions:

- Awareness-raising within society on inclusive education
- Increase assistance for school training of support teachers and adapt education processes (development of a self-evaluation system)
- Memorandum of understanding: every year a new, fully accessible school must be opened, and an existing school adapted
- Increased salary for support teachers and standardisation of number of hours worked in special and normal schools

- EUR 3.7 million earmarked to employ more support teachers; also support to buy material, technical equipment
- Increase medical staff and social services

Aistė Kairienė, Adviser for Education, Government of the Republic of Lithuania

- In addition to the law, to facilitate implementation there is an agreement among all parties on inclusive education. By end 2023 inclusive education should be tested in at least four municipalities
- The teaching assistance system will be developed with minimum standards
- Need for inclusive education starting at pre-school and to increase skills and competences of teachers. An indicator on universal design will be introduced

Filatovaite Lauryna, Advisor for Targeted Assistance at the Ministry of Social Security and Labour

By ratifying the UNCRPD, LT committed to inclusive education and tailored measures to achieve it.

Current situation:

Children with disabilities receive support adapted to the type of disability they have; they can also receive personal assistance to go to school and for extracurricular activities. Students can receive sign language interpretation, but the school must provide for it; reimbursement (EUR 228 or 312) or compensation according to the degree of disability. Students also receive an additional EUR 99 per month to cover expenses.

Audrone Dauksaite-Timpė, Senior advisor of the Legal Affairs Group at the Office of the Lithuanian Equal Opportunities Ombudsperson

The education law should come into force in 2024; complaints have been received from families of children with disabilities; some schools say they do not have skilled staff or the necessary competences.

It is not clear whether there is enough time to prepare for the transition by 2024.

Problems:

- A shortage of support teachers, but also changing the mentality of families, schools, teachers, and society. Municipalities should do more to help families, but they are still too passive
- An inappropriate environment at school, lack of accessibility of premises. For blind children the situation is even worse; non-formal education is not covered;
- Up to now, children with severe intellectual disabilities can study only until they finish general school at 16 and can then only learn a profession.

Edita Žiobiene, Lithuanian Ombudsperson for Children's Rights, and Audrone Bedorf, Senior Adviser

- This institution receives different types of complaints: parents of children who have difficulties when choosing a school and also parents who want their children to study in mainstream schools
- The problem of parents' mentalities - some complain about children with disabilities attending mainstream schools. We need to educate society to tolerate and accept diversity
- Problems in the health sector and service provision (mainstream schools do not offer activities the whole day) – facilities should be adapted and made accessible

Meeting with national and local authorities

Eglė Čaplikienė, Director, and Milda Kristina Mennea, Senior Counsellor, Department for disability affairs at the Ministry of Social Security

- The department develops social inclusion policies; many employers have joined the campaign to employ more PWDs; inclusive education is the basis for better access to the labour market
- Accessibility of schools and curricula is important for inclusion in society
- Information and equipment should be accessible; The Ministry of Education is in charge of this, and the Disability Affairs department provides proposals and observations

Jonas Mickus, Education and Culture Adviser, and Audronė Vareikytė, Social Adviser, the Association of Local Authorities in Lithuania

- Educational assistance in school is something new. Every year there are more and more PWDs in schools. To include them, we need to adapt the physical environment, improve skills of teachers, and parents need to understand the added value.
- A memorandum was signed among Lithuanian Disability Forum (LDF), the Association of Local Authorities, the Ministry of Education and the Ministry of Health Care to increase the accessibility of schools and health care facilities in municipalities. The four parties are responsible for monitoring, but often schools do not understand the accessibility needs for different impairments. We need specific criteria to evaluate the compliance and accessibility of schools, share best practices and better understand indicators
- First the level of disability is assessed, then the family addresses the municipality and they offer support according to the resources available; parents need to address municipalities and they indicate a school which is sometimes not close to home. In Vilnius only 7 out of 100 kindergardens are accessible to PWDs; further support such as transport can also be offered
- Problem: competence of support teachers and the need for individualised support
- There are exchanges among municipalities and among schools
- Funding comes via subsidies from the government; the association of municipalities negotiated with them to increase the amount. Support teachers have the same salary as normal teachers. Local authorities give funding to schools, but teachers are employed by the principal of the school
- The need for accessibility and a change in mentality
- The short time given to complete the transition and comply with all requirements
- Everybody needs to know what it is needed and the criteria; to adapt buildings is very expensive; maybe better to have one school adapted in each municipality instead of adapting them all, which would be too expensive

Meeting with DPOs and the UNCRPD Monitoring Mechanism

Dovilė Juodkaitė, Lina Garbenčiūtė, Vaišnora Kęstutis, Henrika Varnienė, Košel Patil Kristina, Lithuanian Disability Organisations Forum (LDF)

- The LDF is an umbrella organisation which reunites 16 LT DPOs; it aims to implement the UNCRPD in inclusive education; it has asked for a change in the law, which was discriminatory; now the challenge is to implement the new provision
- Problems faced in this transitional period
- Development of the plan: two years; the deadline is slightly short. Namely, for teachers who want to specialise in support teaching, the training takes time. action is preferable to speculation
- Lagging behind in universal design; politicians should be more involved and accelerate the process
- Preparation of specialised teachers is one of the problems faced. The special classes still indicated in the law are not inclusive; there is lack of cooperation among the various ministries involved
- Concern about accessibility for sign language; not only interpreters, but also teachers and families should learn sign language
- Educational content also needs to be updated
- Some schools show resistance, and do not know how to meet children's needs; it would be good if schools and DPOs could cooperate; many parents have also acquired experience and could share their knowledge
- There are no medical services in schools, even the special ones
- Staff refuse to give them food, so children cannot stay in school the whole day
- Often CWDs are grouped and put in the same class. There is a lack of competence among teachers; only 30% of teachers will attend dedicated training (according to the inclusive education plan drawn up)
- Society also seems not to accept diversity ; there is a lack of experts who can come to schools and teach CWDs and support the school

Kristina Dūdonytė, UNCRPD Commission under the Equality ombudsman's office

- This institution monitors the implementation of the CRPD
- There is a lack of support teachers; decision-makers are not very active in implementing the Convention but did set concrete goals; special schools should be closed, and not continue to exist; education should not end at 23, but there should be lifelong learning; teachers of special schools tend not to want to go to normal schools; there are no provisions to ensure lifelong learning; there is a lack of knowledge of the specific problems of PWDs; reskilling should also be covered; there is a need to reduce the number of children per class.
- There are discrepancies between regions: often a better situation in small municipalities, but also a provincial mentality; sometimes parents have low expectations of the possibility of education for their children; we need to improve awareness, including at kindergarden level - we should start inclusion there
- Teachers: classes are full, special needs children require a lot of attention
- Other parents: fear that their children will get less attention from the teacher, plus the belief that special needs children may pose a threat to their children's safety; plus parents themselves grew up without special needs classmates so it does not feel natural that all kids study together.

- Information and awareness-raising campaigns about inclusive education are very much needed
- Until now inclusive education depended on the goodwill of the school management. After 2024, there will be a legal obligation.

Meeting with Platform for Education and the teachers' trade union

Judita Akromienė, Director, the Platform for Education

Network of non-governmental educational institutions

We need measures and benchmarks.

Problems:

- The Ministry of Education does not believe that schools will be ready in 2024; they doubt that the benchmark will be achieved
- There is not enough money to implement the plan; preschool education is fragmented and few measures are planned for inclusion at that level
- When the plan was drafted, there was no cooperation with the Ministry of Social Security or the Ministry of Health
- Lifelong learning is not covered

Rūta Osipavičiūtė, Head of Vilnius Education Trade Union

Problems:

- Safety of teachers; they can be attacked by students with mental health problems, therefore many are scared
- Classes are overcrowded
- The attitude of children towards children with special needs; integration must start in pre-schools
- There are not enough support teachers or funds to hire them
- Curricula and textbooks are not adapted to children with special needs
- Bonuses for teachers are not enough
- Need to work on awareness raising
- Lithuanian Disability Forum could be proactive and meet teachers

26 November 2021

Meeting with representatives from inclusive schools

Dovilų general school, Director Arūnas Grimalis

- We need leadership at all levels, and experts, specialists on inclusive education
- We need to attract teachers from specialised schools
- Inclusion must start in kindergarden. An independent personality must be nurtured
- Teachers, parents and administrations are those who present more obstacles, not children

Dr Alvyra Galkienė and Dr Ona Monkevičienė, Professors at the Academy of Education, Vytautas Magnus University, Lithuania

- Invest in qualification of teachers, skills
- Need for more targeted approach (teacher qualifications)
- Individual approach for every child; allow them to develop the skills they have; they also have strong sides
- Universities are working on training teachers

Stanislovas Milašius, Director, Kaunas Gymnasium

- The institution has 110 students with special needs - four per class (ratio should be 1 in 100) There are assistants that work to support teachers and work with the entire class
- Graduates from their school come back to work there
- All children are included in all activities
- Need for a change of mentality, also in teachers. They have to be motivated
- Children with special needs also receive additional classes, such as speech therapy
- Need for a community approach; healthy children benefit from studying with children with special needs
- Use of music therapy, dog therapy, and help of parents

Aušra Puskunigienė, Member of the Board, Lithuanian Waldorf School Association

- There are four Waldorf schools in LT, with 1100 students; the schools have open for 25 years, are open to everyone, and are not curricular; they are private schools with a long waiting list. There are huge challenges for children with special needs

Challenges:

- Teachers decide if they accept a child in their class or not. If they do, there will be two teachers per class. There is also an assistant for special classes, offering e.g. speech therapy
- In adolescence it is more difficult to keep children in the main class; there are more difficulties of concentration
- We need an inclusive methodology
- There are few teachers, and they are overworked and burnout
- Private schools receive less funding than public schools.

CONCLUSIONS AND RECOMMENDATIONS

- The transition to a fully inclusive educational system is a positive development and goes in the direction indicated by the UNCRPD
- The short timeline to implement the necessary changes and the scarcity of financial resources represent a challenge
- The transition period is seen by some parts of civil society and by organisations of persons with disabilities and their families as a risk as objectives and timelines could easily be circumvented
- Inclusive education in LT excludes some people with disabilities, especially those with more severe disabilities
- There are also significant differences in the situation between bigger cities and rural areas
- For the transition to be successful, we need a change in mentality, among parents, teachers and the general population. Awareness-raising and sensibilisation activities should be carried out at various levels
- There is a need for political will and commitment by all stakeholders; relevant ministries should cooperate and communicate more among themselves; cooperation with DPOs and schools is also essential
- Inclusion should start at pre-school level kindergartens attended by these children, and schools for children with disabilities must be equipped with computers, smart watches, transport, etc.
- Diversity should be seen as an asset
- There is need for more support teachers and adapted curricula and methodology, and also improved working conditions and salaries to make the profession more attractive. Continuous training of teachers working with children with disabilities should also be available. Schools, programmes and services should be accessible for all, with universal design criteria.
- Lifelong learning and extracurricular activities should also be accessible and inclusive. It is necessary to change and improve learning textbooks for children with disabilities adapt the school environment, including leisure activities, to the learning of children with disabilities
- Funding needs to be increased for all schools providing quality learning for children with disabilities
- Setting goals with relevant benchmarks and indicators could be helpful in assessing whether a school is fully inclusive

Thematic Study Group on Disability Rights

Mission: REPORT - Virtual country visit to Germany: Good practices in social services for people with disabilities after COVID-19 in Germany

Date: 3 November 2021

Format: Virtual

Members: BARBIERI, Pietro Vittorio, Gr. III
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Meeting with public authorities

Adrian Hille, Social Service Provider Engagement Act, Focal Point for the implementation of the UN Convention on the Rights of Persons with Disabilities, Federal Ministry of Labour and Social Affairs

They followed the measures taken during the pandemic for PWD. The federal government has limited competences, only coordination. More power at "land" level.

Their observations were:

- PWD are at higher risk of suffering from severe forms of COVID-19, partly because many of them live in institutional settings;
- Reduced social contacts lead to loneliness and isolation and an increased mental health problems;
- Difficulty accessing information on the pandemic, especially at the beginning;
- Decreased income for PWD (many work in sheltered workshops);
- Difficulties for parents of PWD (schools closed, fewer services);
- Difficulties and loss of income for social service providers; however, they never stopped their services and came up with alternative ways to provide them;
- Digitalisation and digital services proved their worth.

Federal government response:

- Adoption of health measures (testing, vaccination, distribution of masks);
- Information made available in easy-to-read (ETR) and sign language;
- Support for employees in sheltered workshops (compensation of income, virtual elections of representatives);
- Support for parents – paid leave for childcare;
- Economic aid for social service providers (funds);
- Research and discussion with relevant actors.

Katrin Libelt, Federal Government Commissioner for Matters relating to Persons with Disabilities

Problems identified:

- Especially at the beginning of the pandemic, communication was often not accessible (e.g. press conferences without sign language, ETR written communication not available);
- Huge pressure on families and parents of PWD (schools closed, care facilities no longer provided);
- People living in institutions were isolated;
- Impact on healthcare and social services: at the start, there was a lack of PPE;
- Rehabilitation services and leisure activities not available during lockdown;
- lack of accessibility to vaccination centres and of communication on vaccination (ETR not available); Coronalert app was barrier-free from the outset.

Recommendations:

- improve accessibility and implement it from the outset;
- give priority to PWD for vaccination;
- home schooling of PWD;
- isolation and loneliness for people living in institutions when visits were banned; it could be avoided with testing;
- Raise awareness about the specific needs of PWD: for example, social distancing sometimes cannot be respected;
- Scope of the Disability Act on Social Services should be extended;
- Digitalisation offers many opportunities but needs to be accessible to all.

Jana Offergeld, Researcher and Policy Adviser, Independent Monitoring Body for the UNCRPD, German Institute for Human Rights

- Hard to assess the situation on the ground, especially in the first months and in the institutions: regional competences and communication difficulties, but they had several discussions with PWD and their organisations;
- PWD particularly affected by the pandemic and by containment measures; lack of disability mainstreaming in the government response;

- Differences among PWD living in institutions or in the community;
- In institutions: PPE was provided but delayed compared to institutions for older people; for vaccination, PWD living in institutions automatically had priority access;
- In the community: difficulty accessing PPE and testing; especially for people on a low income. For vaccination, they had to apply for a priority ranking, to be decided on a case-by-case basis at local level;
- Social isolation was a concern for PWD living in institutions. No more visitors were allowed and sometimes they were confined to their rooms, use of institutional restraint measures (violation of residents' right to participation and autonomy due to containment measures);
- Access to healthcare and intensive healthcare: triage situation: a fragility scale was established, with guidelines to give priority in terms of treatment to those at the bottom of the scale, with less risk. As PWD are among the more vulnerable social groups, it was feared that the guidelines might indirectly discriminate against them. Case brought to the court by nine PWD to ask for guidelines for the health workforce to ensure that PWD are not discriminated against;
- Cases were reported of triage before triage: PWD were not able to access hospitals and were treated in their institution;
- COVID-19 showed the healthcare system is not inclusive and accessible to all: there are barriers;
- Situation of carers: 80% are female and family members;
- There should have been stronger participation of DPOs on healthcare and feedback on legal measures affecting PWD;
- Education system in Germany is still segregated, no Personal Assistance schemes are available nor distance learning;
- Employment: some sectors shut down, sheltered workshops were particularly affected, no access to compensation;
- Big issue of segregation; higher risk of infections, isolation and lack of participation;
- Recovery process: risk that PWD are excluded; there should be more targeted actions.

Recommendations

- More efforts to mainstream disability in the government response;
- Include DPOs in the decision-making process from the very beginning;
- Provide accessible information;
- Participation and involvement of PWD and their organisations should take place at each level: in institutions, in the community, at local, regional and federal level;
- Recognise the diversity of PWD, their differences and their different needs;
- Problems were there before the pandemic; despite the ratification of the UNCRPD, discrimination still exists.

Meeting with representative sheltered workshops

Katharina Bast, German Federal Association of Sheltered Workshops (BAG WfbM' (Bundesarbeitsgemeinschaft Werkstätten für behinderte Menschen)

- Sheltered workshops were closed at the beginning of lockdown to protect the PWD working there. However, it would have been better to assess the situation of each group and their respective needs, which are not necessarily the same. This closure resulted in loss of income and social contacts;
- Some workshops were exempted from closure because they were considered system-relevant; others were not, like service providers, laundry and catering;
- Work in sheltered workshops should be digitalised wherever possible; this would have enabled some people to telework. Digital skills of PWD should be improved, training provided.

Recommendations:

- Take into account the experience of the first lockdown;
- DPOs, service providers and PWD have to be involved from the beginning;
- Recognise the different needs and support needed according to the type of disability;
- Communication should be accessible;
- Digital support should be provided;
- Avoid excessive red tape and bureaucracy regarding reimbursement and funding to make them more easily accessible to PWD.

Antje Welke, Legal Officer and Head of the "Concepts and Law" Department, Lebenshilfe – NGOs for Pw mental disabilities

- Persons with intellectual disabilities had no priority for masks, testing or vaccination; no communication in ETR was available;
- Families during lockdown had to choose: take care of their PWD at home or not see them at all if they lived in institutions;
- From the beginning, a different approach was needed: extended testing for PWD living in institutions, staff and visitors but it took time, partly due to lack of funding;
- During lockdown, no analysis of needs was performed by the authorities;
- Digitalisation: persons with cognitive disabilities more affected by the lack of contacts;
- Emergency assistance for families: not enough; also to prevent violence; no widespread support for PWD or long waiting lists;
- Healthcare and rehabilitation services; healthcare system is not barrier-free, both in hospitals and with GPs. Physical obstacles to accessibility and obstacles to people with cognitive disabilities;
- Digital participation: PWD have learnt and this improved their participation but they need to be offered more support;

- Different rules to access benefits according to the state/lander; too much red tape;
- Participation: for each new rule, DPOs had to contact the government and insist that PWD be given priority: need to promote the digital aspect with adequate funding; barrier-free communication; need to guarantee that PWD participate, and to consult those living in institutions; this would lead to greater acceptance of the rules;
- Authorities should be more aware of the situation in institutions and the services available; the situation has now improved, but was bad at the start of the pandemic.

Debate:

Strong fear of being infected, therefore lockdown was accepted, but the question is if PWD received the necessary equipment and if they were asked what they needed. In the institutions, the question was how lockdown could be applied in a reasonable way. Visits had to be stopped, rules were sometimes too strict.

Participation: in institutions, there is self-representation of PWD, they should have had a voice on the measures.

Schools: internet connection can be a problem; also availability of hardware and software; need to strengthen digital participation; some people are excluded from digitalisation because they cannot afford expensive devices.

Social ministry had regular meetings with DPOs, which was good; but the health ministry had no participation at all.

Support measures for families and community-based services should be strengthened; a certain number of hours of social services could be covered by the state, maybe via the tax system; there is a need for a different social system to take the burden away from families and compensate their loss of income.

Red tape in application for funding should be reduced.

Meeting with sheltered workshops representatives and service providers

Johannes Herbetz, Head of the Board of Members, and Jan Brocks, Workshop councils Germany - Werkstattträger Deutschland

- Impact of COVID-19 on rights of PWD: not a lot of accessible information in sign language or ETR; sheltered workshops were forgotten; no financial support in the first months;
- Isolation, lack of assistance and interpreters; ad hoc solutions were found but not satisfactory;
- What worked well: vaccination programme, priority given to PWD in workshops;
- What could be done better: take into account and involve PWD at all stages, mainstreaming disability in all policies and actions; accessible communication; co-determination in managing the crisis; financial support to be improved; solidarity.
- Some people could work from home, but danger from isolation. Talk with people concerned and ask what are their needs;
- Initially, the main problem was isolation; information was not available in ETR or sign language;

- Lessons learned: in the second lockdown, there was no ban on personal contact and a more nuanced approach; importance of disability mainstreaming and of involving PWD in any taskforce or decision making from the beginning; accessible communication.

Annett Löwe, Referentin, Caritas Behindertenhilfe und Psychiatrie e.V. (CBP)

- PWD were forgotten at the beginning of the pandemic; the health minister did not look at PWD as vulnerable people to be treated differently from older people. No specific measures for PWD at the beginning. For PPE, vaccination and testing: there was no specific focus or priority. Difficult to get support from the social security system (red tape), particularly for people with intellectual disabilities or multiple disabilities in institutions; no physiotherapy was available at the beginning. Difficult for them to understand why they had to wear masks;
- Need for better technical equipment for PWD (free software and hardware);
- Support from Europe is needed, not only funds, but also to pressure the Member States to include PWD from the beginning; they cannot be left without social contact; psychological support for people in sheltered workshops was not negotiated.

GENERAL REMARKS:

Few recommendations were put forward, both in general and for the EU;

Organisations met were mostly service providers or representatives from sheltered workshops: no DPOs were met.

RECOMMENDATIONS

- Participation of PWD in decision making should be ensured at all levels from the start;
- Communication should be inclusive (use of ETR and sign language);
- Need for tailor-made approach – different disabilities require different measures;
- Avoid excessive bureaucracy when accessing support measures;
- Support families taking care of PWD;
- Digitalisation can play an important role in the inclusion of PWD, namely in education, employment and e-health. Adequate measures should be adopted to boost access to digitalisation by PWD;
- Sheltered workshops seem not to be inclusive – invest more in measures to include PWD in open labour market.



**Towards a European Health Union & European Global Health Strategy
fully inclusive of Persons with Disabilities**
**Vers une UE de la santé et une stratégie globale européenne en matière
de santé pleinement inclusives pour les personnes handicapées**
07.03.2023 | 9:30 – 13:00 | Virtual public hearing / Audition publique virtuelle

REPORT

Despite the fact that the right to enjoy the highest attainable standard of health is recognised by the UN Convention on the Rights of Persons with Disabilities (UNCRPD), persons with disabilities (PWD) are still victims of discrimination in access to healthcare both in the EU and globally. The hearing, organised by the EESC Permanent Group on Disability Rights, addressed what can be done to advance the rights of PWD in the field of health within the European Health Union and the EU Global Health Strategy.

Panel 1: Access to health for PWD in the EU

This first panel explored the barriers to healthcare faced by persons with disabilities, and measures taken at EU level to ensure better access.

Speeches

- **Setting the scene: healthcare needs and barriers faced by persons with disabilities – Hannah Kuper, researcher**

Ms Kuper started her presentation with some data on disability, noting that 16% of the world population have a disability, and that disabilities can be wide-ranging and diverse. Persons with disabilities have greater healthcare needs and face greater challenges in access to healthcare and

experience worse health outcomes, such as a higher risk of diabetes, malnourishment and low life expectancy, among others. This can be seen in health data from the COVID-19 pandemic: PWD constitute only 16% of the UK population but made up 59% of COVID victims. Their mortality rate is 2-fold higher, with a life expectancy gap of 10 to 20 years.

This implies that SDG 3 is far from attained, and that states have failed to maximise the quality of life of PWD in line with international human rights laws and to improve health services for all. This has also affected attaining other SDGs, as ill health hinders education and employment, for example.

To improve health equity for PWD we need to act on various fronts and address inaccessible facilities, the lack of accessible transport, financial barriers, the lack of proper assistive technology, stigma and skill deficiencies among healthcare workers.

She then outlined the characteristics of an inclusive healthcare framework: the need for laws and policies protecting the rights of PWD, representation within the Health Ministry, and available health financing. Persons with disabilities must be enabled to make their own decisions, afford healthcare and be provided accessible infrastructure. In turn, health workers must be knowledgeable on disabilities and the difficulties that those with disabilities face in their day-to-day lives.

- **Mental health is health: for a strategy on mental health – Guadalupe Morales, Mental Health Europe**

Ms Morales is an activist with lived experience of mental health issues.

In the EU, PWD are still denied their right to access healthcare on equal footing as the rest of the population. The existing legislative framework on anti-discrimination only recognises discrimination on the basis of disability in employment, but not in other areas such as healthcare.

However, the EU has ratified the UNCRPD and has therefore committed to protecting the rights of PWD in all areas. Nonetheless, PWD continue to be exposed to coercion, forced treatment and involuntary placement, with women with psychosocial disabilities also suffering forced sterilisation, which remains a practice in use across Europe. Similarly, substitute decision-making schemes and the deprivation of legal capacity are still considered to be a viable last resort in virtually all EU Member States. These practices make it hard to obtain adequate information, and take away people's ability to give informed consent and also give a person's preferred choice very little weight. They have a substantially negative impact on the right to health and the overall well-being of individuals.

The upcoming EU initiative on mental health has the potential to address some of the barriers faced by PWD in healthcare. For the measure to be effective, mental health needs to be addressed as a continuum in one person's life, and in an integrated manner across various policy areas.

Mental healthcare should be provided in the community and be based on free and informed consent. Institutionalisation, coercion and forced treatment and placement are human rights violations. EU funds can greatly support Member States to develop and deliver systems that respect human rights.

The European mental health strategy must have a clear timeline, adequate budget and objectives, as well as indicators to monitor progress. Persons with disabilities must be involved in all processes from the beginning, and adequate public funding should be made available to organisations representing them.

- **EU actions to ensure the right to health of persons with disabilities – Christine Redecker, Directorate-General for Health and Food Safety (DG SANTE), European Commission**

Ms Redecker introduced the topic of her presentation by saying that in the EU, on average 4.4% of people with mild to severe disabilities had unmet medical needs in 2020. The main reasons related to costs, traveling distances and waiting times. This level of unmet needs is 2.5 times higher than that of the overall population. The COVID-19 pandemic worsened this situation.

In response to this the European Commission adopted the European Health Union, the objectives of which are to better protect the health of citizens, to equip the EU and its Member States to better prevent and address future pandemics, and to improve the resilience of Europe's health systems. The EU wants to protect the most vulnerable groups, including PWD. This is reflected by the EU's adherence to the UNCRPD and to its favourable view of the Resolution on the WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030. Health systems should be people-focused, data-enabled and based on the core principle of equity.

The EU has also adopted its disability strategy for 2021–2030. An evaluation of the previous strategy showed that accessibility to healthcare was not sufficiently prioritised, and that there were not enough measures in place to ensure adequate access to healthcare services. The EU is trying to address these shortcomings in the current strategy, focusing also on EU support to national, regional and local authorities regarding de-institutionalisation. The support instruments come from the 2021–2027 shared management funds, the Recovery and Resilience Plans, and the Technical Support Instrument. In the field of access to healthcare for PWD, the Commission is launching an action under the EU4Health programme, which will produce guidelines on access to healthcare for people with disabilities. The objective of the project is not only to produce guidelines, but to bring it to implementation level. This will be done through interactive workshops with Member State representatives and organisations representing PWD. As part of this action, data will be collected on access to cancer screening and care for people with disabilities. This data will feed into the European Cancer Inequalities Registry, a flagship initiative of Europe's Beating Cancer Plan.

Of course, the provision of healthcare remains a national competence, and thus the European Commission calls on Member States to close country-specific gaps and improve their health systems through the European Semester. Member States can use funds, including the Recovery and Resilience Facility and cohesion funds, to modernise their health systems and improve access to healthcare.

- **The importance of involving persons with disabilities: Pirkko Mahlamäki, European Disability Forum**

Ms Mahlamäki stressed the importance of involving PWDs in designing, implementing and monitoring health policies, including training healthcare professionals. The latter should be given the possibility to interact with and meet people with different disabilities and in different life situations, which could help to avoid stigma. A disability-inclusive approach should also be taken to prevent abuse and protect the sexual and reproductive rights of women and girls with disabilities. She also highlighted that there are various forms of disability that come with different needs, and that all should be equally considered. Although some differences in health outcomes can be explained (to some extent) by the

underlying health conditions or impairment associated with disability, a very significant proportion are largely due to unjust factors that are avoidable and can be eliminated. In addition, measures benefitting PWDs will also benefit many other population groups.

Panel 2: Access to health for PWD outside the EU: EU Global Health Strategy

The second panel discussed the new EU Strategy on Global Health and addressed the following questions.

- How does the EU plan to match its commitments under the European Health Union with its global responsibilities under the European Global Health Strategy?
- How will it include the voices and the participation of persons with disabilities?
- How will it continue strengthening its strategic dialogue with the WHO and with the EU Member States to ensure global health for all?

Speeches

- **Setting the scene: global health for all, including persons with disabilities – Sarah Collinson, International Disability Development Consortium (IDDC)**

Ms Collinson started her presentation by stating that health inequities for persons with disabilities result from unfair and unjust conditions and are compounded by other intersecting factors, such as age, gender, race, sexual orientation, socio-economic status, displacement or migrant status. PWDs are more likely than others to live in poverty and to find healthcare unaffordable or to face overwhelmingly high health costs. These inequities are intensified during disasters, humanitarian crises and health emergencies. People with psychosocial or intellectual disabilities, older people and women and girls with disabilities are among the most left behind by health systems. Health inequities are avoidable, and promoting health equity for persons with disabilities benefits everyone. Ms Collinson outlined some measures that could be taken to overcome such inequalities, such as strengthening health systems and advancing UHC, improving disaggregated data collection and mainstreaming disability in health.

- **What does the WHO plan to do to bring us closer to a disability-inclusive global health order? – Satish Mishra, World Health Organisation (WHO)**

Mr Mishra outlined WHO action that would build disability-inclusive health systems worldwide. The WHO adopted various measures in 2022, namely the [WHO European resolution on the highest attainable standard of health for persons with disabilities](#), the [WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities](#) and the [Global report on health equity for persons with disabilities](#). To make health equity for PWDs a global health priority it needs to be brought to the attention of decision-makers in the health sector, and evidence on health inequities needs to be rigorously documented. The framework comes with a detailed implementation plan and a monitoring evaluation framework with 14 targets and 51 indicators of progress and success,

which should help countries achieve the objectives. It is important to note that the government alone cannot achieve the full inclusion of PWDs. Cooperation among all societal actors is important.

- **EU Global Health Strategy: how it plans to advance the rights of persons with disabilities in access to health globally – Directorate-General for International Partnerships (DG INTPA) and the Directorate-General for Health and Food Safety (DG SANTE) – Marten Kivi, DG INTPA**

Mr Kivi outlined the Global Health Strategy adopted by the European Commission in November 2022, which positions global health as an essential pillar of EU external policy and represents the external dimension of the European Health Union. It relies heavily on the Team Europe approach, meaning the Commission will work closely with Member States, government agencies and European financial institutions. The strategy seeks to regain lost ground in order to reach the universal health-related targets in the 2030 Sustainable Development Goals. To do so, the strategy refocuses action on achieving universal health coverage, strengthening primary healthcare and eliminating the root causes of ill-health (such as poverty and social inequalities) by acting on the social determinants of health in accordance with the 2030 Sustainable Development Goals. It has three overarching priorities: to deliver better health and improve the well-being of people over the course of their lives; to strengthen health systems and advance universal health coverage; and to prevent and combat health threats, including pandemics, applying a One Health approach. The strategy is compliant with the UNCRPD, as it takes a human-rights-based approach, leaving no one behind. In addition, all projects are assessed and scored against the [OECD disability policy-marker](#).

- **National health strategies: how will they align with the EU's commitments? – Jesús María Martín Blanco, Spanish Ministry for Social Affairs**

Mr Martín Blanco presented the Spanish national health strategy. Focused on prevention and on promoting the health of people with disabilities, the plan has a budget of almost EUR 140 million. Spain's health policies are based on universal and the free provision of public services, on human rights, a person-centred approach, a gender perspective and on independent living. The plan aims to enable those with disabilities to live independently and be included in the community through accessible and community-based housing and services. Special attention is given to the sexual and reproductive rights of women and girls with disabilities, namely in the form of legal safeguards. Furthermore, forced sterilisation and coercive abortions are considered violence against women.

CONCLUSIONS AND RECOMMENDATIONS

To enable persons with disabilities to fully enjoy their right to access to quality healthcare, the following actions are needed.

- Put in place and enforce laws and policies protecting the rights of persons with disabilities.
- Overcome existing barriers in inaccessible facilities, the lack of accessible transport, financial barriers, the lack of assistive technology, stigma and skill deficiencies among healthcare workers by investing in universal design, community-based, people-centred, human-rights-based and whole-of-society approaches.
- Put in place appropriate health financing instruments addressing health inequalities.
- Establish training for healthcare workers on the needs of persons with disabilities in order to fight stigma.
- Incorporate a disability- and gender-sensitive and inclusive approach in health by consulting with and actively involving persons with disabilities and their representative organisations.
- Ensure adequate public funding for the organisations representing persons with disabilities.
- Make health infrastructure, services and communication about health accessible to all.
- Collect disaggregated health-related data to make informed decisions in relevant policies and programmes.
- Take measures to ensure comprehensive, accessible and affordable access to health systems and care for all persons with disabilities, while recognising unique vulnerabilities in times of public health emergencies.
- Adopt intersectoral and multisectoral actions, as the government alone cannot achieve the full inclusion of persons with disabilities.
- Foster partnerships and international cooperation.



**Climate justice: how it is affecting
people with disabilities
in Europe and in the world**

**La justice climatique et son incidence
sur les personnes handicapées en
Europe et dans le monde**

19.10.2022 | 9:30 – 13:00 | JDE 62 | Virtual public hearing / Audition publique virtuelle

Permanent Group on Disability Rights

REPORT

Panel 1: The views of the EU and international organisations

Moderator: Marie Zvolská, Member of the Permanent Group on Disability Rights

Speeches by:

Stefanie Dannenmann-Di Palma, UN Office for Disaster Risk Reduction (UN DRR)

- Unless changes are made, by 2030, the world will have 560 disasters per year and an additional 100.7 million people will be pushed into poverty.
- Vulnerability to disasters is entirely determined by humans – we can reduce exposure through effective early warning, provision of temporary shelter or reviewing infrastructure, for example.
- Governments' commitment to SDGs, will help in preventing disasters. Achieving the SDGs to end poverty, have zero hunger and reach gender and disability equality, will help in making progress to prevent disasters, as it is the underlying vulnerability of people and systems that turns a hazard into a real disaster. However, we are not on track for achieving the SDGs. Greater political will and stronger ambition are key.
- Referred to the Sendai Framework for Disaster Risk Reduction which calls for a human rights-based approach that is inclusive of and accessible to persons with disabilities (PwD).
- Persons with disability are often socially and logistically isolated, lack access to evacuation warnings and appropriate transportation, and lack any medical equipment necessary for their well-being.
- Referred to the Global Platform for Disaster Risk Reduction which was held in Bali in May. The number of participants with disabilities in this event has almost doubled.
- Mentioned some findings from the EDF's review of disability-inclusive disaster risk reduction policy, which concluded, amongst other things, that out of the 55 countries included, only five had demonstrated attempts to develop disability inclusive DRR policies in line with the Sendai

Framework. This shows that accelerated action is needed to reduce the disproportionate impact of disasters on PwD.

- Engagement of disability communities is critical, to ensure that strategies are inclusive and that data is disaggregated.

Franco Pinto, European Climate Pact Ambassadors (speaking on behalf of his son Rinaldo)

- Mentioned that speaking about the environment and disability, is not popular in the media, as it lowers proceeds from publicity. On the other hand, speaking of gossip is more lucrative.
- They created a project – "Un alberello in più", which involves other people with disabilities and marginalised people. They have also worked with mayors. In cities, they involve associations, thus raising awareness on social inclusion and the environment. They work with young children and ask them about the actions they take for the environment. Climate change has an impact on psychology as it is a source of stress and worry.
- Mental health issues will likely increase. We know, however, that politics and policies take time and for the enacted measures to have an impact.
- Disabled people are not included in the aid and emergency plans when a disaster takes place. Policies need to protect and include disabled people and their rights, and a change is badly needed.

Monica Silvana González, Member of the European Parliament

- We need to focus on the needs of the most vulnerable, including PwD. We need to tackle climate change as a cause of migration and as a phenomenon that directly or indirectly threatens human rights, including accessibility. The most vulnerable are the ones that are most affected.
- The EP has carried out work in this regard, but the concept of "climate refugee" still lacks definition. She mentioned that there is a direct link between the effects of climate change and migration. The risk to life threatened by climate change should be among the eligibility criteria for humanitarian protection. Disasters are becoming more and more frequent. Climate-related justice needs to be promoted and developed as soon as possible.
- Despite gaining prominence on the European agenda in the last years, there is not yet a defined strategy for the inclusion of disability in humanitarian action. Whilst the new European Disability Strategy has committed to ensure that the needs of PwD are adequately addressed in EU-funded humanitarian aid, this does not set targets, priority areas or specific dates.
- She mentioned the EP's call for an updated and specific strategy on the impact of climate change, including to increase financial support for disaster prevention and preparedness. There also needs to be a Development and Humanitarian Aid Policy with gender-perspective and sensitivity to disability, which addresses geographical vulnerabilities.
- She mentioned the need to define a strategy in humanitarian action, including basic information in easy-to-read QR, and training key humanitarian actors in sign language.

Q&A

Ms. Petraitienė: It is important that there are safety measures to enable PwD to receive the assistance they need in cases of disasters. In Europe, they should have equal conditions to be able to live a fully-

fledged life. Mentioned that in Italy they have a disability card, but that the validity of this card should also extend to other European countries.

Ms. Dannenmann-di Palma: They have a programme called "Making cities resilient". They will be launching a toolkit in December on how to include PwD in plans for cities and on how to consult PwD, as many do not know how to include them, even though they are committed to the disability agenda.

Panel 2: The views of civil society organisations

Moderator: Fernando Mauricio Carvalho, Member of the Permanent Group on Disability Rights

Nadia Hadad, Executive Committee member, European Disability Forum (EDF)

- Accessibility is a basic human right and having this from the outset will lead to better outcomes. Measures need to be taken so that PwD can make sustainable choices – rail transport, air transport etc.
- It is important that the rights of PwD are included in climate goals – communication and participation in reaching these goals have to be inclusive.
- All persons have to have the necessary capacity to adapt to climate change, mobilise sufficient resources, and ensure equity in climate action. The transition to a green economy should be done in a way that promote security and inclusion for PwD, and they should have the tools for this participation. Training is crucial.
- Funding for adequate measures for the inclusion of women and children with disabilities. No measures that are counterproductive to PwD should be taken without their consultation. Certain plastic items that are crucial for PwD will no longer be produced.

Kamil Goungor, European Disability Forum Youth Committee

- He looked at the issue of climate justice from the disabled youth perspective. Although young people are at the forefront in the fight against climate action, the disability perspective needs to be taken into account.
- The impact of the effects of the energy crisis and of the cost of living is higher, given the very low employment rate and insufficient, and sometimes inexistent, state support.
- He mentioned the importance of including disabled youngsters in the European Solidarity Corps and voluntary projects. This way, young disabled activists working on climate change can get skills and experience to defend the inclusion of disability within the green transition.

Mary Keogh, Christian Blind Mission (CBM) Global Disability Inclusion

- She mentioned actions that her organisations are working on, including actions that focus on COP.
- Spoke about the need for funding for climate mitigation and infrastructural changes, and the need for disaggregated data which includes PwD. Working in partnership with OPDs is important to articulate the changes that are needed.
- Mentioned some research that has been carried out this year, including in the context of the Pacific disability forum.

Q&A

In response to a question on who to begin further cooperation on climate justice with (question from Ms. Sif Holst), CAN International was recommended, as it is a large organisation with over 1800 affiliated organisations. EDF, European Disability Forum, is important since it speaks on behalf of PwD. Local organisations in cities are good, as there can be more action at a local level. Having a public call for such involvement would be helpful in order to involve as many organisations as possible (even smaller ones). Countries have obligations both in climate change and human rights, and Member States need to be reminded of this. The disability movement has to make use of these documents to create a movement for change.

Ms. Dovile: the community of PwD needs to be strengthened via human and financial resources.

Franco Pinto: There needs to be a centralised system for invitations to such events to increase the involvement of PwD in their action in favour of the environment.

CONCLUSIONS AND RECOMMENDATIONS

- Adopt a clear definition of "climate refugee" and further develop climate justice.
- Disaster risk reduction policies need to integrate a disability perspective and promote inclusive decision-making based on data disaggregated by sex, age, and disability. Data is needed to understand the situation and to shed light on the policies that are needed.
- Accessibility should be taken on board from the start of every action taken. This should include communication, instruments for participation and access to training.
- People with disabilities and their organisations should be involved in the planning, implementation and monitoring of any action affecting them in the field of climate justice, as well as in the transition to the green economy.
- Within EU-funded humanitarian aid, specific targets, priority areas and milestones should be defined, taking into account the needs of PwD.
- Update the strategy on the impact of climate change and adopt a Development and Humanitarian Aid Policy which is gender and disability inclusive.
- The knowledge and leadership skills of women and PwD are essential for building resilient, inclusive and equitable societies and should be taken into account.



Virtual public hearing

Transport accessibility for persons with disabilities

Audition publique virtuelle

Accessibilité des transports pour les personnes handicapées

23/06/2022 | 9:30-13:00 EESC/CESE - JDE 60



Permanent Group on Disability Rights

REPORT

The aim of the event was to reflect on which steps the EU could take to make progress on this topic, in particular by identifying the existing barriers and obstacles and good practices. The hearing also aimed to offer a space for debate to organisations representing persons with disabilities and other stakeholders.

Introduction by Pietro Barbieri, President of the EESC Thematic Study Group on Disability rights (TSG DIS) and Dovilė Juodkaitė, member of the TSG DIS

Panel 1: The view of EU

Moderator: Marie Zvolská TSG DIS Member

Interventions by:

Inmaculada Placencia Porrero, Unit for Disability and Inclusion, DG EMPL, European Commission

- Presented the framework provided by the European Accessibility Act (EAA), which covers services and products.
- Services: regarding transport, certain elements of air, bus, rail and waterborne passenger transport services (namely: websites, mobile device-based services, electronic tickets and ticketing, transport service information. For urban, suburban and regional transport services, only interactive self-service terminals are covered by the Act.

- Products: self-service terminals are covered, namely payment terminals; automated teller machines; ticketing machines and check-in machines.
- Other elements covered include: for emergencies, calling the single European emergency number 112; built environment is optional; public procurement for products and services in the EAA and EU acts containing accessibility obligations (so-called "presumption compliance").
- The EAA is not a replacement for obligations under other EU legislation.
- Link with transport legislation in Art. 5.
- Transposition deadline almost over, then assessment; implementation max. 6 years after entry into force (2025).

Eddy Liegeois, Head of Unit B.1 on Transport Networks, DG MOVE (TEN-T)

- The TEN-T policy is based on 2013 EU guidelines that defined the technical requirements for the planned transport infrastructure and the network layout. Network construction is also supported through EU funding, including the dedicated Connecting Europe Facility programme.
- Having evaluated the progress on TEN-T implementation, the European Commission put forward revised TEN-T guidelines in December 2021, to ensure sustainable connectivity through a reliable and high-quality infrastructure network, aligned with the objectives of the European Green Deal. MS are obliged to make transport accessible; particular effort to ensure accessibility of infrastructure.
- As co-legislators, the European Parliament and the Council will have to agree on the final form of the proposed regulation.
- A general approach in the Council is expected in December, the EP has started work on it (two rapporteurs, from the IMCO and TRAN committees); the IMCO report will be adopted in July and has a stronger focus on disability; trilogue will start in 2023.

Marton Spohn, Desk Officer, Unit on Rail Safety and Interoperability, DG MOVE (TSI-PRM)

- Technical Specifications for Interoperability (TSIs) are legislation directly applicable to everybody in the rail sector and do not require implementation, but proper enforcement.
- Harmonisation and interoperability within the Single European Rail Area ensures smooth crossing of EU borders and major transport nodes.
- After decades of TSIs, low interoperability of infrastructure is still the barrier to an accessible railway market.
- Commission policy remains to ensure gradual transition to target system.
- Proposed new approach is currently heavily discussed with Member States.

Elisabeth Kotthaus, Head of Unit B.5 on Social Aspects, Passengers' Rights and Equal Opportunities, DG MOVE

- Article 9 of the UNCRPD imposes an obligation to ensure access of persons with disabilities, on an equal basis with others, to transportation.
- Transport policy: the EU has shared competence with Member States, therefore measures are taken at EU level as well. Four Commission initiatives listed in the EU Disability Strategy 2021-2030, in the chapter on accessibility (review of passenger rights, TEN-T, Inventory of Accessible Rail Assets, Sustainable Mobility Planning in the new Urban Mobility Package).
- Passenger Rights include non-discrimination, free assistance and accessible information.
- [New European Urban Mobility Framework - COM\(2021\) 811 final](#) provides guidance for local action on sustainable mobility.

Recent developments in 2021 include:

- Adoption of the Recast Rail Passenger Rights Regulation [(EU) 2021/782], strengthens the rights of PRM.
- Evaluation of three passenger rights regulations covering PRM rights when travelling by air, waterborne and bus and coach transport.
- Good practices study on passenger rights covering all transport modes.

In 2022:

- Call for Evidence [Better protection for passengers and their rights](#).

Katrin Langensiepen, member of the Disability Intergroup, European Parliament

- The existing legal framework is not comprehensive and accessible transport is not a reality everywhere in the EU.
- We need to call for a new accessible EU centre composed of experts including DPOs to advise MS.
- The EU Disability Card can be an important step.
- Prior notification still represents discrimination towards PWDs, even if the deadline has been reduced from 48 to 24 hours before travelling.
- It is about political will and how cities are planned, PWD need to be involved.

Q&A

It would be useful to introduce accessibility requirements in airports outside the EU where European airlines operate.

Rules cannot be optional, otherwise often they are not implemented.

Panel 2: The views of civil society organisations

Moderator: Fernando Mauricio Carvalho, TSG DIS Member

Interventions by:

Thekla Georgiou, PRM & Customer Care Officer, Larnaca Airport, Winner of the Accessible Airport Award

- Hermes Airports manage the two international airports on the island: LCA is the major airport and PFO in the West is a smaller tourist airport.
- New terminal buildings were constructed in 2008 and 2009 and accessibility and special assistance were taken into consideration in the design. Prior to opening, they were inspected by the strategic partners of the airport and the local disability organisations which provided us with their suggestions.
- They have been awarded the title of "Accessible Airports" for two years in a row, in 2017 and 2018 ; this was possible thanks to the cooperation with the service provider, the broader airport community and disability organisations in Cyprus.
- Their accessibility goals are to meet and exceed the requirements of the regulations, to involve passengers with disabilities in the process as well as to work collectively with all the airport stakeholders towards accomplishing our goal.
- Their assistance services are organised around three pillars: comfort, safety and dignity.
- There are designated help points at Lca & two at PFO located in the parking lots and the entrances of the terminals, where people may call for assistance and an agent will go to escort them into the building. An audio and animated video showing the assistance process is played on screens, which are also equipped with buttons in Braille, so they can be used for persons with hearing or vision disabilities.
- There are also purpose-built blind paths, bright yellow in colour to provide a "high contrast", guide people with visual impairments from the parking area, right up to the special assistance desks inside the airport terminals.
- Charging stations are also available for all types of sockets where PRM can charge their electric powered wheelchairs or scooters.
- Desks at a lower height at immigration and migration booths.
- Self-service kiosks for passport control, suitable for wheelchair users.
- An innovative system, placed at an accessible toilet block, is the "ADI Roommate". This is an electronic device, custom-made for each room, which gives a bespoke description in English and Greek to aid navigation into the room for persons with visual impairments. This device was endorsed by the Cypriot blind association and feedback was received by the people who use it.
- In October 2018, they built the first "Changing Place" in Cyprus, for use by persons with multiple and profound mobility and mental disabilities and their escorts/carers. It is equipped with a hoist, changing table, shower facilities in addition to a toilet and washbasin. In March 2020, we also built

the same room at Pafos airport. The rooms were inspected and accepted by the Cypriot paraplegic organisation as meeting the best international practices.

- I CAN FLY programme for persons with autism. With this programme, priority is given to all airport procedures for arriving and departing passengers. Relevant material such as a storybook and a checklist are available on the Hermes website for parents to download and practise with their children, like a game, before they travel.
- All of the airport community has been trained to use this programme so that they recognise the "Blue hat" and give priority to the persons with autism.
- They also organise awareness-raising activities on Autism Day (2 April) and the International Day of PwD.
- Sunflower Lanyard Scheme: designed to assist people with hidden disabilities.
- new & upgraded Hermes Airports website, which offers easier and faster navigation, a structured design and is accessible to people with visual impairments, reduced mobility and disabilities.
- Training for frontline staff: Disability and Equality Awareness Programme; engages all airport stakeholders; endorsed by disability organisations
- Cooperation with DPOS: seeks their feedback by inviting them to present new facilities and innovations.

Marie Denninghaus, Policy Coordinator, European Disability Forum (EDF)

- They hoped the EAA would have had a broader scope; implementation of existing rules is also a problem; MS sometimes not implementing correctly, not all transport modes are covered; patchwork of laws; progress since first version of TSI but still many exceptions; problem of platform heights; new infrastructure should not be inaccessible; incorporate accessibility from the start and include DPOS; major shortcomings in airports; PwD are still denied boarding.

Gaps:

- Horizontal coordination needed and legislation in all transport mode/infrastructure including urban transport.
- Focus on air travel in passenger rights.
- Foster collaboration among different services in the EU institutions.
- Confusing instructions for operators in the procurement process; need for clearer guidelines.
- European standards not inclusive yet.

Blaž Pongračič, Senior Policy Adviser Passenger, Community of European Railway and Infrastructure Companies (CER) and Linda Ristagno, Assistant Director, External Affairs/Global lead accessibility, IATA(Airlines)

- Accessible and inclusive aviation is not just about people with disabilities or older people, it is about everyone. IATA's position on EU Regulation 1107/2006 on the rights of disabled persons and persons with reduced mobility when travelling by air:
 - Review of definitions

- Address the issue of pre-notification
- Wheelchair assistance
- Medical documentation
- Pre-notification
- Assistance dogs
- On the EAA, EU Accessibility Act:
 - Aviation stakeholders to be included in consultations
 - Cross-sector WGs
 - Clarity and certainty in the application of the Directive
 - Consistency between European Accessibility Act and Regulation 1107
 - "Start small first" principle
 - Phased approach with initial leniency in case of non-compliance
- Landmark Resolution and Principles:
 - Safety #1 priority
 - Dignified travel
 - Consistent, global approach
 - Appropriate training
 - Multi-stakeholder coordination
 - International reach
 - Understanding of operational realities
- The future
 - Raise awareness, commitment and resources from airlines' senior management
 - Addressing the regulatory gap in ICAO
 - Policy guidance on invisible disability
 - Mobility Aids Guidance Material needed (canes, crutches, wheelchairs, etc.)
 - Promoting consistent application of IATA standards (e.g. Special Service Request codes)
 - Promoting consistent training standards

Sandra Lima, Project Manager, European Passengers' Federation (EPF)

- Persons with disabilities are often not considered when building new mobility infrastructure (including digital solutions).
- They want (and should be able) to move autonomously in their city, town or small village.
- Freedom of movement is crucial in overall social interactions; it is at the core of autonomous living.
- Anyone can be a person with a disability at some point in their lives (after surgery, a broken leg) or will be as they get older.
- Disregarding persons with disabilities does not contribute to a balanced, equal and more sustainable society.

- Persons with disabilities are persons with rights.
- "Patching" solutions that might be expensive but are not really suitable.
- Dangerous situations (such as wheelchairs on the street/bicycle lane).
- Different disabilities = different solutions.
- There's no "one size fits all" solution.
- Identifying concrete needs and working together with citizens of **all** ages and from **all** groups.
- Accessibility concerns need to be taken into account with different groups.
- When addressing accessibility concerns, we will also improve transport for other passengers.

Recommendations:

- Current laws and regulations need to be monitored.
- Passenger organisations are often the main contact point between the interests of the citizens and public transport operators.
- Public transport operators also need help in moving to more accessible solutions.
- Often the will is there, but resource constraints mean that they choose the "easy solution".
- Passenger organisations that have the resources to do research can help guide local operators.

CONCLUSIONS AND RECOMMENDATIONS

- It is about political will and also planning: PWD and DPOs need to be involved.
- Rules cannot be optional, otherwise often they are not implemented; need for effective monitoring.
- Accessibility and special assistance have to be taken into consideration in the design phase with the involvement of PWD and DPOs.
- Aviation stakeholders, passengers organisations and transport operators should also be included in consultations on any legislation in this field; need for a multi-stakeholder approach.
- Ensure proper implementation by providing clear guidelines - operators need clarity and certainty and a consistent and global approach.
- Set up a new accessible EU centre composed of experts including DPOs to advise MS.
- Legislation should cover all modes of transportation; there are still too many exceptions and a patchwork of laws; focus on air travel as there are major shortcomings in airports.
- New infrastructure should not be inaccessible.
- There's no "one size fits all" solution; need for adapted solutions for each type of disability.



Employment of young people with disability L'emploi des jeunes personnes handicapées

08.04.2022 | 9:30 – 13:00 | JDE 60 | PUBLIC HEARING / AUDITION PUBLIQUE

The introduction was delivered by **Pietro Barbieri**, President of the EESC Thematic Study Group on Disability rights (TSG DIS), who highlighted how our previous target of granting access to employment to people with disabilities (PwD) has not yet been met because of the stigma of unproductiveness. There appears to be a widespread belief that PwD are not very productive and as a result, they have encountered significant discrimination. There is even a risk of double discrimination in the case of young people due to their being both new to the market and disabled. Some countries have made progress in understanding how to include young PwD in the labour market, but the EU has yet to set a benchmark for this.

Panel 1: The view of EU and international organisations

The first panel was moderated by **Hana Popelková**, TSG DIS member. She gave the floor to **Susanne Kraatz**, Unit for Disability and Inclusion, DG EMPL, who explained how the Commission has tackled the issue. Ms Kraatz said that data have shown that half of PwD are employed, as opposed to 75% of people without disabilities. Moreover, in all EU Member States, PwD have lower employment rates than their counterparts without disabilities. This indicates a huge unemployment gap between the two categories of people. Most PwD work in sheltered workshops, where adequate working conditions are not always provided, with a lack of or weak labour rights and no prospect of joining the open labour market. Furthermore, even in the recruitment processes of these schemes, discrimination is highly likely to occur. For instance, young PwD are likely to be discriminated against. Other general factors to consider are gaps in education attainments and problems in the recruitment phase due to lack of accessibility, reasonable accommodation and adequate individual support. Alternative forms of employment should not be pursued as they encourage segregation and do not often provide adequate working conditions or a clear connection to the open labour market.

Through the new Strategy for the rights of persons with disabilities, the Commission has taken steps to deliver targeted support to Member States' employment policies. The European strategy comprises an employment package which would ensure and strengthen integration and employment services (integration with public services), hiring prospects, reasonable accommodation at work, safety at work (assistance for people with chronic impairments) and vocational rehabilitation schemes. The Commission is exploring how apprenticeships can also be a tool for social inclusion through the European Alliance for Apprenticeships (EAfA) and is working on the reinforced Youth Guarantee. DG EAC is focusing on making education more inclusive.

In terms of implementation, she emphasised mainstreaming young PwD throughout the EU institutions and Member States and across different policy fields. She also stressed the provision of individualised support (for instance, some staff should be trained to assist people with specific needs), monitoring, and stepping up the involvement of Member States, stakeholders and social partners through the disability platform. Additionally, Member States have been urged to design more inclusive vocational programmes. Lastly, a subgroup specifically dedicated to job support for PwD will be created as part of the European Platform on Disability.

Daphne Nathalie Ahrendt, Senior Research Manager at Eurofound, stressed the importance of disaggregated data about PwD. Eurofound has launched a [new e-survey \("Living, working and COVID-19"\)](#) which has already provided aggregated data showing that young PwD are significantly more affected than their counterparts without disabilities. The survey highlighted that young PwD are negatively affected in terms of their unemployment rate, financial fragility (higher risk of poverty), sense of exclusion from society, and susceptibility to depression. Another [study published in April 2021](#) found that more young PwD are dropping out of school at an earlier age than their counterparts without disabilities. As a result, considerable emphasis should be placed on vocational training and the fact that access to this is not equal. Croatia, Slovenia and the Netherlands have all implemented successful measures to ensure equal access to vocational training. This included working with businesses to provide first-hand experience for young PwD, a transition phase between schools and the labour market involving stakeholders and educational institutions, and providing counselling, training and involvement in sport and certain forms of employment.

Stefan Tromel, from the International Labour Organization, described the various initiatives on disability currently underway more broadly (e.g. UN Convention, Sustainable Development Goals) and emphasised the need for inclusive solutions over segregation. He criticised the lack of attention to disability inclusion in social dialogue. He emphasised that although the platform/digital/green economies may provide opportunities (IT experts in artificial intelligence, cybersecurity and blockchain technology), they may also present obstacles, for instance in terms of working conditions. Another concern is the lack of upskilling in certain areas for PwD. The answer is to ensure that projects mainstreaming digital skills incorporate disability inclusion. This strategy should not be restricted to

measures relating to digital skills, but should be adopted in all policy initiatives (e.g. employability initiatives for young people). Artificial intelligence may assist PwD, but it may also discriminate (by blocking remote hiring processes). Fortunately, talks regarding disability inclusion have become far more common in global climate change debates on the green economy.

Several participants raised the following **questions**: what constitutes reasonable accommodation; how to optimise social dialogue between organisations representing PwD and national and international actors; how to address the issue of some Member States stipulating that people choose between the Youth Guarantee and disability benefits; what types of disability support for internships could be provided; how to make our regular schools more accessible without resorting to specialised institutions; how to make sure that school staff are trained to accommodate PwD; what initiatives exist to remedy the lack of social dialogue in this area; how social isolation will be addressed in the case of telework; the consequences for Member States that fail to adopt more inclusive policies.

Susanne Kraatz said that the Commission issued an initial set of practices in 2021 on the concept of "reasonable accommodation". In terms of social protection, the Commission is preparing a study on the difficult relationship between work and disability support. In terms of social dialogue at European level, the inclusion of young PwD will soon be included in the structure of European social dialogue. As regards Member States which fail to implement more inclusive policies, penalising them is outside the scope of the EU's competences.

Daphne Nathalie Ahrendt presented a list of resources touching on all aspects of schooling.

Stefan Tromel responded to the question about social dialogue by saying that the social partners needed to be more interested in addressing this topic. He also said that it was tricky to guarantee full respect for social dialogue in this area because of the need to strike a balance between demands from the disability movement and decisions regarding PwD made by non-disabled people. On the subject of telework, he recognised the problem of isolation. However, while in general, teleworking remains an opportunity for PwD, they should never be forced to resort to it. Concerning the contradiction between the Youth Guarantee and disability benefits, the latter should be designed to supplement rather than replace employment.

Panel 2: The views of the EU social partners and civil society organisations

The second panel was moderated by **Marie Zvolská**, TSG DIS member. She gave the floor to **Giuseppe Guerini**, EESC member, Confcooperative, who described the strategy of Italian social cooperatives which have developed enterprises integrating PwD that do not depend on public subsidies and that operate in the market. These enterprises employ 30% of PwD, which is an incredible achievement because inclusion takes place directly in the workplace. These enterprises began with public procurement but gradually became sufficiently competitive to be able to join the private market. Other companies may realise that partnering with social cooperatives is beneficial both due to the specialised work they perform and their ability to adapt to the demands of businesses, and in order to avoid penalties for refusing to recruit PwD. Surprisingly, the public sector continues to lag behind and should strive to achieve comparable outcomes.

Michela Vogrig, from Legacoop, emphasised certain good practices, such as the Italian system of social cooperatives, which minimises segregation of PwD while allowing for inclusion. PwD are supported by non-disabled employees who have been trained to assist them. Throughout the pandemic, less productive people have been gradually excluded from the labour market, making integration of PwD more difficult. Instruments such as EU Directive 2014/24 (EU Procurement Directive) and the "social cooperative" option are available, but we still need an integrated and comprehensive strategy that involves stakeholders and institutions. Another good practice is the role of mediators, who are given responsibility for identifying solutions for disabled employees within the company. Lastly, we must abandon the notion that integrating PwD into the labour market would relegate them to marginal jobs.

Anca Davis, from Views International, talked about an Erasmus+ project called [VIP-Tech-Job: Time 2 Act](#). This two-year project has focused on the employability of persons who are visually impaired. It is hoped that this initiative will serve as a springboard for the adoption of digital solutions for visually impaired young people by businesses and professionals committed to inclusion. The project has included a range of resources, including a portal to assist stakeholders interested in learning more about inclusion and accessibility, postcards depicting successful tales of young visually impaired people, and a documentary portraying the challenges facing them.

Francesca Sbianchi, from the Youth Committee of the European Disability Forum, said that PwD tend to end up in poor quality jobs, meaning that they are unable to be economically self-sufficient. She was particularly critical of certain Member States' decisions to abolish disability benefits when PwD begin working. She argued for decreasing disability benefits without eliminating them altogether. She said that assisting PwD will benefit society as a whole by providing additional workers. She emphasised that disabled people's labour mobility could also be jeopardised because disability benefits might be lost during the transfer to another Member State, and it may take an extended period of time to get new disability benefits in the host country. Thus, she advocated for extending the European Union's disability card. Lastly, she called for funding to assist companies with providing reasonable accommodation.

Christian Takow, from Autism Europe, pointed out that there are no disaggregated data on the state of play of unemployment of autistic people. The primary difficulties faced by autistic people include lack of access to education or vocational training, lack of assistance while transitioning into adulthood, and barriers in recruitment processes (communication and managing time issues are not taken into account during interviews). Individualised transition management is required to guarantee the development of independent living skills. Autistic people have difficulty shifting from one activity to another and from one workplace to another. Tactics such as providing early notice of a change as soon as feasible and using time management apps to prepare for the subsequent activities might be beneficial. Individualised reasonable accommodation should be provided starting with the recruiting process. For example, job descriptions should be free of jargon, application forms should contain instructions, and a support person should be present during interviews. Other types of accommodation include adjustments in communication, changes in work schedules and the provision of special leave.

Ignacio Doreste, from the European Trade Union Confederation (ETUC), praised the efforts undertaken in support of PwD (the Commission's strategy for the rights of persons with disabilities, the call to implement the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the [European Parliament resolution of 10 March 2021](#) establishing a general framework for equal treatment in employment and occupation in light of the UNCRPD). He stressed that statistics do not always reflect the quality of the jobs secured by PwD, or whether the jobs are in the open labour market or in designated workplaces. He argued for greater availability of data disaggregated by type of disability, adequate funding, collective bargaining, more awareness of disability and a common definition of "disability".

Anna Kwiatkiewicz-Mory, Senior Adviser for Social Affairs at Business Europe, emphasised the need to expand the workforce and train young people with vital skills. Employing PwD would create an extra pool of applicants. Employment fosters a sense of belonging and participating in society and promotes self-sufficiency, personal growth and social protection. Diversity is important since it brings new ideas to businesses and enhances their image in terms of corporate social responsibility. Opportunities for remote work and learning should be encouraged. She emphasised the need for accessible education, since PwD have a higher rate of early school leaving than their non-disabled peers. Many steps can be taken to help young PwD transition from school to work, such as focusing on their potential rather than their disabilities, offering specific services, providing alternative recruitment strategies, and ensuring that disability benefits are not lost when they enter the labour market.

During the question and answer session, a few of the participants reflected on the following **points**: how to ensure that parents have the resources they need to support children with disabilities; whether providing a support person in ordinary schools could be a good practice for inclusion in education, given that not all teachers are trained to support PwD; and what solutions can be offered to make employing PwD one solution for the labour shortage. The following points were raised: how to raise awareness among business owners and executives and get their CEOs and other senior executives on

board with recruiting PwD; how to demonstrate, including to regular workers, that recruiting PwD would not make their jobs more difficult; and how to guarantee that small and medium-sized enterprises keen to participate in including PwD get comprehensive and continuous support. The following points were made with regard to disaggregated data: how to ensure that the data available have a focus on quality as well as quantity (e.g., an indicator of the attitude of PwD towards their future) and how to change the perception that PwD cannot perform work of equal quality to that of their counterparts (data could be used in this regard). It was pointed out that thought must be given to how to develop economic models for implementing good practices, how to address the challenges of teleworking, how to raise awareness among employers (and among PwD) about the latest technological advances that can help PwD work more effectively, and how to facilitate the gathering of statistics at national and European level.

It was noted that disability NGOs can already act as mediators, initiatives such as seeing how PwD perform a given task and giving them guidance and advice can be encouraged, and social cooperatives and support for long-term social relationships between PwD, their families and society are excellent examples of good practices. It was pointed out that it is important to involve PwD in trade unions to enable collective bargaining.

Pietro Barbieri concluded by emphasising the need to address the challenges facing young people in terms of disabilities in the discussions on the European Year of Youth. He added that although the EESC has tackled disability problems in its discussions about labour, the hearing had identified new concerns that can be addressed by the specialised subgroup of the European Platform on Disability.

CONCLUSIONS AND RECOMMENDATIONS

- The specific needs of young PwD must be mainstreamed across EU institutions, Member States and policy domains.
- Member States are urged to design more inclusive education and employment programmes through an integrated and comprehensive strategy that involves stakeholders, including organisations representing PwD and young PwD.
- Programmes should seek to ensure equal access to education and vocational training, and to address the problems of lack of accessibility, reasonable accommodation and adequate individual support.
- Sheltered workshops should ensure adequate working conditions and labour rights and offer support for creating a pathway to the open labour market. Segregation should be avoided at all costs.
- Individualised transition management from school to work and adulthood should be strengthened in order to develop the skills needed to live independently.
- The lack of upskilling in certain areas for PwD needs to be addressed.

- Good practices include working with businesses to provide first-hand experience for young PwD; partnerships with social cooperatives; providing specific services such as counselling, training and involvement in sport and certain forms of employment; support for long-term social relationships between PwD, their families and society; support by non-disabled employees who have been trained to assist PwD; the roll-out of a mediator in the company, with responsibility for identifying solutions for disabled employees; and initiatives such as seeing how PwD perform a given task and giving them guidance and advice.
- As regards autism, tactics such as offering early warning of changes and using time management apps to prepare for future activities may be beneficial. Clear job descriptions, application forms with instructions, and an interview support person should be welcomed. Other types of accommodation include adjustments in communication, changes in work schedules and the provision of special leave.
- Adequate funding should be available to support SMEs committed to including PwD.
- The lack of qualitative and quantitative disaggregated data about people with different disabilities should be addressed.
- The social partners should address disability inclusion in social dialogue. Full respect for social dialogue should be promoted by involving PwD.
- It is important to be wary of the obstacles that the platform/digital/green economies may present, such as working conditions (teleworkers' isolation, for example) and/or discriminating against remote hiring practices.
- Remote work and learning opportunities should be promoted, not imposed.
- Regarding the contradiction between disability benefits and the Youth Guarantee, the latter should be designed to complement rather than replace employment entirely. Similarly, disability benefits should not be abolished entirely when PwD begin working.
- People should stop thinking that integrating PwD into the labour market would relegate them to marginal jobs, and should instead focus on how they can contribute to society.
- Thought should be given to extending the European Union's disability card to avoid hindering the labour mobility of PwD. A common definition of "disability" is needed.
- The importance of involving young PwD in trade unions and their participation in collective bargaining must be recognised.
- It is important to raise awareness about disability among business owners and to get their CEOs and other senior executives on board with recruiting young PwD and training them on the latest technological advances which can assist PwD as they work.