

# **EURECO Forum 2022: Report**

New perspectives on quality and outcome measurement of services for persons with disabilities

24-25 March 2022, Brussels Belgium











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# **Executive summary**

On 24<sup>th</sup> and 25<sup>th</sup> March 2022, the European Association of Service providers for Persons with Disabilities (EASPD) and its partners co-hosted the sixth annual European research platform for inclusive community planning and service development for people with disabilities (EURECO), to discuss recent developments linked to quality of services for persons with disabilities.

The EURECO-Forum 2022 has tackled this question by bringing together service providers and users, researchers, public authorities, and other stakeholders, with the objective of discussing the ongoing trends and the key priorities for the development of quality frameworks for services of excellence.

With regards to a UN CRPD-oriented and user-centred philosophy for services, the Forum has identified commonalities and differences between the former quality assurance debate and the more recent discussion on effectiveness and outcome measurement. Additionally, the participants have identified crucial areas for further research and collaboration in order to make services more efficient, inclusive, and adaptable. As the new generation of services emerges from the ongoing COVID-19 pandemic and the twin green and digital transitions, developing and implementing quality frameworks is a priority for the whole disability support sector.

# **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 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.

#### 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 quality of services

On European and national level there is a renewed interest in what quality means for services for persons with disabilities. This relates to the upcoming EU Care Strategy, as well as the European Commission's intention to launch a European framework for social services of excellence for persons with disabilities.

- What impact do support services have on the quality of life of persons with disabilities they support?
- How can quality of life outcomes be measured? What works and what doesn't?
- How can the UN CRPD principles be an integral part of these concepts and methodologies?
- What indicators are appropriate to measure to what extend services comply with the UN CRPD principles?
- How are service users involved in measurement? What happens with results?
- What current practices are regarded as successful? Are there innovative practices?
- What expectations have Public Authorities as funders of services for persons with disabilities towards outcome measurement? What does this mean for service providers?

These questions seem familiar to the disability sector and its scientific community. They link to debates on quality of life and quality assurance in disability services. The origins of these debates can be traced back to the US, Australia, New Zealand, and the UK in the 1980s, followed by similar developments in other European countries in the 1990s. Yet, the formal quality assurance systems in this field continue to predominantly relate to measuring the quality of service, with too little progress made towards measuring quality of living conditions.

During these decades, there was also a major shift in funding systems for social services in many European countries. These systems were restructured as market systems with elements of contracting and competition between services. The philosophy was to foster self-determination by creating "consumer choices" between services for persons with disabilities, primarily through the public procurement systems, that was expected to achieve 'value for money' from service providers. In addition, consumer choices were to be increased by implementing user-driven funding mechanisms such as personal budgets.

Quality of services became a crucial element in the contracting procedures between authorities and services. One of the concrete results was the establishment of quality management (QM) systems, that in some EU-countries became even obligatory for certain types of disability services (e.g. for sheltered workshops in Germany). Critics of the time observed that within this framework service providers successfully implemented QM-

systems in their institutions. However, they did so without questioning the appropriateness of the institution format for a modern individualized support service. Institutional care and budget-based funding (either for entire facilities or for single places) obviously tend to favour approaches of measuring the overall quality of a service organization and to focus on correctness of institutional procedures rather than the outcomes of the services on persons with disabilities.

The impulses of the UN CRPD promoted a rights-based approach on the understanding of disability that focussed on the interaction of a person's impairment with barriers in his/her environment. This opened the perspective to aspects of participation and inclusion in community life in the life-courses of people with disabilities beyond the boundaries of services. This can partly explain why so far outcome-based quality measurement systems have remained only of low importance for the practical funding and reporting procedures between by public authorities and service providers in most European countries.

But is this satisfying? What is the state of the debate /what are the bottlenecks? What can be learnt from a cross-European perspective? What are next steps? What role is there for the EU?

One hypothesis is that guaranteed individual entitlements for social services in welfare state arrangements encourages practices of person-centred support for persons with disabilities in some countries. This is further strengthened when added by individualized funding systems for support needs. Concepts for outcome measurement of services should focus both on an informed individual assessment of persons with disabilities on the quality of their service arrangement and an assessment on the standards of their living conditions. This raises questions on how persons with disabilities can be involved in outcome measurement procedures in substantial ways that go beyond simple subjective satisfaction measurement instruments.

These considerations were the focus of the 2022 EURECO Forum, as detailed in the overview of the sessions below.

#### Overview of the event

# Keynote address 1

Prof Julie Beadle-Brown (University of Kent, IASSIDD) (PPT)

**Professor Beadle-Brown** presented the <u>report</u> that she, together with Jan Šiška, have been working on over the past year. This research was commissioned by EASPD to investigate the existing quality frameworks in use around the globe with the objective to develop a draft set of indicators of service quality that EASPD could use as a framework for measuring service quality. This framework is part of the upcoming initiative for a European Framework for Social Services of Excellence.

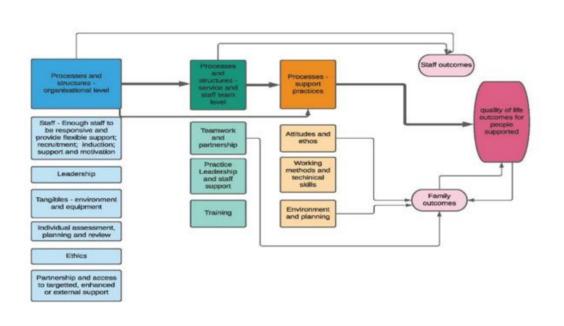
The motivation of the study arose from the observation that from 2007 to 2020 there has been very little change about the independence of persons with disabilities. The researchers found that there was no consistency across services when measuring the quality, and that data was difficult to obtain or even non-existent. In those cases, where data was available, the researchers found that it did not lead to an improvement in the quality of services. Therefore, the main objective when developing a framework to measure service quality should be to lead to measurable, concrete improvements in the services and in the quality of life (QoL) of the users, rather than focusing on collecting data with no direct link to improvements.

Together with the literature review, the report includes an analysis of templates that were given to organisations requesting the available voluntary frameworks, the current policy in their country and the expectations of the users of these services. As a result, the researchers have identified two major frameworks across the globe: the Schalock et. Al (2002) quality of life dimensions, and the Donabedian's model focused on structure-process-outcomes.

On this basis, the research team has developed quality indicators by combining the successful elements of the mentioned models, which focus on three levels: outcomes, support practices, and processes and structure.

By analysing the family outcomes such as personal development and the staff outcomes such as the ethics or the leadership of working in the organization, the indicators seem to be successful in capturing the key aspects of the reality of users, and to be accepted by the stakeholders. The most innovative aspect of these indicators is the inclusion of personal assessments.

During the questions and answers session following her presentation, professor Beadle-Brown stated the importance of visiting the organisations to verify the services provided and the need to adapt indicators and measures to every service, since the expectations and necessities will vary from one to another. An interesting contribution from the audience was shared by Elisabeth Lammers, from UNAPEI, who shared the quality label used in her organisation in France. Professor Beadle-Brown commented that such labels would be part of the next stage of the framework.



# Panel: Policy debate – What role for the EU?

Moderator: Thomas Bignal (EASPD). Panel: Emmanuelle Grange (European Commission), Haydn Hammersley (European Disability Forum), Karin Astegger (Lebenshilfe, Austria).

Emmanuelle Grange addressed some of the latest efforts of the EU Commission regarding services for Persons with Disabilities (PwD). Ms. Grange highlighted that the main goals are to achieve accessible and inclusive services for PwD and their families. As all persons must have equal conditions to enjoy their human rights, services need to be inclusive and accessible, with the objective to allow people to live independently. In this context, Ms. Grange introduced the initiatives and documents of the European Commission for 2024, the framework of which will broaden the scope of previous initiatives, including improving and upskilling the staff of services providers. In addition to this, the care strategy of the Commission will examine considerations of availability and accessibility, as well as the challenges facing long time care and informal care. Finally, Ms. Grange emphasised the

importance of such events in order to connect stakeholders and to continue reflecting on the topic.

Haydn Hammersley stated that a main concern of European Disability Forum (EDF) is to give PwD the right to choose how to live their own lives and include them in the community in equal conditions like others. Mr. Hammersley emphasized the necessity of funding services in the communities rather than in residences, since one of the challenges for PwD is the availability of services in their communities, including remote areas. Moreover, he also underlined the importance of having upskilled staff and therefore, the necessity of making the sector more attractive for new workers by improving salaries and working conditions. By increasing the number of workers, PwD will also have the chance to choose among a greater variety of staff for their service delivery.

**Karin Astegger** explained that Lebenshilfe Austria is enthusiastic about the tools developed to improve services and the QoL of PwD. However, she also emphasized that there is room for significant improvement. Ms. Astegger stressed the support needed to develop these improved frameworks, such as research-oriented expertise, increase in resources to integrate quality frameworks in services, and support from public authorities in terms of logistics for PwD.

During the Q&A section moderated by Thomas Bignal, **Ms. Astegger** was asked to share examples of key improvements for services users. She answered with the example of supporting people with personal budget or the availability of home sharing with assistance for PwD. However, Ms. Astegger also emphasised that when such innovative support services are being delivered to service users, they often encounter legal challenges in Austria.

Closing the session, **Mr. Hammersley** discussed the missing concept of Quality of Services in the article 19 of the UN CRPD. He stressed the possibility of choosing among the different settings to quantify what QoL is. Additionally, he underlined the importance to not separate the article 19 of UNCRPD from the rest of the Convention, since it does not operate independently. These considerations brought the Policy Panel to a close, with a clear view of the priorities of public authorities, but also of what is expected from and by service providers and users. These thus highlight both the existing frameworks and instruments available to support the development of quality frameworks, and the next steps identified by the stakeholders in this perspective.

#### Fishbowl discussion

Moderator: Alice Schippers (Disability Studies NL, IASSIDD). Speakers: Simon Duffy (Citizen

Network Research) presenting the UNIC project, Marije Blok (Leyden Academy on Vitality and Ageing) presenting the narrative accountability, and Martin Konrad (NuevaGmbH) presenting the quality assessment models.

A Fishbowl discussion is a debate format that takes place with participants sat in two circles, where those who want to actively participate in the conversation take a seat in the inner circle, before leaving their seat to the next participant. This session was introduced by presentations from Alice Schippers (Disability Studies NL, IASSIDD), Simon Duffy (Citizen Network Research), Marije Blok (Leyden Academy on Vitality and Ageing), and Martin Konrad (Nueva GmbH), before opening the floor to the other participants.

Alice Schippers (PPT) placed the emphasis of her opening presentation on the framework of QoL in the families. She stated the importance to include families, together with professionals, when moving from institutionalised care to community-based services. In this context, aiming to improve the QoL, considering values, laws, services, conditions of life and cultural factors, researchers have found a research gap in the outputs at both the system and individual level. At the organizational level, it is known that employment leads to improvements in the quality of life, but more research should be focused on exploring the impacts on QoL of the UN CRPD and the freedoms to choose a career path.

Among the participants joining the inner circle of chairs, Julie Beadle-Brown entered the discussion by stating her view that the problem is the persisting lack of services and support targeted to the family of a child with disability. Therefore, in this context the quality of services is key to improve the QoL not only of PwD but also of their families.

Elisabeth Lammers, from UNAPEI, continued the conversation pointing out the social pressure of families of PwD and recognising that nowadays, families are facing the same problems that she personally observed and experienced years ago. It is thus both concerning that so little progress has been made and encouraging that such events take place to bring this topic higher on the agenda.

Representing APPACDM Coimbra from Portugal, Alex Rebelo added that in his own experience, the outcomes of the assessments to measure the quality of life of his son have been useful and beneficial for the whole family, thus stressing those constructive initiatives do exist. To this, speaker Marco Lombardi from the University of Gent, added the consideration that research should be continuous, improving and identifying strategies that improve the QoL. Subsequently, Sasa Mlkar, representing public authorities from Slovenia, shared her personal experience of the services and support that Slovenian government gave her and her daughter such as the availability of psychologist and social workers at the school, or a paid personal assistant, thus emphasizing the role that public authorities can have in ensuring the delivery of quality services.

**Simon Duffy** introduced the UNIC project (website), which challenges the funding system and provides a framework and quality monitoring system for personal budgets designed for PwD. The project is ambitious since it challenges the resistance of the system by giving service users the control of their funds. This project, and the personal budget system in general, are examples of key initiatives designed to improve service delivery by putting the user at the centre, while also innovating in the way the quality of these services is monitored.

Dimitris Nikolsky, representing Greek public authorities, contributed that in his daily work in the public sector, the most important focus is to create an impact in the life and quality of life of people. After this, Nadia Hadad from European Network for Independent Living (ENIL) supported the importance of the project UNIC because it gives the freedom to people to decide how to spend the money allocated for their services. Ms. Hadad also stated the necessity of creating new services and making them personalized and adapted to the needs of the service user. She considers that we need to think in diversity and public authorities should have a greater level of implication, otherwise the transition from institutional care to daily care and the many challenges it comprises, will not be achievable.

Marije Blok (PPT) explained the key points of her research carried in two institutions in the Netherlands. Ms. Blok emphasized the need of giving elderly persons the time and the space to express themselves on their experiences about the services they receive. For this purpose, she emphasized the importance of including open questions and internal accountability when reporting the QoL, rather than giving service users closed forms and leading questions. In this way, it is possible to learn from their personal background when providing personal care. This lesson drawn from the sector of elderly care is eminently pertinent and suggests that further cooperation between the elderly care and disability support sectors would be beneficial to both.

Martin Konrad could not attend the event, but he has kindly prepared a video (<u>link</u>) of his presentation to be shared with the participants. His organisation involves users and services providers when defining quality, since their experiences help to shape the services. In this context, users develop questionnaires where they can express how they spend their leisure time, or their educational background, etc. After each evaluation of the data, which is collected by peer interviews, the team works to improve the quality of services in the light of the data provided by the key stakeholders.

This concluded the Fishbowl discussion, which was an effective method to actively engage the participants in the discussion process and discuss together some examples of innovative approaches to service delivery and quality assessment. As the first sessions of the day were designed to provide the participants with an overview of the key components of the

development of quality frameworks, before exploring the policy context and examples of existing practices, the rest of the day was dedicated to networking activities. These were designed to enable the participants to exchange on how various types of actors (e.g. service users and providers, researchers, public authorities, etc) can collaborate on these topics.

# Keynote address 2

Professor Johannes Schädler (ZPE Siegen University) (PPT)

Johannes Schädler, founder of the EURECO Network started the second day of the 2022 edition of the EURECO Forum. In his keynote speech, he underlined the necessity to define quality at the European level, in order to improve quality of services from the national to the local level. This need for common conceptualization arises from the observation of different developmental paths of disability services being developed in various countries. Mr. Schädler contrasted the analysis of the QoL domains presented by professor Beadle-Brown the previous day, stating that rather than focusing on efficiency, indicator should focus on legitimisation. This means that when creating a framework for measuring QoL, important aspects are that it is relevant for all stakeholders, that there is a common agreement on this approach by all parties, and that it is legitimised for every organization. When measuring the quality management, professor Schädler elaborated on assessment practices and stressed the importance of evaluating outcomes when measuring quality of services.

Then, Mr. Schädler introduced the perspectives of the evolution of quality assurance along the years: professional development, public management, and market model and its limitations, such as the active citizens needed in the market model. In this context, he presented the drives of innovation: disability rights movement and user control, governmental steering by contract management and public procurement, and individual service planning and isomorphic dynamics and development of services.

Finally, the presentation concluded by stating the need of creating conditions for independent living. This is done by analysing how people develop support, considering local quality dialogues, and reflecting on whether the quality of a region complies with a good implementation of the infrastructure.

#### Project development workshop

Speakers: Jolanda Huizer (ZonMw) (PPT) and Timothy Ghilain (EASPD) (PPT).

Following the previous sessions designed to present the key aspects of quality of services and to provide networking opportunities for the participants, the focus moved to the next

steps and what can be achieved in terms of projects and research. In this context, this session was prepared to give participants the chance to do brainstorming in groups and develop a potential proposal for a European project. Before this exercise, the speakers introduced the process and key aspects of developing a project.

Jolanda Huizer focused her presentation on essential factors to reach the desired impact with project and the things to consider when setting up the outline of the project. Firstly, there is not a common definition of impact, but at her organization, impact is defined as "being knowledge utilisation – the use of results of projects and programmes by people in the field, policymakers, educators and/or researchers".

Ms. Huizer explained that even though everyone seeks to have impact, it is really difficult to achieve it with only one project. Therefore, productive interactions are useful to see the impact of the project. In this context, she presented the four core elements that are key in every project of the organisation ZonMw to achieve the desired impact. These are: collaboration with relevant stakeholders, co-funding, deliverable of usable knowledge products, and specific dissemination.

**Timothy Ghilain** presented the different calls for projects that include quality of services. They are: JUST, AMIF, Horizon and Erasmus+. Since the following brainstorming session focused on the call for Erasmus+ projects, the speaker described this specific programme in detail. For any of these calls, the most important part is the idea, once you have developed this rationale, it is comparatively simpler to move to the next steps and search for funds.

Inside the Erasmus+ programme, we find KA1 focused on learning mobility, Erasmus students, teachers learning in other schools/universities, etc; KA3 is related to support policy development and cooperation; and KA2 focuses on cooperation among organisations and institutions. Inside KA2 itself, there is the alliance for innovation that is divided into Lot1 (education and enterprises) and Lot2 (sectoral cooperation on skills). This alliance aims to boost innovation through cooperation and flow of knowledge among higher education, vocational education and training as well as providing new skills and addressing skills mismatches by creating new curricula.

More specifically, Lot1 confronts societal and economic challenges, such as climate change, changing demographics, digitalisation, artificial intelligence, and rapid employment changes. As the European Commission encourages projects that cover green transition and inclusion, it is important to include them as elements of any project. On the other hand, Lot2 tackles skills gaps on the labour market that hamper growth, innovation, and competitiveness in specific sectors or areas. These projects are comparatively more difficult to develop and get approved, since the European Commission only accepts one project for each sector, which are tourism, digital, renewable energy, retail, among others.

For the brainstorming session which followed these presentations, the participants were divided into four group according to the topic of interest: cross-sectoral approaches for elderly care and persons with disabilities, skills to address demands of vulnerable groups, digital transition for quality of services, and green transition. Each group was tasked with identifying, for their proposal: the rationale, target groups, beneficiaries, deliverables and activities, expected results, and partnership.

The resulting projects proposals of this session were the following:

**Topic**: cross-sectoral approaches for elderly care and persons with disabilities.

The ambition stated by this working group was to develop a methodology to identify and exchange good practices in the care of elderly people, as well determining how these approaches could complement those developed in the disability sector, as many of the challenges faced by both sectors are similar, yet there is a lack of collaboration between the two, as well as a general lack of knowledge about where innovation could be focused. In order to implement such a project, the participants would gather a network of organisations working in the sector of the care of older adults, including service providers, universities, and other civil society organisations. Together, they would develop a state of the art report, an identification of good practices, and a course or training programme leading to improved skills for the workers of this sector.

**Topic**: skills to address demands of vulnerable groups.

The focus of this group was on a framework to evolve and improve services: service providers would share their experiences and explain how they have changed and continue to change their services. In order to provide experience and knowledge-sharing activities on how service providers change their services, the following points would be covered: how the process is structured, who is involved, how the community, is involved etc. This would cover various dimensions such as the organisations, the workforce, and the services delivered themselves. The project would plan a few meetings over 2 or 3 years with service providers and potentially local stakeholders who have been involved in the change of services. At the end of the project, there would be ideally a framework at EU level to design the change of services, in order to upscale this mechanism and transfer it to other regions.

**Topic**: digital transition for quality of services.

When considering the topic of digital transition, the participants mentioned the key element of the digital tools during the Covid-19 pandemic. All agreed on how essential was the digital transition during the months of lockdown when service delivery was heavily disrupted, even though this transition was done unexpectedly. Considering the lessons learnt from the pandemic, the participants have highlighted the lack of digital skills at all stages of the workforce involved in services for people with disabilities. In this context, the proposal

discussed would be for a project focused on implementing digital tools in the delivery of services for persons with disabilities, aiming to increase the quality of these services. To do so, the target group are teachers and students, as they were considered the beginning of the chain to implement digital tools in the delivery of services. In this line, the beneficiaries will be persons with disabilities. During the conversation, the activities proposed included workshops for teachers, digital classes for students, spaces where teachers and students can exchange digital practices, etc. During this project, the ideal partnership will be composed of service providers and universities but also technology companies that can provide digital devices. The expected results are the improvement of digital skills in the workforce of services for persons with disabilities, as well as, regarding the organisations involved, the transition to digitalise most administrative tasks, thus leading to more efficient work practices.

#### Topic: green transition

With many crises happening across the world, especially climate change, it is important to start educating people on the environment and how to practice green sustainability. The objective of this project would be to create a green and sustainable community in each area that it is introduced. Not only does it take a lot of education, dedication, and understanding to create a green community, but it also takes all types of people with different skills and passions, as well as different organisations. Starting at the local level in various countries such as Spain, France, Germany, Finland, and possibly the UK, the project would target people with disabilities and their communities. This project would focus on activities such as training workshops both on educating others about green transition and more practical workshops to be held amongst communities. It would also be ideal to have outputs such as online MOOCs available to every type of person that would be part of each community and have the MOOCs themselves be accessible and focused on mainstreaming green transition. The end result would be to have functioning and sustainable communities that focus on sustainability, the environment and working together. If these communities are successful, they can then create and lead other communities and make the idea of green transition more mainstream. There would also be a knowledge repository that helps those interested educate themselves on how to create a community, how to be environmentally friendly and how to educate others on the subject. No more than 8 different partners would be needed to create the feeling of community amongst the partners. This would help the partners to lead by example in their idea of community. It will also be important for all partners to be environmentally conscious and sustainable whilst working on the project throughout all stages, again to lead by example.

# Research panel

The closing panel was moderated by Martin Reichstein (ZPE Siegen University) and it received the presentations of Claudia Claes (university of Ghent/IASSIDD) and Marco Lombardi (HOGENT University of Applied Sciences and Arts, EQUALITY Research Collective, IASSIDD) (PPT) about shaping the research agenda for user-centred approaches.

Professor Claes started the presentation stating that it is important to understand the context and the multiple factors that are related between the different levels: micro, macro, and meso. With a holistic view and a broad picture of the environment it is easier to create a support system.

Then, Ms. Claes continued her presentation by explaining the difference between interdependency and autonomy when talking about independent living of people with support needs. Interdependency stresses the fact that help is still needed even though some people with needs are now living independently. Considering this concept of interdependency, it is easy to have a better understanding of deinstitutionalisation. It means that inclusion is achieved by giving people the space to live independently and by supporting them in their needs, as a collective organized community services. This perspective is different from organising people with complex needs in a residential care or moving directly from institution into a house without the proper necessities.

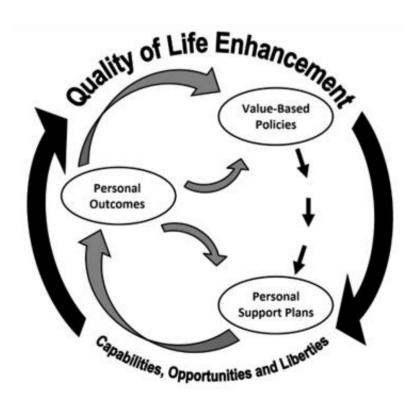


Figure 1. A Systematic Process to Enhance Personal Outcomes

Professor Lombardi continued the presentation showing the trends of institutionalisation and underlying the decrease in number of people in institutions. This means that there are encouraging examples of independent living that have been developed over the past years.

When seeking to improve the quality of services, it is important to compare PwD with the rest of the society and not only between PwD. This comparison without segregation will help to know more things about PwD. For example, PwD have higher rates of feeling excluded in the society compared with the rest of the population. Given this data, we can state that we have to work more on adapting the environment to PwD, so that the whole community becomes more inclusive rather than limiting inclusion to disability-focused services.

When talking about deinstitutionalisation, it is important to, first, have a common definition in order to have better research. In this context, the European Union Agency for Fundamental Rights (EFRA) provides various inputs on how to promote deinstitutionalisation. It has been seen that day care centres cost more than residencies, therefore it is essential to ensure that sufficient financial support is given to deinstitutionalised services. Some good examples contributing to the implementation of the UNCRPD declaration are: the UNIC project, which provides personal budgets to service users; the setting up of independent users council in all services; the employment people with intellectual disabilities in the service staff; ensuring user involvement in complaints procedures; supporting assessments procedures; personal future planning, and shift from participation in sheltered employment to supported employment.

Overall, these considerations helped the participants determine the priority areas for future research. More theoretical work can be done the devise the quality frameworks of tomorrow, and to support the implementation of these quality systems into disability support services.

#### **Conclusions**

Throughout the event, the participants including service providers and users, researchers, and public authorities, have discussed the key dynamics of quality of services. Some of the crucial questions raised were how quality systems have evolved over time and across regions, how they relate to improvements in the quality of life of service users, and what is needed to support the development and implementation of innovative quality frameworks designed to support 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 two closing sessions of the Forum. In any case, such cooperation will seek to always involve peer experts and service users as key stakeholders, and use the principles of the UN CRPD as their guiding document.

For more information on these considerations, please review the <u>study coordinated by EASPD</u> and presented in the first keynote, which serves as the foundation of our work on this topic in 2022 and beyond, and please <u>monitor the announcements</u> of EASPD regarding our upcoming events on this topic.

# **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 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 being connected with other researchers to identify topics or initiatives of interest.

For updates on upcoming studies and events, please contact:
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