

**European Research Platform
for inclusive community planning and service
development for persons with disabilities (EURECO)**

EURECO 2020 FORUM: REPORT

5-6 March 2020

**Brussels Office of the University of Warwick
Avenue D'Auderghem 22-28, 1040 Brussels**



International Association
for the Scientific Study
of Intellectual Disabilities



4TH EURECO-FORUM 2020

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Executive summary

On 5th-6th March the European Association of Service providers for Persons with Disabilities (EASPD) and its partners co-hosted the fourth annual European research platform for inclusive community planning and service development for people with disabilities (EURECO), to discuss how we can achieve inclusive healthcare services for persons with disabilities. The event raised awareness of the poor health outcomes and lower life expectancy of persons with disabilities, while calling on the European Union to facilitate the development of high-quality healthcare services for persons with disabilities via the Horizon 2020 funding programme and the European Disability Strategy.

Persons with disabilities have the same health needs as non-disabled people, but they often face additional health risks. In particular, people with severe disabilities are often more susceptible to common diseases or co-morbid conditions. Despite the increased likelihood that persons with disabilities will experience poor health outcomes, today's **current healthcare systems fail to provide adequate health care services to those who need it.**

Systematic failures within the healthcare system have been linked to the poor health outcomes and lower life expectancies of persons with disabilities and it is estimated that **the average life expectancy of men with disabilities is over 13 years lower than those without a disability**, while being over **20 years lower for women** with disabilities.¹

In response to the current state of healthcare for persons with disabilities, **EASPD**, the **International Association for The Scientific Study of Intellectual and Developmental Disabilities (IASSID)**, the **University of Warwick**, the **University of Siegen** and **ZonMW** co-hosted the EURECO Forum to set the agenda for inclusive, accessible health care services for all.

Bringing together health professionals, academics, persons with disabilities, support service providers, representatives of the European Commission and civil society organizations, participants identified the:

- lack of awareness with regard to specific health care problems of persons with disabilities
- lack of accessibility of affordable health care facilities or treatment;
- lack of sustained collection of disaggregated data and systematic adoption of evidence-based health care strategies for persons with disabilities;
- lack of capacity of healthcare professionals to have the time and training to provide persons with disabilities with the appropriate care; and
- lack of cooperation and communication among professionals and agencies from the health and social sector, from disability services, from disabled people's organization and governments
- lack of involvement of specific needs of persons with disabilities in public health care planning

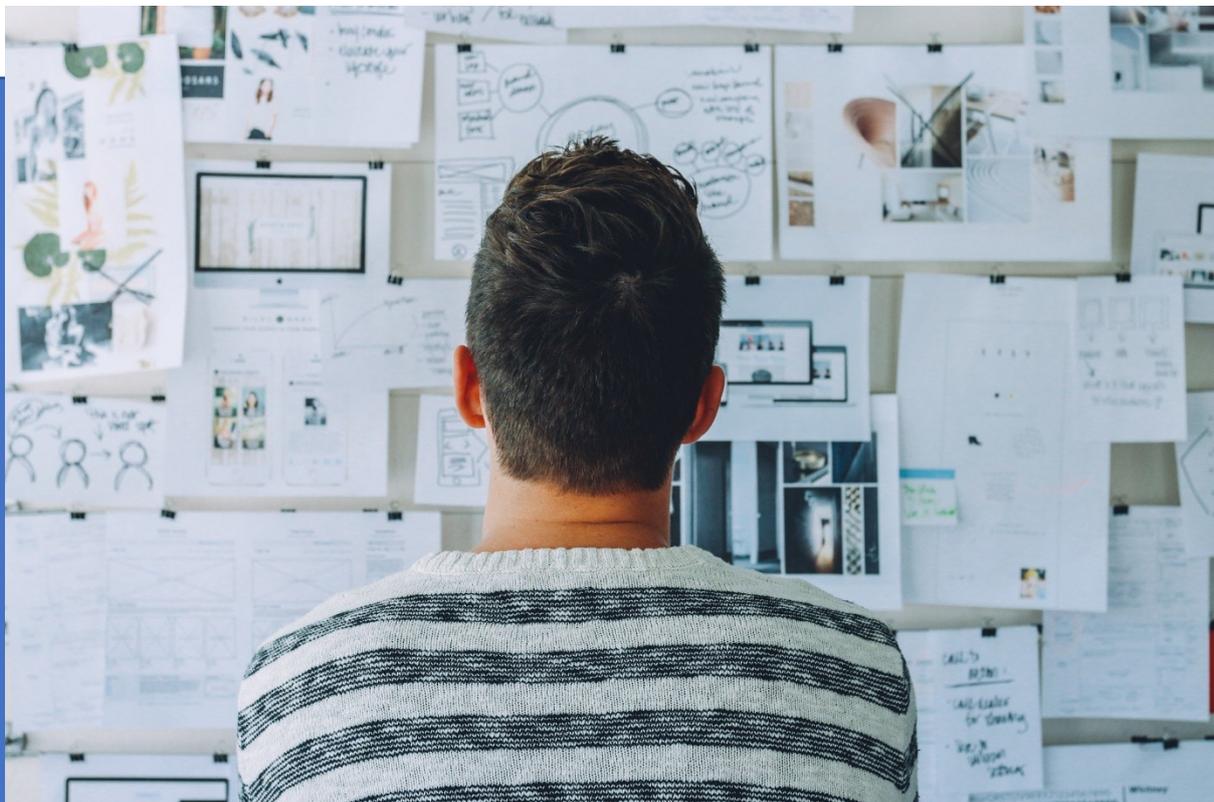
as key barriers, preventing person with disabilities from having full access to health care.

¹ Heslop, Lancet, 2014, 383; 889-95

While health policies remain under the competence of national governments, the European Union (EU) also has **an important role to play in promoting the development of quality health care services for persons with disabilities.**

In particular, **the Horizon 2020 funding programme is a key tool which can support increased data collection** to support the development and implementation of evidence-based policies for inclusive health services. Despite health being a key area of action of the programme, **the fund currently underutilizes the opportunities** it has to stimulate innovations healthcare of persons with disabilities. As a lesson from effective fighting against the Corona-virus, inclusive local public health policies that coordinate cross-sectoral cooperation between services for persons with disabilities and providers of health care should seem to be of important future relevance. To be effective, such initiatives for promoting access to health and support services for persons with disabilities must be integrated across a number of EU initiatives, including the **European Disability Strategy.**

EASPD, as part of the EURECO Forum, will continue to work with its partners and the European Union, to facilitate **the local and regional development of more inclusive health and support services for persons with disabilities.** Over the coming years, partners will work to **increase the European exchange of knowledge in this field** between regional actors and promote further opportunities for the funding of research and action in this area.



EURECO

The platform

EURECO is a European collaboration platform of academic researchers and service providers working on inclusive community planning and development of in the perspective of the UN Convention on the Rights of Persons with Disabilities (CRPD). The platform originated from a joint initiative of the European Association of Services Providers for Persons with Disabilities (EASPD) and the Centre for Planning and Evaluation of Social Services (ZPE), University of Siegen, Germany to foster European theory-practice cooperation in the disability services' sector. It was intended to develop a network of academic researchers and research affined service providers specifically interested in developing inclusive communities. Furthermore, regular meeting for platform members in a format mixing elements of academic conferences and project development workshops were to be organized. In the following years, the partnership grew to include the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) and ZonMW.

Since 2017 the research platform has yearly organised European forums in Brussels to discuss current trends and problems relevant for European research activities concerning disability, inclusive communities and service delivery. The focus of EURECO meetings was on "cooperation and co-production in comparative European research" (2017), on "implementation of innovations in local disability fields" (2018), and on "Social impact measurement frameworks for disability services" (2019) in Europe. The forum meetings not only resulted in productive debates and concrete ideas for European project activities but also led to valuable networking among participants from all over Europe.

The partners

EASPD: The European Association of Service providers for Persons with Disabilities is a non-profit European umbrella organization, established in 1996, and currently representing over 17,000 social and health services for persons with disabilities. EASPD advocates effective and high-quality disability-related services in the field of education, employment and individualised support, in line with the UN CRPD principles, which could bring benefits not only to persons with disabilities, but to society as a whole. (<https://www.easpd.eu/>)

Centre for Planning and Evaluation of Social Services (ZPE), University of Siegen, Germany: The ZPE is an interdisciplinary scientific unit at the University of Siegen. The research centre aims at bridging the gap between theory development and the development and implementation of conceptual and practical approaches. ZPE activities include systematic theory development, applied research, evaluation and consultancy services in the field of social services, rehabilitation, non-formal education and health care. ZPE's interdisciplinary approach is supported by the internal cooperation of scientists from different disciplines, including social work, educational sciences, sociology, social policy, architecture and urban planning. (www.zpe.uni-siegen.de)

DSiN: Disability Studies in The Netherlands is a foundation, started in 2009, with the purpose to realise the academic discipline of Disability Studies. DSiN stimulates and initiates research and education. Creating, sharing and evaluating knowledge is used as a means to contribute to social

change and to improve participation and inclusion of people with disabilities in society. (<https://disabilitystudies.nl/>)

IASSIDD: The International Association for the Scientific Study of Intellectual and Developmental Disabilities is the first and only world-wide group dedicated to the scientific study of intellectual disability and related developmental disabilities and of conditions of persons with these disabilities and their families. Founded in 1964, IASSIDD is an international, interdisciplinary and scientific non-governmental organization which promotes worldwide research and exchange of information on intellectual disabilities. (<https://www.iassidd.org/>)

ZonMW: the Dutch Organisation for Health Research and development, finances and stimulates innovation through research in all health domains. We aim to ensure that healthy people stay that way for as long as possible. Also ZonMW aims to help recover people that are ill, or that people with a certain illness can live their lives to the best of their abilities. Participation of patients in research is of paramount importance, for they can contribute with knowledge gained through experience. ZonMW focusses primarily and prevention and successful implementation in research and practice. (<https://www.zonmw.nl/>)



Focus on Inclusive Health

The EURECO Forum 2020 has been designed to discuss current policy trends and major challenges for health care provision for persons with disabilities (PwD). Besides exchange of knowledge and information and networking among participants, more concretely the general objectives were:

- to discuss the actual implementation of Art. 25 of the UN CRPD;
- to identify (local) promising policies and practices in different European countries and discuss options for 'cross-European borrowing';
- to identify research needs and research questions for comparative European project activities;
- to identify key elements for policy recommendations addressed to EU decision makers aiming to influence current and future policy and funding frameworks related to access to health for PwD.

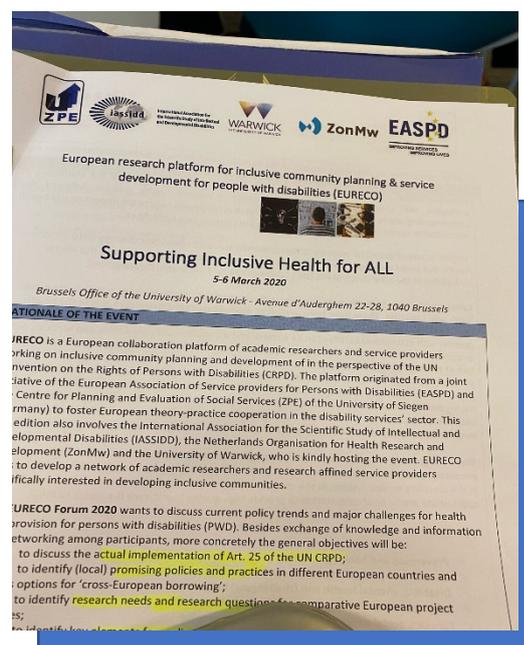
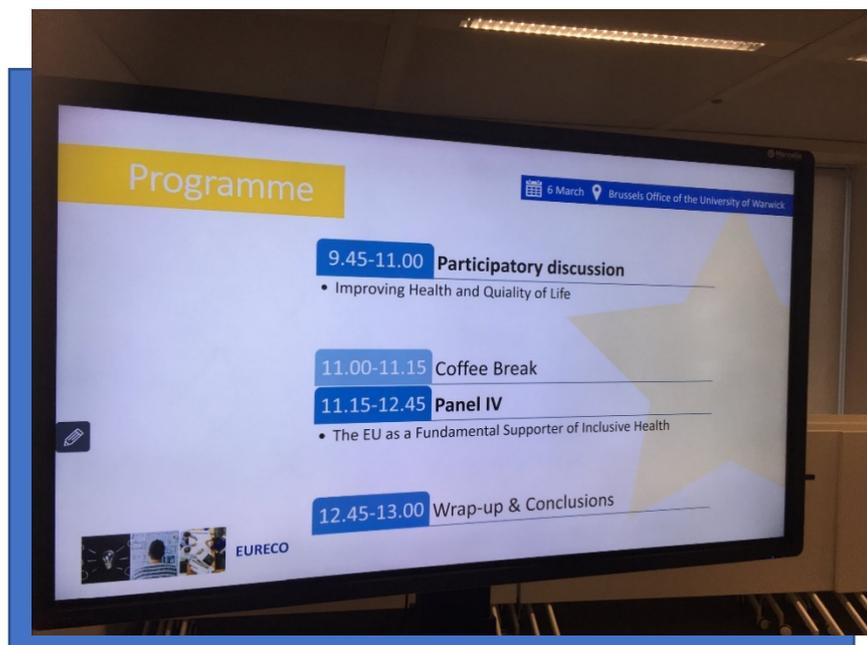
Why this focus on inclusive health? The understanding of health has changed over time. The World Health Organization (WHO) brought up an important definition in 1984 whereby health is a state of "physical, mental, and social well-being, and not merely the absence of disease and infirmity". This was added by a more process-oriented understanding of health as "the extent to which an individual or group is able to realise aspirations and satisfy needs and to change or cope with the environment". In this perspective health results from an interactive process of the individual with its socio-ecological environment and becomes a "resource for everyday life, not the objective of living". In this sense, individual and collective health conditions in a population can be promoted or harmed by the conditions of ecological and social environments (WHO 1994). European health policies followed this understanding and in a number of programmes and strategy papers, where the importance of health promotion in combination with effective health care systems was underlined.

'Health' is one of the eight areas for action under the European Disability Strategy 2010-2020. Health and social care must serve all people at all ages and leave no one behind – this idea is embedded in the core vision of the UN's 2030 Agenda for Sustainable Development.

Care provision has become more complex, with demand and increasing costs outstripping public funds and capacity. There have been persistent multi-dimensional barriers to access the health care services across the EU, at individual, provider and health system level. On the demand side (persons with disabilities) barriers can be summarised as: unaffordable medicines and services, out of pocket payments, waiting times, geographical distance and limited mobility, fragmented care, lack of financial support across systems and socio-economic disparities. On the supply side (care providers and care practitioners) barriers include: inadequate legislation, policies and strategies, gaps in service provision, problems with delivery of services, overworked care practitioners not having time to listen to or understand the needs of people with disabilities, disrespect/distrust between professionals from different training streams, poor communication and lack of genuine involvement of people with disabilities in decisions which directly affect their lives.

There is a growing tendency to generally strengthen patients' rights in the medical system and to encourage patients' empowerment. This is particularly relevant on the local level, and the actors in the disability service system, in the medical system and in the administration have to come to appropriate practices of cooperation to provide high quality health care & support to PwD.

Overview of the event



Keynote address

Prof. Hannah Kuper (*London School of Hygiene & Tropical Medicine*) delivered the Forum's keynote speech, focusing on various key aspects of inclusive health ([PPT](#)).

Prof. Kuper stated the difficulty of assessing access to health care for persons with disabilities due to the lack of available data and to perceptions linked with the medical model of disability. Nevertheless, findings consistently point towards the existence of wide-spread, systemic barriers to access of healthcare. These include inaccessible facilities and equipment, financial barriers, lack of support and training for healthcare personal, and societal stigma. These barriers can thus be approached from both the demand (insufficient autonomy, awareness, financial capacities) and the supply (insufficient infrastructures, capacities, and knowledge) sides.

Actively tackling these barriers is essential as, currently, [Goal 3](#) of the global goals for sustainable development, is not attainable due to these obstacles.² In turn, this results in a failure to maximize the individuals' quality of life, to comply with international law, to improve health services for all, and to achieve other development goals (such as the goals related to education or employment which necessitate inclusive health as a precondition).

Prof. Kuper has identified several crucial areas where progress could significantly improve access to health for all:

- Generating more data on impact of disability on health and healthcare access
- Improving accessibility of services and use of existing tools

² The Global Goals for Sustainable Development – *Goal 3 – Good health and well-being*
<https://www.globalgoals.org/3-good-health-and-well-being>

- Improving and expanding training of healthcare workers, including on the specificities of disability
- Prioritising inclusive health in the policy agenda to secure funding and innovative policies, as well as more thorough implementation of the existing policies.

Panel 1: Access to Health – Barriers and Challenges

Presentation: Laurence Taggart (*Ulster University & IASSIDD*). Moderation: Carmen Arroyo de Sande (*EASPD*). Panel: Fabrizio Fea (*Associazione Scuola Viva onlus – Italy*), Rosalía López Sánchez (*COGAMI – Spain*), Tess Van Deynse and Rados Keravica (*European Network on Independent Living*), Giulia Oggero (*WHO*)



The first panel of the Forum focused on identifying the key challenges impeding inclusive health. Moderator **Carmen Arroyo de Sande** introduced this session by mentioning the lack of awareness and training of healthcare workers as crucial factors.

Laurence Taggart delivered a presentation during which he highlighted several factors which can significantly affect health and access to healthcare for persons with disabilities ([PPT](#)):

- Biological factors (age, gender, behavioural phenotypes, etc)
- Lifestyle factors (diet, exercise, sedentary behaviour, obesity, drug usage, mental and sexual health, etc)

- Health access and promotion factors (communication barriers, reliance on others, lack of coordination between services, physical barriers, lack of training, reasonable adjustments, user-friendly literacy, etc)
- Socio-economic, cultural, and environmental factors (attitudes, discriminatory practices, poverty, limited social support, etc)

During the panel discussion, **Fabrizio Fea** addressed these factors by stressing the importance of employing a multidisciplinary approach within care organisations, to reflect this variety of barriers. Similarly, mainstreaming disability healthcare approaches should be reinforced.

Tess van Denyse discussed existing financial barriers and their cumulative effect, illustrating this point with the lack of financially accessible healthy food options. This underlines the importance of understanding undercurrent dynamics in the relations between disability and various health aspects such as obesity.

Rosalía López Sánchez further described the interconnectedness of the factors affecting inclusive health. In particular, issues of intersectionality and the role of gender dynamics were stressed as amplifying factors ([PPT](#)).

Giulia Oggero emphasised the role of assistive technology in addressing the factors identified throughout the panel. In order to maximize the positive impact of such technologies, Ms Oggero encouraged efforts towards tackling the lack of data, awareness, staff, and research on the benefits of assistive technology for persons with disabilities.

In her conclusion following exchanges with the audience, **Ms Arroyo de Sande** summarised that combatting these barriers is not just a matter of cost: improving training, involving persons with disabilities in care, and improving cooperation do not necessarily cost more. Solutions will require creativity, cooperation to break silos, and not fearing change.

Panel 2: Health and Persons with Intellectual and Psychosocial Disabilities, Challenging Behaviour

Moderation: Peter Langdon (*University of Warwick & IASSIDD – England*), Valerija Buzan (*SOUSS – Slovenia*), Prof. Richard Hastings (*University of Warwick – England*), Prof. Kylie Gray (*University of Warwick – England*), Jan Berndsen (*Mental Health Europe*)

The second panel of the Forum focused on examining the key dynamics affecting access to health for persons with intellectual disabilities. Peter Langdon introduced the panel by stating the prevalence of diseases and mental health problems for persons with disabilities ([PPT](#)).

Valerija Buzan discussed various axes of intervention such as the need to improve mental health assessment, the need for improving the training of staff, promoting positive engagement of staff with users, and ensuring services are open and welcome visitors ([PPT](#)).

Prof Richard Hastings then delved into the specific dynamics of challenging behaviours and emphasised the need for specialised and multidisciplinary challenging behaviour teams as well as the importance of promoting processes of co-creation with persons with disabilities ([PPT](#)).

This focus on challenging behaviour was furthered by **Prof Kylie Gray** who presented results of studies conducted in Australia which stressed the role of parents, caregivers and families ([PPT](#)).

Finally, **Jan Berndsen** similarly focused on the role of informal caregivers, and on their contributions to mental health. In particular the role of the community in mental health recovery has been illustrated by efforts currently employed in the Netherlands ([PPT](#)).

Panel 3: Local Planning and Person-centred Integrated Services

Prof. Dr. Marco Garrido y Cumbreira & Sergio Sanz (*University of Sevilla – Spain*), Jos Sterckx (*Odisee VZW – Belgium*), Prof. Dr. Johannes Schädler (*University of Siegen – Germany*). Moderation: Renaud Scheuer (*EASPD*)

The first day of the Forum concluded with three presentations from experts focusing on taking stock of the challenges and barriers identified in the previous panels and on exploring potential solutions, with a focus on the local level.

Dr Marco Garrido y Cumbreira introduced elements of the Spanish care systems and efforts to improve delivery of care at all levels. Future perspectives could focus on improving the generation and collection of scientific data on disability from a holistic approach, as well as improving the cooperation between legislation and practice to ensure that such data is used to improve policies and practices ([PPT](#)).

Jos Sterckx then discussed the first attempts of the Flemish regional authorities to introduce public procurement in the social domain. In particular, Mr Sterckx stressed that opening the markets via public procurement is irreversible ([PPT](#)).

Dr Johannes Schädler, founder of the EURECO network, closed the first day of the Forum with a presentation on the topic of the promotion of local health care for persons with disabilities in the inclusive community planning model, with a particular focus on the issue of missing indicators.

Community health planning can be apprehended as a cross-sectional approach for local governments to plan the improvement of the health situation of the inhabitants, based on the principles laid out already in the WHO-published 'Ottawa Charter' (1986) or recently in the UN's Sustainable Development Goals (2015).. Planning inclusive communities, which requires appropriate models of action, can thus be seen as a learning process for all stakeholders under the leadership of the local government. It should be focused on identifying commonalities and shared interested among citizens so as to involve stakeholder sin the agenda-setting.

A key challenge for public health assessments at the political level is the aggregation and use of data. This includes the question of which indicator to select, which data-collection and -analysis processes to employ, and the purpose of reporting ([PPT](#)).

Participatory discussion: Improving Health and Quality of Life

Alice Schippers (*IASSIDD – The Netherlands*), Peter Langdon (*Warwick University & IASSID – England*), Laurence Taggart (*Ulster University & IASSID - Northern Ireland*), Henriette Sandvoort & Eva Haverkort (*Disability Studies – The Netherlands*), and all delegates

The second day of the Forum started with a participatory discussion (in the ‘fishbowl’ arena model) designed to involve participants and to address a variety of topics determined by the audience’s suggestions. These involved questions of modern eugenics, questions of terminology (e.g. ‘patients’ or ‘users’), and the self-perceptions and stigma of persons with disabilities in the context of disability as an identity. The panellists and participants also extensively discussed the importance of lived experience and experiential knowledge in health issues. This importance was illustrated through a discussion on the topic of assistive technologies, considered as a prerequisite for inclusion ([PPT1](#), [PPT2](#)).

Panel 4: The EU as a Fundamental Supporter of Inclusive Health

Moderation: Luk Zelderloo (*EASPD*). Laurence Taggart (*Ulster University – Northern Ireland*), Dorota Sienkiewicz (*EuroHealthNet*), Anna Ramon Aribau (*UVic-UCC - COHERE – Spain*), Katie Gallagher (*European Patients Forum*), Haydn Hammersley (*European Disability Forum*), Hana Velecka (*European Commission – DG Employment*)

The final panel of the Forum addressed the challenges identified in the previous sessions by focusing on the possible axes of intervention at the EU level, so as to plan the research and policy agenda.



Luk Zelderloo introduced the context of the panel by reminding participants that the European Commission has recently launched reflections on the next Disability Strategy 2021-2030, as well as on the implementation of the EU pillar of social rights. This Forum could thus lead to the identification of areas of improvement in the domain of healthcare access.

Laurence Taggart stated the importance for political interventions in the fields of health and access to health to include logic models, evidence-based approaches, and co-creation processes. Mr Taggart further suggested that best practices should be implemented on a systemic level ([PPT1](#), [PPT2](#)).

Focusing on the work pursued at EU level, **Haydn Hammersley** explained the issues arising from the repartition of competences between the EU and the Member States. Additionally, it will prove important to unblock the implementation of the 2008 Directive on the principle of equal treatment and non-discrimination, which would provide better tools at national level.

Katie Gallagher then addressed the issue that currently-used indicators fail to capture several subdimensions essential to healthcare access assessments. It is also crucial to ensure that information is available, possibly through the State of Health in the EU cycle. Ms Gallagher also encouraged further involvement and participation of patients and users as a means towards empowerment.

Considering the areas where the EU can have the most impact, **Dorota Sienkiewicz** highlighted social policy areas such as access to social protection, protection from the adverse health effects of pollution, and the prevention of non-communicable diseases. Overall it is important to address these through a holistic approach so as to avoid competition between health and social policy, and more broadly to evolve mindsets towards an integrated view of health.

Anna Ramon Aribau considered key areas in which the EU could impact inclusive health, including policy and legislation (assessing past policies, developing healthcare standards with enforcement mechanisms), financing (to reduce inequalities in access for persons with disabilities), education (to change views and the current discourse on health and disability) and research, essential to generate data.

Sharing the views of the European Commission, **Hana Velecka** confirmed the importance of health to be mainstreamed, in spite of the issues of competences shared with Member States. Ms Velecka identified social inclusion as a key challenge to be tackled by the EU, with the lack of data as a key issue in this perspective. The European Semester and the next Disability Strategy will be opportunities to better apprehend these topics.

Key messages from the Forum

1. Main issues and challenges identified

- Inaccessibility of affordable health care or treatment;
- Absence of sustained collection of disaggregated data and systematic adoption of evidence-based practices;
- Capacity of healthcare professionals to have the time and training to provide persons with disabilities with the appropriate care;
- Lack of cooperation and communication among stakeholders, particularly with regard to integrated care; and
- Lack of health and daily life support for persons who develop a disability following a disease or accident.



2. Main axes of intervention identified

- Use of new assistive technologies
- Community-based approaches, at local level in particular
- Empowering persons with disabilities by changing terminology ("patients")
- Changing attitudes regarding who assesses quality of life and who generates knowledge (coproduction)
- Social inclusion as a key axis for the EC. Should include focus on intersectionality

3. Key upcoming policy developments

- [European Disability Strategy](#): The European Commission 2010-2020 has shaped the European Commission's actions for the past ten years related to the implementation of the UN CRPD; in areas such as the use of EU funds and the adoption of the European Accessibility Act. The European Commission is currently consulting on the development of the follow-up: a European Disability Strategy for the next few years. It is essential that this new strategy tackles head on the issues of health inequalities experiences by persons with disabilities and considers the issues mentioned above.
- [European Semester](#): Focused on economic coordination within the EU, the European Semester's outcomes include specific recommendations for member states, including with regard to the provisions for the inclusion of persons with disabilities into the labour force, as

well as policies linked to healthcare policy. It should also be used issues of healthcare inequalities, including for persons with disabilities.

- [Action Plan for the implementation of the European Pillar of Social Rights](#): The 20 principles comprising the EPSR structure initiatives and policies in the fields of employment and social affairs, including with regard to the right of persons with disabilities to income support and non-discrimination. The European Commission is currently preparing an Action Plan on its implementation, which should include a targeted action on tackling health inequalities and issues of access to healthcare for persons with disabilities and other often excluded persons.
- [Multi-annual Financial Framework](#): The EU budget provides for many opportunities linked to health-related policies. It should far more systematically ensure that EU-funded projects particularly address the aforementioned issues regarding access to health for persons with disabilities, including ESF+, Horizon Europe & Erasmus+.
- [State of Health in the EU](#): This cycle is an essential tool for the collection and dissemination of data and good practices related to health in the EU Member States. The reports produced through this process form a pertinent basis for the development of health policies. We strongly recommend that this instrument look far more systematically into issues affecting health for persons with disabilities in Europe.

Next steps

The EURECO partners are currently exploring potential follow-up research based on the key messages of the Forum. As a number of crucial topics and avenues for future research have been identified, it will be important to capitalise on the Forum's momentum to strengthen cooperation between various stakeholders and shape the policy and research agenda.

Additionally, researchers and academics who wish to join the EURECO network can do so by contacting the email address mentioned below. Joining the network will ensure that you receive information on future events and research or funding opportunities, as well as granting access to the D-LoT Agora where the forums provide a useful platform to connect researchers and identify topics or initiatives.

For updates on upcoming studies and events, please contact:

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