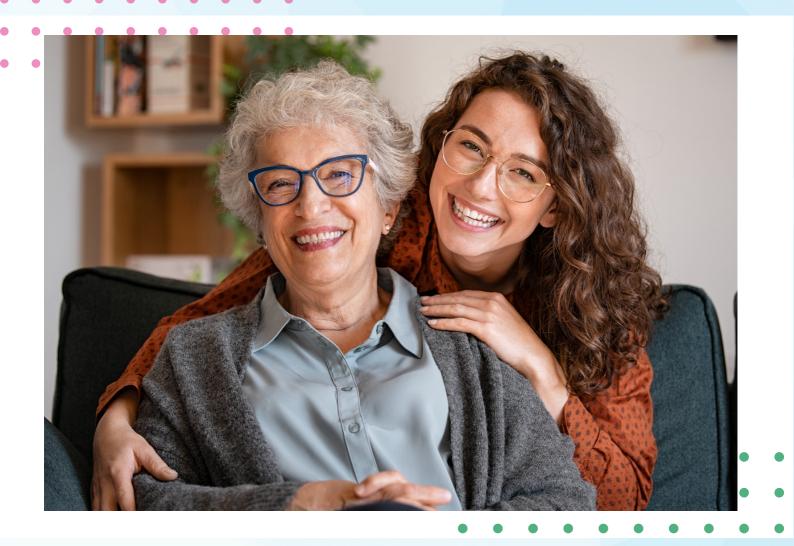


## EURECO FORUM 2023 Final Report

Supporting Older Persons with Long-Term Care Needs and Persons with Disabilities Common challenges and learning opportunities





















## **Table of contents**

| Executive Summary                                                                              | 4               |
|------------------------------------------------------------------------------------------------|-----------------|
| EURECO The Platform                                                                            | 7               |
| Overview of the event                                                                          | 8               |
| Keynote address                                                                                | 8               |
| Dr. Martin F. Reichstein (ZPE University of Siegen)                                            | 8               |
| Parallel Workshops: sharing innovative practices and next steps for research and policy agenda | , 0             |
| Workshop 1: Independent Living and integrated care support                                     |                 |
| Workshop 1.1: UNIC                                                                             |                 |
| Workshop 1.2: AtOrl                                                                            | 11              |
| Workshop 1.3: Integrated care & support-challenges providers                                   |                 |
| Workshop 1.4: Promoting independent living via con                                             | •               |
| based approaches                                                                               | 14              |
| Co-funded by the European Union                                                                | • • • • • • • • |



.





| Workshop 1.5: Improving collaboration between care for older persons and persons with disabilities15                                |
|-------------------------------------------------------------------------------------------------------------------------------------|
| Workshop 2: Assistive technologies and integrated care & support                                                                    |
| Workshop 2.1: Robotics & New Eugenics17                                                                                             |
| Workshop 2.2: Technology can support older adults to self-<br>manage health and wellbeing18                                         |
| Workshop 2.3: SweetHome19                                                                                                           |
| Workshop 2.4: CUPID project20                                                                                                       |
| Workshop 3: Bridging local service systems for persons with disabilities and for older persons with long-term care & support needs  |
| Workshop 3.1: Integrated social planning in Siegen-Wittgenstein.21                                                                  |
| Workshop 3.2: A perspective on integrated care for people with disabilities and for older people with long-term care needs in Tuzla |
| Workshop 3.3: A perspective on Integrated care for people with disabilities and for older people with long-term care needs25        |









| Workshop 3.4: Perspective on integrated support for p          | people |  |  |  |  |  |
|----------------------------------------------------------------|--------|--|--|--|--|--|
| with disabilities and for older people with long- term care ne |        |  |  |  |  |  |
|                                                                | 27     |  |  |  |  |  |
| Fishbowl discussion                                            | 29     |  |  |  |  |  |
| Fionnathan Productions                                         | 29     |  |  |  |  |  |
| Policy Panel                                                   |        |  |  |  |  |  |
| Q&A session                                                    |        |  |  |  |  |  |
| Conclusions                                                    |        |  |  |  |  |  |
| Next steps                                                     |        |  |  |  |  |  |









### **Executive summary**



The 2023 EURECO Forum took place in person at the Renaissance Hotel in Brussels, Belgium, on March 15. This year's edition was focused on older persons with long-term care needs and persons with disabilities: exploring common challenges and learning opportunities in care and support. As always, the aim of the Forum has been to bring research and practice together for more innovative research on inclusive community development.

The event has discussed the following questions:

• What are the similarities and challenges between care and support for older persons and persons with disabilities on both individual cases and local service system levels?

• What can they learn from one another? What promising solutions and relevant research questions exist?

The key outcomes that participants took away from this event include (1) improved connections between both sectors, (2) identifying key items for future research agenda and (3) fostering potential cooperation for future project proposals.















The forum has welcomed representatives of European research institutions working in the fields of disability, community planning and inclusive services, as well as other stakeholders, including representatives of disability service providers and of the European institutions.

Click <u>here</u> to access all PowerPoint presentations showed at EURECO Forum 2023.

















## EURECO The platform

DISABILITY STUDIES

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 <u>UN Convention on the Rights of Persons with</u> <u>Disabilities (CRPD)</u>. The platform originated from a joint initiative of the <u>European Association of Services Providers for Persons with Disabilities</u> (EASPD) and the <u>Centre for Planning and Evaluation of Social Services (ZPE)</u>, 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 meetings for platform members in a format mixing element 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), on "Social impact measurement frameworks for disability services" (2019) in Europe, on inclusive health (2020), on digital transition in the context of the pandemic (2021) and on technology gaps for regions beyond metropoles (2021). 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.















## Overview of the event Keynote address



**Dr. Martin F. Reichstein** (ZPE University of Siegen)

Dr. Reichstein presented two research projects, KoKoP and iTP.si-wi. Both focused the needs cooperation and coordination between local disability and long-term care support systems, alongside social psychiatry. Building on results of the KoKoP project, iTP.si-wi focused on approaches to integrated local planning in the aforementioned fields.

The goal of these studies is fostering a broader approach within social security services and widening the focus and targeted groups, as support needs constitute a common experience over one's lifetime. In fact, most people with a disability acquire their impairment at some point in their life, with an increasing likelihood with ageing. The cooperation between social security services is necessary to ensure that gaps between them are identified and addressed. Not bridging the existing gaps between services may lead to sectorisation, as emerged in the KoKoP research.

As an example of sectorisation, Dr. Reichstein discussed the fictional case of Fiona Fink. Fiona, a 63-year-old woman, lives in a residential facility for 24 persons with ID. After injuring herself, she undergoes surgery. Once completed, Fiona returns home. The healing process takes time and consequently the support needs increase posing a challenge to the staff that support Fiona who are not trained to deal with them. This results in three potential outcomes:

• Fiona remains in the residential facility with insufficient medical support due to the lack of trained staff.











- Fiona moves to a long-term care facility, losing her network and living with much older people.
- The residential facility cooperates with local services (intersectoral cooperation).

BILITY STUDIES

Both intra- and inter-sectoral cooperation are crucial, but they are not part of the services' daily routine. Therefore, cooperation between service providers is vital to reach coordination, which should ensure a smooth and effective service provision.

Creating a coordinating actor ("neutral third party") that knows the capabilities of the various fields involved and establishes coordination would represent an improvement in this direction. To this extent, these aspects need to be defined:

- Definition of decentralized planning spaces to reduce complexity and approach individual living environments.
- Initiation of case-related and case-nonspecific cross-field network relationships with spatial reference.
- Establishment of cross-field contact points (example of TePS: service that can help individuals using foster cooperation of social service provision).

During the Q&A session that followed, representatives from Moldova encouraged the use of the social valorisation approach which prescribes that targeted individual should live within the community and be included in the social fabric. They would also like to broaden the overall scope by targeting other types of services.

At the same time, it was acknowledged that the development path strictly depends on each country's social system background. Nevertheless, it is assumed that policymakers play an important role, so do service providers and municipalities which are asked to foster the integration of the services to help people in need.

ZonMw





DISABILITY STUDIES







# Parallel Workshops: sharing innovative practices and identifying next steps for research and policy agenda

## Workshop 1: Independent Living and integrated care & support

The workshop was introduced by the explanation of UNCRPD Article 19, which stresses the right of Persons with Disabilities to live independently and be included in the community. The focus of the workshop was sharing models and interventions that had successfully applied this community-basedinclusion practice to older populations with long-term-care and support needs.

## Workshop 1.1: UNIC



**Renaud Scheuer** EASPD Head of Knwoledge and Innovation

Renaud Scheuer, from <u>EASPD</u>, presented <u>UNIC</u>, an EU-funded project which aims to support the transition to user-centred funding models in long-term care by developing innovative instruments to support the take-up and scaleup of the Personal Budgets system.

The project is divided into four phases:

- Mapping out existing practices.
- Developing a toolbox for the quality & compliance monitoring of Personal Budgets by service users, service providers and public authorities.
- Piloting the toolbox.













Scaling up and transferring to Austria, Czechia, Finland and Spain.
The project design - promoting user-centred funding models, empowering users to improve quality of services and quality of life, contributing to deinstitutionalisation – should be transposed and applied to long-term care systems for older people.

## Workshop 1.2: AtOrl

DISABILITY STUDIES



**Eléonore Segard** Université Sorbonne Paris Nord, ATORIProject

Eléonore Segard from the <u>Université Sorbonne Paris Nord</u> presented the ArOl project, which concerns autonomy, intended as a human right, and the autonomy-oriented interventions for elderly and persons with disability.

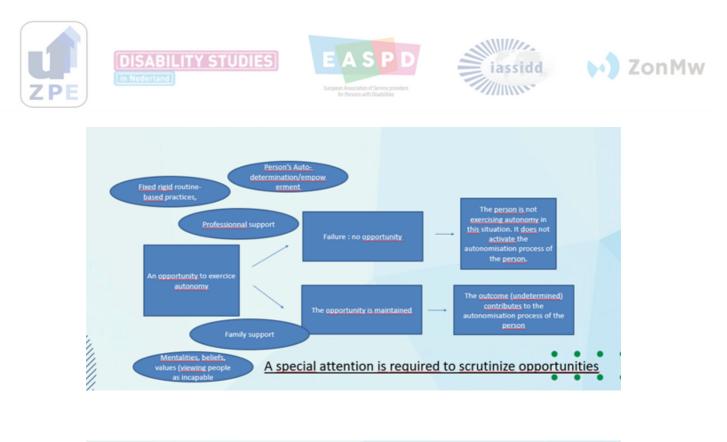
Autonomy, as an inner human being component, depends on a variety of factors that are different for every individual. Therefore, as a multi-faceted feature of life, it requires a comprehensive approach. There is a new paradigm should shift from "rational autonomy", focused on individual independence and being autonomous "alone" to a "capabilities" approach, where capacity and capabilities are considered as a combination of internal and external factors. This would result in "relation autonomy", where the focus is set on the interdependence that the environment (external) and the relations (internal) posed to one's autonomy.

Research acknowledges the process to reach autonomisation is a dynamic one and – as stated in the previous paragraph – it depends on and could be hindered by internal and external circumstances. This implies that the role of family and professionals is crucial in fostering autonomy opportunities and

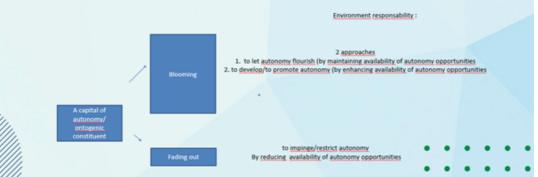
avoiding potential threats.







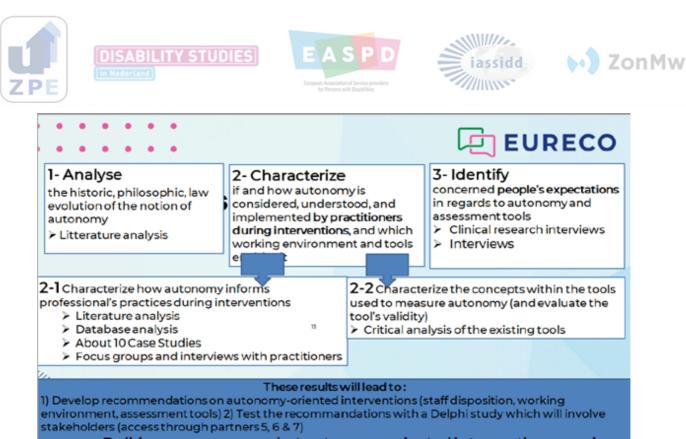
Autonomisation : a dynamic process through the life cycle highly influenced by the environment



Hence, the final aim of the project is building a consensus on what should guide "autonomy- oriented interventions". For such interventions these requirements are assumed to be pivotal:

- A specific professional disposition.
- A specific working environment that enables that professional disposition.
- A support and evaluation of autonomy that considers the uniqueness of the people concerned and their aspirations towards autonomy.

| ٠ | ٠ | • | • | • | ٠ | • | ٠ |                                          |              | • | ٠ | • | • | • | • | ٠ | • |
|---|---|---|---|---|---|---|---|------------------------------------------|--------------|---|---|---|---|---|---|---|---|
| • | • | • | ۰ | ٠ | ٠ | ٠ | • | 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1 | Co-tunded by | • | ٠ | ٠ | ٠ | ٠ | ٠ | ٠ | • |
| ٠ | ٠ | ٠ | ٠ | ٠ | ٠ | ٠ | ٠ |                                          |              | ٠ | ٠ | ٠ | ٠ | ٠ | ٠ | ٠ | ٠ |
|   | • | • | ۰ | • | ٠ | • | • |                                          | -            | • | ٠ | ٠ | • | • | • | ٠ | • |
|   |   |   |   |   |   |   |   |                                          | 12           |   |   |   |   |   |   |   |   |



Build a consensus on what autonomy-oriented interventions require

## Workshop 1.3: Integrated care & support-challenges for service providers



#### **Inge Skestere** Latvian Movement for Independent Living

Inge Skestere, from the Latvian Movement for Independent Living, gave a presentation on the approach to independent living focused on finding balance over the lifetime cycle. The impact of life activities balance on health and well-being (self-care, productivity, and leisure) is defined through "Occupational balance". To help older persons and persons with disabilities achieve such balance, support should target active ageing for older people and "reaching maximum potential" for persons with disabilities, respectively. Such a goal is still hampered by an ongoing strong focus on inability within both groups, which leads to passive care approach and limits independent living opportunities.













Workshop 1.4: Promoting independent living via community-based approaches



**Ludmila Malcoci** Keystone Moldova Executive Director

Prof. Ludmila Malcoci, Executive Director at <u>Keystone Moldova</u>, discussed the community-based approach to independent living. To achieve this mission, she outlined these main activities:

- Deinstitutionalisation and prevention of institutionalisation.
- Inclusive policies, in line with the CRPD.
- Inclusive mainstream services and community-based support services.
- Advocacy and self-advocacy.
- Friendly community environment.

The pillar supporting the project is the "Social role valorisation framework". In this framework, individuals at risk of not being seen as valued members of society should be included in social groups that are meaningful to them, developing skills and projecting a positive image of themselves. From this derives a person-centred-planning approach, which is based on:

- Assessing individual's needs.
- Active involvement of persons in the planning and implementation process.
- Supporting role by relatives and community stakeholders.
- Follow-up sessions to measure progress and establish new objectives.







Within the scope of the project, "self-advocacy groups" – established worldwide since 2014 – play a substantial role. They aim at building capacity in human rights, self-determination, advocacy activities, discussing draft laws/policies, developing recommendations as well as monitoring the implementation of policies.

Workshop 1.5: Improving collaboration between care for older persons and persons with disabilities



#### **Tim Kind**

Policy Advisor ActiZ (NL), Dutch employers organization for long term careproviders

Tim Kind, from the <u>ActiZ Dutch employers' organization for long term care</u> <u>providers</u>, introduced the different approaches used for the elderly and persons with disabilities in the Netherlands. While the first group is still subject to medical/nursing models, the second benefits from participation





• • • • • • • •









and inclusion models. However, the differences between these models are slowly diminishing due to demographic changes and policy developments. The ageing Dutch population has become a political theme which has boosted a shift from professional care to:

• Wellbeing and participation.

ISABILITY STUDIES

- Self-reliance.
- Informal care and support.
- Community care/housing.
- Prevention.

These changes have already taken place – at least to some extent – for persons with disabilities, which makes the sector more advanced and richer in practices that could be transferred and implemented within the elderly sector, such as:

• A more 'open' labour market due to a broader variety of work and a more inclusive approach to workers.

• The education programs curricula focus more on self-reliance, wellbeing and participation.

- A more inclusive approach to informal caregivers.
- More experience with innovative community care/housing projects as well as with creative concepts concerning wellbeing.
- Digital innovations concerning independent living.

However, with ageing, many persons with disabilities face difficulties that are more common within older persons (e.g. dementia or physical problems). This means that also the sector for older people could pass good practices onto the other. For instance, significant experience with geriatric illnesses and the application of digital innovations may be relevant to persons with disabilities.











Workshop 2: Assistive technologies and integrated care & support



**Robert Jabroer** ZonMw

In the second workshop, the discussion investigated the practicalities of technology use by people with disabilities at home. Reality is far from being what research suggests. Though a powerful tool, technology must be tailored to individuals' needs, which results in higher costs and poses challenge in making it affordable to end users.

In his introduction to the workshop, Robert Jabroer, from ZonMw, explained the nature and role of assistive technologies and the importance they play in the lives of people with support needs.

## Workshop 2.1: Robotics & New Eugenics



Jane Stugar Kolesnik Disability Studies NL

Jane Stugar Kolesnik, from the <u>Disability Studies NL</u>, focused on the stigma of robotization and how robots in families can take away agency. Assistive technology is often designed and handed over to people with support needs who must adjust it to their needs. This paves the way to self-stigma. Supported persons may consider themselves as a "social failure", internalising negative aspects of their external perception, feeling of being "broken" and having to use such technology in their everyday life. Hence, co-designing,

the European Union









supporting, and assisting rather than adapting, fixing, or improving become crucial in avoiding the end users' stigma perception.

To conclude, these arguments need to be considered:

**SABILITY STUDIES** 

- Being aware of the impact of technology before developing it.
- Avoiding self-stigma.
- Including assistive technology's end users in its development.

• Combining techno-social design processes with Inclusive Research principles and avoiding technological language and techno-centric approaches.

# Workshop 2.2: Technology can support older adults to self-manage health and wellbeing



**Dr. Julie Doyle** <u>NetwellCASALA</u> Dundalk Institute of Technology,Ireland

The second presentation was given by Dr. Julie Doyle, from the <u>Dundalk</u> <u>Institute of Technology</u>. She said that with more than 10% of Europeans living with a form of multimorbidity, technology could play an important role in helping them manage their health and data related on their own. To this extent, Dr. Doyle stated that developing apps that track and store data is the easy part. The real challenge revolves around making them userfriendly.

Dr. Julie Doyle proceeded to present the <u>Horizon2020 SEURO project</u> tool, PROACT, which enables individuals to monitor and manage their own health data.

Data gathered through the platform showed that users improved their overall health parameters, which resulted in a lower amount of symptom alerts















reported. They also became more aware of their conditions and were more inclined to use ProACT to notify on health changes and wellbeing behaviours.

The success of these kinds of platforms depends on several factors, such as:

- Understanding users' needs and requirements.
- Co-design.
- Usability and accessibility.
- Benefits experienced.
- Training and support when needed.
- Clinical oversight.

## Workshop 2.3: SweetHome



Lilith Alink EASPD/SweetHome project on accessible home

Lilith Alink, from EASPD, presented "<u>SweetHome</u>", a project for assistive technology for persons with disabilities. The aim of the project, which is currently ongoing in five different countries, is to enable users to live a more comfortable, independent, and self-determined life in their own homes, using smart home technology. The project foresees a period of guidance, where needs, problems, interests and solutions are to be established in the users' home. As the second output, the course, persons with disabilities will be trained to adapt their Smart Homes for independence and autonomy. Lastly, the Learning Platform. This is to foster interaction and feedback from users, which make innovation possible, improving autonomy.

















## Workshop 2.4: CUPID project



#### John Wells South East Technological University &CUPID

John Wells, from the <u>Waterford Institute of Technology</u>, introduced the <u>CUPID project</u>. The aim is to improve the understanding of cancer prevention among people with intellectual disabilities through the establishment of an interdisciplinary network.

The rationale behind the project derives from WHO and UNICEF forecasts on the sheer increase in the need for assistive products in the next 30 years. The benefits of keeping up with demand and providing such technology are demonstrated by a consistent stream of research.

- Too often the focus is on cost of technology, instead than on cost-benefit analysis.
- Ecosystem is the bigger problem than technology itself. It is easier to focus on the technology and try to fix or adapt the product.

Technology also has the potential to do early diagnosis among older people with intellectual disabilities, but more research is needed. Overall, new technologies present clear opportunities, but also bring about new challenges.

















Workshop 3: Bridging local service systems for persons with disabilities and for older persons with long-term care & support needs



**Prof. Dr. Johannes Schaedler** University of Siegen

The workshop tackled the question of linking up various service systems, covering the current situation in four countries Italy, Czech Republic, Germany and Bosnia-Herzegovina, listing current practices, exploring problems and identifying future research questions. Prof. Dr. Johannes Schaedler, from the <u>University of Siegen</u>, shared the introductory remarks on the topic and presented the Integrated Social planning in Seigen-Wittengstein region.

## Workshop 3.1: Integrated social planning in Siegen-Wittgenstein

#### **Reiner Jacobs**

Social Welfare Counsellor (District of Siegen-Wittgenstein Germany)

Reiner Jacobs, Social Welfare Counsellor (District of Siegen-Wittgenstein Germany), introduced the general situation in Germany, where welfare state and local policy face major challenges including demographic changes – with marked differences between rural and urban regions – social inequality, rising cases of people dependent on support and segregation tendencies.













The political objective of the region is full participation, reliable provision extending social services in rural districts as well.

A four-field integrated planning for the Siegen-Wittgenstein region was presented, focusing on youth services, social aids, healthcare, and local politics. With ensuring and improving participatory opportunities of citizens and service provision in mind, the strategy relies on three pillars:

- Prevention  $\longrightarrow$  set of challenges the project could be faced with.
  - o Defining the understanding of service delivery in the municipality.
  - o Establishing unbureaucratic, life-course-based, tailorized support systems.
  - o Focusing on strategy rather than reaction.
- Procedure  $\rightarrow$  methods of evaluation.
  - O Having a comprehensive look at living conditions in the social space on a small scale and over time.
  - o Quantitative and qualitative methods to assess such conditions.
- On-site → local integrated approach.
  - o Cooperation between administration, service providers.
  - o Social reporting and monitoring.
  - o Recommendations for action and strategic decisions.
  - o Local government supervision.

















Workshop 3.2: A perspective on integrated care for people with disabilities & for older people with long-term care needs in Tuzla



**Prof. Dr. Bratovčić** University of Tuzla, Bosnia-Hercegowina

Prof Dr. Bratovčić, from the <u>University of Tuzla</u>, presented an analysis of the existing support models for people with disabilities and older people with long-term care needs in Tuzla.

The original development of such models was conceived under the framework of the "caritative" and "medical" approach, without the consultation of relevant organisations and targeted persons. Currently, a significant extent of health care services are not properly targeted and are often unavailable to all who need them. In addition, the provision of services is demanded from NGOs and depends on financing from donors. This results in services that are not tailored made on the users' needs and are financially unsustainable in the long run.

The establishment of new support models is opposed by many. People who would not benefit from such models do not deem them as necessary, while people with disabilities prefer models based on providing direct money transfers, which contribute to their monthly income.

From a legal point of view, Bosnia Herzegovina is a signatory of several international acts that support fundamental rights, freedom and the principles of elderly protection. The national constitution prohibits any form of discriminatory conduct.

0 0 0 0 0 0















Prof Dr. Bratovich then focused on the elderly, which represent a highly vulnerable category. Low monthly income, increased living costs, and a variety of conditions that hamper daily living are among the main issues this group faces. This results in a limited capability of maintaining healthy life standards and a lack of inclusion and active participation in the social fabric, which worsens the former.

This vicious cycle also impacts the national health service. Medical examinations waiting lists are getting longer and the inadequate support offered makes the costs soar up. Insufficient housing units – mostly located in the urban areas – and inadequate training of staff intensify the discomfort for old people and persons with disabilities.

New models of support should focus on:

DISABILITY STUDIES

- Providing independent living.
- Personal assistance and planning.
- Opportunities to participate in the activities of the local community.
- Social housing and rehabilitation services.

The implementation of this system requires several steps. Firstly, special laws should be passed to regulate them. Secondly, models of financing should be based on a mixed approach where different institutions and authorities could participate. Entity regulations should ensure the coverage of the costs of the basic package services. People with disabilities and the elderly could also participate in covering some of the costs to the extent of their usage if it is greater than expected.

To conclude, though disability and old age are complicated conditions, Prof Dr. Bratovich stated that solutions in the Bosnia Herzegovina region can be found. Special law on local authorities should address geographical imbalances, a new support system with target financing from multiple sources should be set up and professionals working with these vulnerable groups should be trained in a holistic approach.

















Workshop 3.3: A perspective on Integrated care for people with disabilities and for older people with long-term care needs



**ABILITY STUDIES** 

**Simone Zorzi** Director of services for people with disability, Azienda Sanitaria Universitaria Friuli Centrale

Simone Zorzi, Director of services for people with disability within the <u>Azienda</u> <u>Sanitaria Universitaria Friuli Centrale</u>, focused his intervention on the case of Friuli Venezia Giulia region, north-eastern Italy, where one in four inhabitants are over 65.

Within the region, approximately 11 thousand elderly people are hosted in 166 residential facilities. At the same time, the regional social health system follows around 1700 people with intellectual disabilities. The main service provided is health day-care centres programs, which represents the most used one compared to the newer community-based or individual support plans.

Between these two groups needs are similar. However, in the fulfilment of their rights (e.g. social inclusion, independence, and self-determination), people with intellectual disabilities face barriers from an early stage, while older people's main issue is the interruption of services.















#### The needs of older persons and persons with disability – FVG Region Services

| Needs                                       | Persons with intellectual disability                                                                                                                         | Older persons                                                                                                                 |
|---------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|
| Support needs for<br>individual functioning | A continumm of supports needs<br>From minimum to very high level<br>(APA, 2013)                                                                              | A continumm of supports needs for<br>From minimum to very high level<br>(Slangen-De Kort, Midden, Aarts, van Wagenberg, 2001) |
| Cognitive impairments                       | A continuum of cognitive impairment<br>From profound to mild<br>(APA, 2013)                                                                                  | 73% of persons had a cognitive impairment<br>From profound to mild<br>(Murman, 2015)                                          |
| Behavioural disturbs                        | The 47,4% had one ore more behavioural disorders<br>(Rattaz, Michelon, Munir & Baghdadil, 2018)<br>(Crocker, Mercier, Lachapelle, Brunet, Morin & Roy, 2006) | The 10% had one ore more behavioural disorders<br>(van der Linde, Stephan, Matthews, et al 2010)                              |
| Health conditions                           | More of the 50% had a health conditions vulnerabilty<br>(Uao, 2021)                                                                                          | More than 70% had a health conditions vulnerability<br>(Jaul, 2017)                                                           |
| Psychopatological<br>disorders              | The 65,6% had a psychopatological disorder<br>(Borthwick-Duffy, 1994; Cooper, 2007; Sheehan et al.,<br>2015)                                                 | The 45% had a mood disorder<br>(Palese et al. 2018)                                                                           |

Improving the services offered requires a change in the political and organisational system of the region. For instance, a questionnaire has been created to map and evaluate the living conditions of people with disabilities aiming at tracking the impact of the change. However, current data shows that living conditions are hampered by several risks including spending time in the same service, having few opportunities to learn about self-care, develop cognitive skills, and participate in the life of the community. Estimates suggest that these figures are even worse for the elderly with longterm needs.

The final aim should be to target the integration needs with rights (through both objective and subjective indicators). To this extent, quality of life models are relevant in defining a path to reach it.

A person should be prioritized as a human being with a specific identity, whose construction – crucial to the quality of life – largely depends on the opportunities that are provided. Data shows that providing opportunities to access community life through, for instance, community-based programmes, has a positive impact on learning outcomes and building relationships for old

people.













To conclude, implementing a person-centred approach would represent an advancement from a social perspective and would be beneficial towards the wellbeing and inclusion of old people and persons with intellectual disabilities in the social fabric.

Workshop 3.4: Perspective on integrated support for people with disabilities and for older people with long-term care needs



DISABILITY STUDIES

Dr. Sarka Kanova University of West Bohemia



Mrg Lukas Maran <u>City of Pilsen</u>

Dr. Sarka Kanova and Mrg Lukas Maran presented the case of Pilsen. The Czech city counts around 190.000 inhabitants of which roughly 40.000 are people of over 65 years of age.

Historically – before 1989 – social services were provided by the State only. In the following 15 years, with the creation of an ad hoc legal system, new providers were created and alongside the transformation of the old ones the differentiation of the services nature (institutional, semi-institutional, and community-based) became a reality. The current structure is composed of a large proportion of registered social services services provided within the city or within driving distance. The overall capacity of residential facilities for senior citizens in the city is equal to 781 units.











To give an overview on the different services still in use and their transformation, the speakers shared three examples:

- Institutional service  $\longrightarrow$  Children Centre Pilsen programme
  - o Services to infants (0–3-year-olds) and young adults with intellectual disabilities. It has recently started a transition into a more inclusive centre of complex care.
- Semi-institutional service → Senior residence Terasy
  - o Services provided are not limited to the ones required by the law.
- Community-based service
  - Revamping of former large institutions for persons with disabilities, regional volunteer centres and newly established Department of accessible housing and social inclusion

In their final remarks, Dr. Sarka Kanova and Mrg Lukas Maran stressed the importance of creating a community environment on a local and small scale to foster specialized and individualized support and create opportunities for life in ordinary conditions.

















### Fishbowl discussion



#### Alice Schippers IASSIDD/Disability Studies NL

During the discussion, Alice Schippers, from the <u>IASSIDD-Disability Studies NL</u>, summarised the various instances brought up in the morning into a clear message. She addressed the tendency of administrations to objectify persons with disabilities and old persons, creating segregated age-specific life domains. Dr Schippers supported the necessity to shift towards more collaborative and inclusive policies and practices.

## **Fionnathan productions**





**Fionn Crombie Angus** IASSIDD/Fionnathan Productions

Jonathan Angus IASSIDD/Fionnathan Productions

Following this introduction, Fionn and Jonathan Angus presented the <u>Fionnathan productions</u>, a social enterprise based on three pillars:

- Education
- Media
- Arts

They are involved in several research activities with from volunteer organisations, academic partners, inclusive research networks, governments,













and independent research. Fionn and Jonathan's experience shows that directly involving people with disabilities in research design and implementation has a substantial impact in re-organising and re-shaping mainstream research. The importance of this practice had been also highlighted by Jane Stugar Kolensik, in the morning session.

The floor was then given to participants for an open discussion. These were some of the key discussion points:

BILITY STUDIES

• Our sectors should work on individuals' needs and a person-centred approach, rather than a generalized and fit-to-all one.

• Speakers discussed the centrality of social inclusion and evolution of care needs over the lifetime.

• There is renewed interest over the notions of relational autonomy and interdependence. The focus should be on working to support an individual towards autonomy in their interaction with the surrounding environment.

• We observe a shift to a new paradigm of social services, taking into consideration a multidimensional approach, integrating persons' quality of life, but also the environment.

• The deeper integration of support systems and needs remains a key objective, although its many challenges will require further discussion.

• These notions, as well as the crucial focus on inclusive research, are elements of answer towards effectively steering research questions and boosting their funding.

















## Policy panel



A policy panel followed by a Q&A session took place as the final session of the event.

As introduced by moderator Konstantina Leventi, from EASPD, the discussion focused on the strategies and recommendations on long-term care. Participants agreed on the need to improve access to relevant services and instruments and assess whether these have a positive and tangible impact on service users.



#### Flaviana Teodosiu

**European Commission** 

Flaviana Teodosiu, from the European Commission, stressed how the ageing of the EU population prompted the development of the <u>EC Strategy on long</u> <u>term care</u>, which was further propelled by the outburst of the COVID-19 pandemic. Among others, quality and affordability of services, lack of trained workers, and the uneven development of new programs (e.g. communitybased care) around the Union are crucial issues to be addressed. Through the Communication on the EU Care Strategy, the Commission demonstrate its intention to financially support the sector, targeting the quality-of-care services, work-life balance, and the monitoring and evidence-collection progress. The Commission has also invited Member States to nominate referents to supervise the implementation of the measures on long care.













.

This plan relies on a person-centred approach aiming at full integration among services to avoid people from falling between the cracks of a system that is not yet coordinated.



DISABILITY STUDIES

#### **Klaus Niederländer** Director of AAL Programme from 2017-2022

Klaus Niederländer, former Director of the <u>AAL- Active Assisted Living</u> <u>Programme</u>, emphasised the demographic transition as a common concern the Union is facing. In such a situation, technology plays an important role in guiding the transition. Digital tools represent both a means to build social infrastructure and a learning tool. Leveraging these instruments to collect data and information from people would help us shape a better future. The use of such systematic innovation represents an unprecedent opportunity to tackle issues such as physical and mental frailty or loneliness. However, to reach such a goal, new financing models and more integration among different sectors are required.



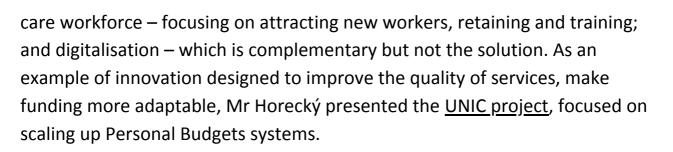
#### **Jiří Horecký** European Ageing Network

Jiří Horecký, from the <u>European Ageing Network</u>, recalled what had been said by previous panellists demanding a call for actions on re-shaping and reforming the long-term care system. Postponing this action to change, which is a mere political decision, increases current and future costs. According to Jiří, the three main challenges in the sector are: funding – which is scarce,insufficient to cover real costs and unsustainable in the long run;









1/////

ZonMw



DISABILITY STUDIES

Haydn Hammersley European Disability Forum

Haydn Hammersley, from the <u>European Disability Forum</u>, stressed the importance of giving users the right to choose their preferred types of care. He also underlined how care is key in allowing users live independently and access the surrounding environment autonomously. Indeed, keeping the user at the centre of service delivery and research is essential, not only to respect the values and principles of the UN CRPD, but also to lead to more accurate and efficient results. This is an area where the sectors of long-term care for persons with disabilities and for older persons can learn from one another.



Sylvain Renouvel Social Employers

Sylvain Renouvel, from the <u>Social Employers</u>, focused his speech on the need for investments on sustainable financing and appropriate wages for staff, which implies a more in-depth work on the image of the sector to – for example – attract more talents, foster healthy working conditions, trainings and career opportunities. Furthermore, re-skilling and clear career perspectives are needed to retain current and new staff. Overall, these

. . .



Co-funded by the European Union .

. . .



DISABILITY STUDIES







priorities should improve the attractiveness of the sector for its workforce. As demand for services will continue to grow over the coming years, the sector's potential for employment is considerable, but this potential will only be realised if adequate funding is allocated to tackle its current challenges in staff attraction and retention.

## Q&A

In the discussion that followed, migration of care workers and working conditions were brought up as topics of interest among the participants. As for the first topic, Flaviana Teodosiu underlined that, even if the trend of Eastern European care workers migrating towards Western or Northern European countries is not as marked as in other sectors, improving working conditions in their home countries is crucial. It also emerged that in the countries of origin, wages are increasing at a faster pace than those in the hosting western European countries.

As currently Eastern European countries are lacking professional staff in the sector due to relocation, increasing wages in their home countries makes their willingness to move back in the next future plausible, which will likely create a shortage of care workers in the hosting countries.



**Martijn Da Costa** ZonMw

To conclude the event, Martijn Da Costa from ZonMw, underlined that the commitment of persons with disabilities and older persons to contribute to the discussion is crucial for substantial progress. He also stressed the importance of technology accessibility in research, which could pave the way for practical suggestions and contributions to new scientific proposals.













. . .

## Conclusions

SABILITY STUDIES

Throughout the event, the participants including service providers and users, researchers, and public authorities, have discussed the key dynamics of services for older persons and for persons with disabilities. Some of the crucial questions raised were how the integration efforts have evolved over time and across regions, what each sector can learn from the other, and what is needed to support the development and implementation better integrated services designed to support older persons and persons with disabilities in the enjoyment of their rights and of a valuable role in their communities.

In addressing these questions, the participants have highlighted the importance of further collaboration, not only across types of stakeholders (as, for instance, continued dialogue between academia and organisations working on the ground is essential), but also across sectors. This collaboration could be structured along further research, or European projects, as discussed in the closing session of the Forum, as well as in the project proposal brainstorming session that took place the following day. In any case, such cooperation will seek to always involve peer experts and service users as key, central stakeholders, and use the principles of the UN CRPD as their guiding document.

### Next steps

The EURECO partners are currently exploring potential follow-up research and projects 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 visiting <u>the brand new EURECO website</u>. Joining the network will ensure that you receive information on future events and









research or funding opportunities, as well as being connected with other researchers to identify topics or initiatives of interest.

For updates on upcoming studies and events, please contact: Renaud Scheuer EASPD Head of Knowledge and Innovation +32 2 233 77 20 <u>Renaud.scheuer@easpd.eu</u> <u>www.easpd.eu</u>







