

EPR National Awareness Raising Event

Excellent Services! How to measure and improve services for persons with disabilities. Looking at Portugal and Europe.

24 October 2024

Lisbon, Portugal

On 24 October 2024, European Platform for Rehabilitation (EPR) in collaboration with Associação Portuguesa para a Qualidade (APQ) and Fundação AFID Diferença, hosted the EPR National Awareness Raising Event “Excellent Services! How to measure and improve services for persons with disabilities. Looking at Portugal and Europe”. 46 participants attended the in-person session in Lisbon, and were joined by speakers Dr Francisco Murteira Nabo (AFID), Paulo Sampaio (APQ), António Hilário David (APSA), Marta Morgado (Irmãs Hospitaleiras) and Dulce Coutinho (EQUASS auditor), Portugal, Donal McAnaney, Ireland, Laura Jones (EQUASS consultant), Greece, and Geir Moen (EQUASS expert), Norway. Carla Cunha, Associação Portuguesa para a Qualidade (APQ), Edite Sobrinho and Mauro Fonseca, Fundação AFID Diferença, Portugal, and Alicia Gómez Campos, Benedetta Galeazzi, Eberhard Lueder, EPR, Belgium, facilitated the meeting which was held in Portuguese and English with interpretation.

Welcome and EPR presentation

Alicia Gómez Campos, Secretary General EPR, welcomed participants to the EPR awareness raising event. It should be noted that among the attendees were primarily front line practitioners in the area of social service and disability service provision in Portugal, including therapists and social workers as well as quality assurance experts with EQUASS certified organisations.

For many, this was a first direct encounter with EPR, Alicia therefore provided an overview of the platform members across Europe, networking, advocacy and project activities at EU level, and pointed out the explicit ambition for this event to offer a comprehensive insight into EPR for attendees to explore the benefit for their organisation in future collaboration with the network.

Alicia then introduced the co-hosts of this event, Dr Francisco Murteira Nabo, Chairman of the board of directors, Fundação AFID Diferença, a member organisation of EPR, and Paulo Sampaio, President of the Associação Portuguesa para a Qualidade, EQUASS National Representative for Portugal.

The Portuguese perspective on quality assurance

In his address, Paulo Sampaio, President APQ, welcomed participants and European guests to the event and pointed out the importance of quality in services provided to people with disabilities. Quality is not limited to simple compliance with technical or regulatory standards, but a genuine response to the specific needs

of those who depend on the commitment and dedication of service providers. Quality is about values such as inclusion, respect for human dignity and the promotion of conditions that enable people with disabilities to live full and integrated lives in their communities.

Quality assurance thus refers to more than managing social organisations, it helps organisations to be prepared and able to respond to increasingly complex and diverse realities. The diversity of needs of people with disabilities continues to grow, which requires a true commitment to continuous improvement in offering responses that meet these needs. APQ has a leading role in encouraging service providers to use certification systems and pursue good quality practices. Frameworks like EQUASS help service provider organisations to achieve high standards on effectiveness and, moreover, the humanisation of services. Thereby, promoting quality means creating an organisational culture that reaches all levels of an institution, which strengthens the capacity to innovate, to create more sustainable structures while maintaining the focus on the people being served. Opportunities to discuss quality, such as this event, are therefore important as they advance the collective capacity to innovate and ensure that services for people with disabilities continue to evolve towards excellence.

Dr Francisco Murteira Nabo, Chairman of the board of directors at Fundação AFID Diferença, provided an insight into the work on quality frameworks at AFID, a social solidarity organisation established by the National Association of Families for the Integration of People with Disabilities in 2005. Services are provided children and young people with disabilities and their families, as well as support to the elderly, reflecting AFID's commitment to the care, health, integration and rehabilitation of young people with special needs and other socially disadvantaged groups. Special attention is paid to rehabilitation, deinstitutionalization and integration of persons with disabilities and other disadvantaged groups. Activities include art-therapeutic and cultural activities aimed at promoting the inclusion of people with disabilities and other disadvantaged groups.

AFID is equally interested in raising community awareness about disability and disadvantaged group, and activities concerned with protection and early detection of disabilities. From the very beginning, AFID seeks to integrate quality assurance in the leadership, management and delivery of services. Quality frameworks are considered a fundamental tool for developing social work and for many years, AFID pursues certification with ISO 9001, EQUASS excellence as well as the national ISS, and fosters a far reaching commitment to quality throughout the organisation and its services. Here, the participation of employees is crucial to establish a quality culture in the organisation, carried by the principle of co-creation.

EU initiatives for the disability sector, rehabilitation and social services of excellence

Laura Jones, EQUASS consultant, shared latest information about activities at EU level to promote quality in services, in particular initiatives currently or soon coming up with potential impact on service provision in Portugal. Among those, one initiative worth mentioning is the EU Recommendation on access to affordable, high quality long-term care adopted in 2022. The recommendation was extensively discussed by EU member states in view of elderly care and disability sector, and became important for the sector when governments committed to the recommendation's quality principles for long-term care, focusing on respect, prevention, person-centred services, comprehensiveness, and transparency. National governments are now reporting progress, including the Portuguese government pointing to issues with resource allocation

and financing models, and initiatives included in an Active and Healthy Aging Action Plan. Laura also noted that employment in the sector, the professionalization of care workers and support for informal carers are of crucial importance in Portugal.

She then shared outcomes from a European project QUASAR which undertook an analysis and comparison of four quality frameworks including ISO, EFQM and EQUASS. Of interest for participants would also be the EU Strategy for the Rights of Persons with Disabilities 2021-2030, which covers a broad range of areas relevant for the disability sector. Among the deliverables, the framework for social services of excellence for persons with disabilities would be the most relevant for this event. Consultations are currently ongoing and the publication is expected for end of the year. Quality assurance shall have a dedicated chapter in the framework which would provide orientation regarding principles, criteria and indicators for quality assurance. Finally, Laura recommended looking out for three other deliverables of the EU Disability Strategy i.e. Manual for managing chronic diseases and preventing the risk of acquiring disabilities, Guidelines for effective vocational rehabilitation schemes, and Guidance for independent living & inclusion in the community.

The EQUASS Experience for service provider organisations

António Hilário David, Executive Director of the Associação Portuguesa de Síndrome de Asperger (APSA), shared experiences of his organisation with EQUASS certification. APSA started as a parents initiative established by people like Antonio whose son was diagnosed with Asperger at young age. While several organisations already exist in Portugal concerned with Autism, none so far was specialised in Asperger. This group of parents established the organisation in the form of a charity, and in view of the specific care and support needs for their children. Crucial elements of the work are the promotion of independent living and dignified living. In the context of organisational development, APSA chose to conduct audits with financial and legal organisations, and decided to add a quality management system suitable for the disability sector. With the support of APQ, the organisation managed to obtain EQUASS certification, which allows adapting the audit processes to the sector and the organisation. Antonio pointed out the importance of context for quality assurance in the practical work with service users. He referred to Casa Grant in the Benfica suburb of Lisbon which is specialised in supporting the transition of young people with asperger to adult life. Here, the quality of services is closely linked to measuring results and impact in view of constantly changing personal development processes. Every young service user would receive support on the basis of an individual plan. Typically this plan requires constant adapting, for example in employment context, where a young person may start a new job, finds out after three months it is not suitable for them and quit. The suitability could have to do with the employer lacking experience with Asperger. The person may return to the parents, then to the organisation and ask again for support. Plans, goals and expectations need to be adapted.

Marta Morgado, gave a presentation of the work at the Casa de Saúde da Idanha which belongs to Irmãs Hospitaleiras, private social solidarity institution in Portugal specializing in psychiatric and mental health care, dementia, rehabilitation, brain injury, addiction, and palliative care. The vision and mission of the organisation is built on respect for individuality and dignity, and a care model based on science. Irmãs Hospitaleiras operates in 25 countries around the world including in five European countries. In Portugal, including the north, centre, Lisbon, Alentejo, Madeira and the Acores, 12 health units have been established. They follow an integrated, comprehensive assistance model that promotes interdisciplinary working, quality

in services, innovation, humanity and empowerment for the people being served. The institution has a national network with a capacity of 2,973 inpatient beds and offers specialized care in areas such as psychiatry, pedopsychiatry, psychogeriatrics, dementia, brain injury, intellectual disability, developmental disorders, palliative care, and physical rehabilitation.

Since 2011, the health units have gone through EQUASS certification, which was a long process to go through the different entities, and is continued with the recertification process in 2024/2025. However, the efforts ensure uniform processes and procedures, sharing of best practices, innovation, and continuous improvement. They allow for benchmarking and benchlearning, developing further innovation projects, and integrating all services of the health units under a common quality culture. Various challenges were observed in the process, such as adapting to different realities of health units having fairly different realities such as the size and number of beds. The implementing of procedures became particularly difficult during the pandemic.

Campfire groups: Ideas and suggestions for improving quality in services

Laura Jones invited the audience to join small groups for discussing what are the current challenges with quality in services in Portugal, and what would help to improve the processes in the organisations towards better quality in service delivery. Groups were asked to take note of their findings and report back to a plenary session with Laura Jones, Dulce Coutinho, Donal McAnaney and Geir Moen. The following was reported:

Group 1	
Challenges	Solutions
<ul style="list-style-type: none"> • Systems are too bureaucratic. • Involving the beneficiaries in the different management bodies in the conception and implementation of the system. 	<ul style="list-style-type: none"> • Having a team only with the responsibility of quality • Having a team that has all the social responses in all the parts of the organisation

Group 2	
Challenges	Solutions
<ul style="list-style-type: none"> • Lack of resources to hire and retain staff • Creation of a platform with the metrics for registration for uniform indicators. This platform would allow the better monitoring which would facilitate benchmarking. • Clarify in which condition a service user with a disability have a work contract and still get a benefit from social security. 	<ul style="list-style-type: none"> • Create EQUASS working groups to share results, ideas, procedures, decentralized across Portugal • Technological resources • On the job training • Articulate social network with health • Benchlearning. Promote international events for sharing

Group 3	
Challenges	Solutions
<ul style="list-style-type: none"> • After covid higher staff turnover – which caused difficulties in EQUASS • Difficulties of staff to measure quality of life • Higher sensibility of EQUASS system for the specificities of individuals 	<ul style="list-style-type: none"> • Standardization quality of life scale

Group 4	
Challenges	Solutions
<ul style="list-style-type: none"> • Resistance to change • Transmitting a quality culture • Turnover of staff • Training • Promoting critical thinking 	<ul style="list-style-type: none"> • Create internal consultancy roles • Creating groups for negotiations between teams (operation vs. management) • Having empathy for the role of everyone • Consultancy services

Ask the service user: About the impact of services on quality of life

Donal McAnaney invited participants to learn more about the important role of service users for quality in services, emphasizing the importance of measuring service user perceptions to improve service quality, if one goes beyond basic satisfaction surveys onto meaningful engagement of service users. Understanding how users truly feel about services is essential for continuous improvement, ensuring that services align with their needs and expectations. The challenge lies in collecting honest feedback, particularly from individuals with cognitive impairments, communication difficulties, high dependency needs, or psychological vulnerabilities. Service users may struggle to articulate their experiences, and traditional surveys often fail to capture their true perspectives. Another key point is that feedback should not be collected just once a year but through an ongoing process integrated into the individual service plans. Still, gathering honest opinions is complicated by the power imbalance between service provider and service user. If the person providing the service is also the one asking for feedback, users may hesitate to express negative opinions. Ideally, the feedback process is conducted by independent individuals, such as external volunteers or staff from different departments.

Donal presented QIAT, a new online tool developed by a recent European project by a consortium of service provider organisations. QIAT is a specialized tool designed to assess the impact of services on the quality of life of service users. Instead of relying on complex pre- and post-assessments, the tool directly asks users whether the service has improved their quality of life in specific areas, such as emotional well-being, employability, and community participation. This approach simplifies data collection while ensuring the responses are relevant and actionable.

The tool is flexible, accommodating users with different abilities, literacy levels, and communication needs. Five different versions of the tool exist: A full version with 47 items for in-depth assessment, a screening version with 30-31 items for quicker evaluations, a simplified language version for service users with literacy challenges, a two-point scale version for users who struggle with numerical ratings, and an assisted rating system that breaks questions down into three steps to ensure comprehension. Additionally, QIAT allows for proxy assessments, where caregivers or staff members answer on behalf of users who cannot provide direct feedback. The scoring system is designed to generate clear and actionable insights. It aggregates user responses into percentage scores across different quality-of-life dimensions, such as emotional well-being, self-determination, and employability.

The results can be compared with staff perceptions, highlighting discrepancies between what service providers believe they are achieving and what users actually experience. For example, if staff believe they are effectively helping users manage stress but users report otherwise, it signals an area for improvement. This structured approach ensures that feedback leads to meaningful change. By continuously collecting and analysing user perceptions, services can identify strengths, address weaknesses, and make data-driven improvements. These insights can also be used to justify funding, refine program goals, and enhance accountability to stakeholders.

Donal reiterated the value of user-centered evaluation systems. The tool aligns with key performance indicators (KPIs) in quality management, ensuring that services remain person-centered and responsive to actual user needs. By adopting this model, organisations can demonstrate ethical practices, commitment to continuous improvement, and genuine participation from service users. He attendees to explore the tool further, highlighting its ease of use and effectiveness in driving quality enhancement.

Wrap up and farewell

Alicia thanked Donal and the other speakers, the participants, the interpreters and the co-organisers for this event at AFID and APQ for their important contribution. She expressed the hope that participants found inspiration and take home new ideas that can help improving the work. Findings from this event will certainly be brought to the ongoing revision of EQUASS. Alicia invited all participants to contribute to the online evaluation and closed the event.

Evaluation

In their post-session evaluation, attendees gave a score of 4,39 for this national awareness raising event. One respondent recommended improving support for participants with disabilities e.g. with visual impairments. Respondents also pointed out group discussions revealed different levels of knowledge about EQUASS that should be addressed. Almost all respondents expressed interest in attending other events on similar topics. Respondents proposed more practical discussions e.g. about quality of life for service users. Several suggested more events in similar format e.g. annual meetings, creating “benchlearning and for benchmarking groups” or EPR facilitating a platform “where we could choose similar institutions for international benchmarking”.