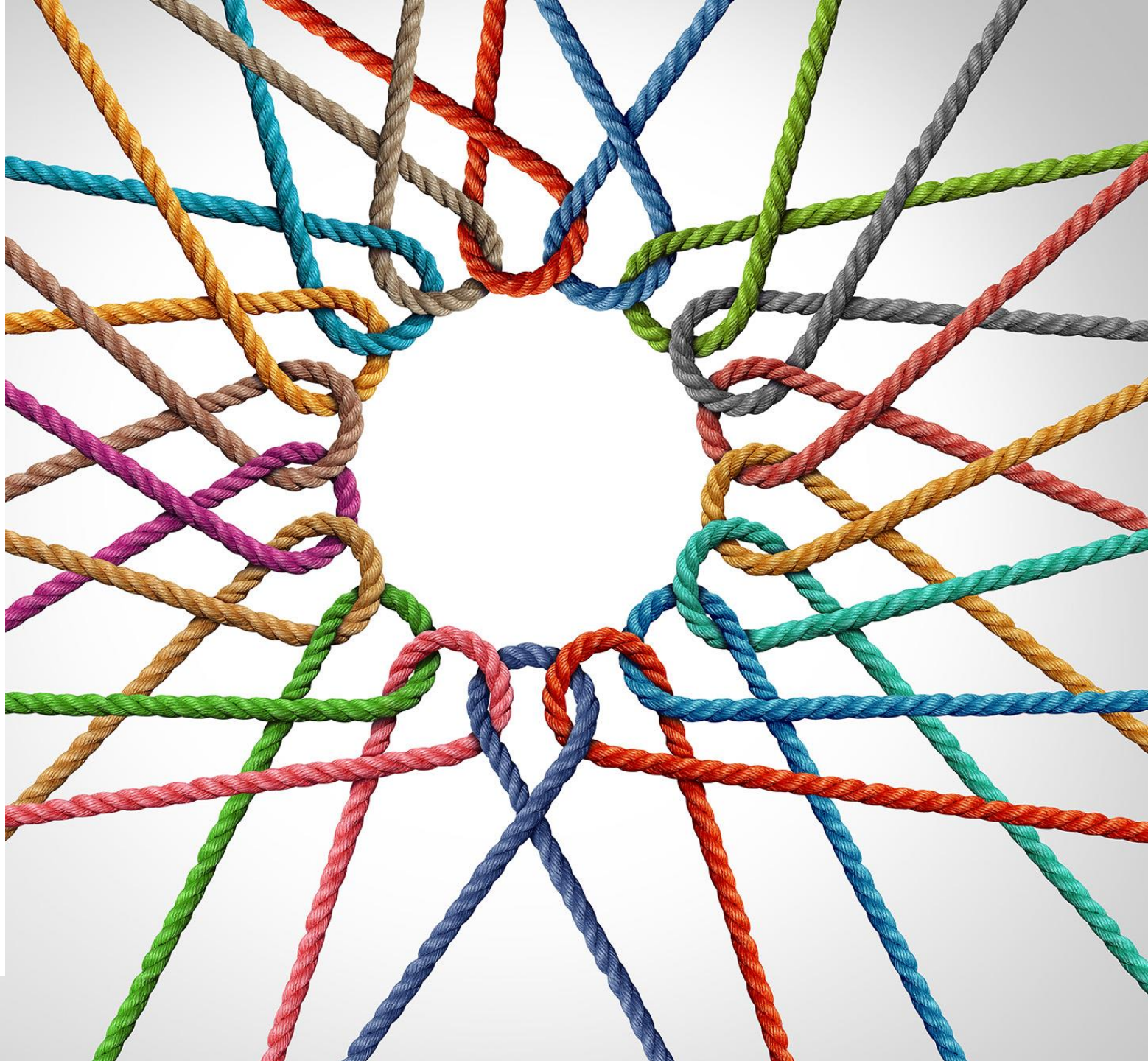**EPR Annual Conference Workshop Round 1**

QoL, Quality Services and Rights

Donal McAnaney Ph.D.

22nd September 2022

The link between QoL and Rights

The Schalock/Verdugo 8 Factor Model of QoL

- Personal Development

- Self-Determination

- Interpersonal Relations

- Social Inclusion

- Rights

- Emotional Wellbeing

- Physical Wellbeing

- Material Wellbeing

Schalock, R. & Verdugo, M. (2012). A Leadership Guide to Redefining Intellectual and Developmental Disabilities Organizations: Eight Successful Change Strategies. Baltimore: Brookes.

The Link between QoL and the CRPD 1

Rights:	Access and Privacy
Self-Determination:	Autonomy, Independence, and Choice
Physical & Material Wellbeing:	Work/Employment
Social inclusion:	Accessibility and Participation
Emotional Wellbeing:	Freedom from Exploitation, Violence, and Abuse
Personal development:	Education, Rehabilitation and Habilitation

Buntinx, W., & Schalock, R. (2010). Models of Disability, Quality of Life, and Individualized Supports: Implications for Professional Practice in Intellectual Disability. Journal of Policy and Practice in Intellectual Disabilities, 7(4): 283–294.

The Link between QoL and the CRPD 2

- Art 19 Living Independently

- Art. 24 Education

- Art. 25 Health

- Art. 26 Habilitation and Rehabilitation

- Art. 27 Work and Employment

- Art. 28 Adequate standard of living and social protection

McAnaney, D. (2009). It is your Business: An Analysis paper on the implications of the UNCRPD and its Optional Protocol for Service Providers. European Platform for Rehabilitation.

Crosswalk between the CRPD and QoL Factors

UNCRPD		QoL Domains							
	Verdugo, M., Navas, P., Gómez, L. & Schalock, R. (2012). The Concept of Quality of Life and its Role in Enhancing Human Rights in the Field of Intellectual Disability. Journal of Intellectual Disability Research, 56(11): 1036–1045.	Personal Develop.	Self-Determin.	Interpers Relations	Social Inclusion	Rights	Emotional	Physical	Material
5	Equality and non-discrimination					🟩			
6	Women with disabilities					🟩			
7	Children with disabilities					🟩			
8	Awareness-raising				🟩				
9	Accessibility		🟩		🟩				
10	Right to life					🟩			
11	Situations of risk & emergencies					🟩			

Crosswalk between the CRPD and QoL Factors

UNCRPD		Personal Develop.	Self-Determin.	Interpers Relations	Social Inclusion	Rights	Emotional	Physical	Material
12	Equal recognition before the law		■			■			
13	Access to justice					■			
14	Liberty and security of person		■			■			
15	Freedom from torture					■			
16	Freedom from exploitation, violence and abuse					■	■	■	
17	Integrity of the person					■	■	■	

Crosswalk between the CRPD and QoL Factors

	UNCRPD	Personal Develop.	Self-Determin.	Interpers Relations	Social Inclusion	Rights	Emotional	Physical	Material
18	Liberty of movement & nationality				🟩	🟩			
19	Living independently		🟩		🟩				
20	Personal mobility				🟩	🟩			
21	Freedom of expression/Info Access		🟩		🟩				
22	Respect for privacy					🟩			
23	Respect for home and the family			🟩			🟩		

Crosswalk between the CRPD and QoL Factors

UNCRPD		Personal Develop.	Self–Determin.	Interpers Relations	Social Inclusion	Rights	Emotional	Physical	Material
24	Education	🟩			🟩				
25	Health						🟩	🟩	
26	Habilitation and rehabilitation							🟩	
27	Work and employment	🟩			🟩				
28	Adequate standard of living								🟩
29	Participation in political & public life				🟩				
30	Participation in cultural life…			🟩	🟩				

The link between QoL and monitoring quality services

Enabling and Empowering through Services

- **Enabling:** To provide people with the means and opportunity to achieve their life goals

- **Empowering**: To equip people with the capacity to exercise control over their lives

- **Two Strategies:**

  - Change the person – Build Capacity

  - Change the environment – Adapt the context

- **Two Types of Facilitation**:

  - Substantive – Teaching, Training

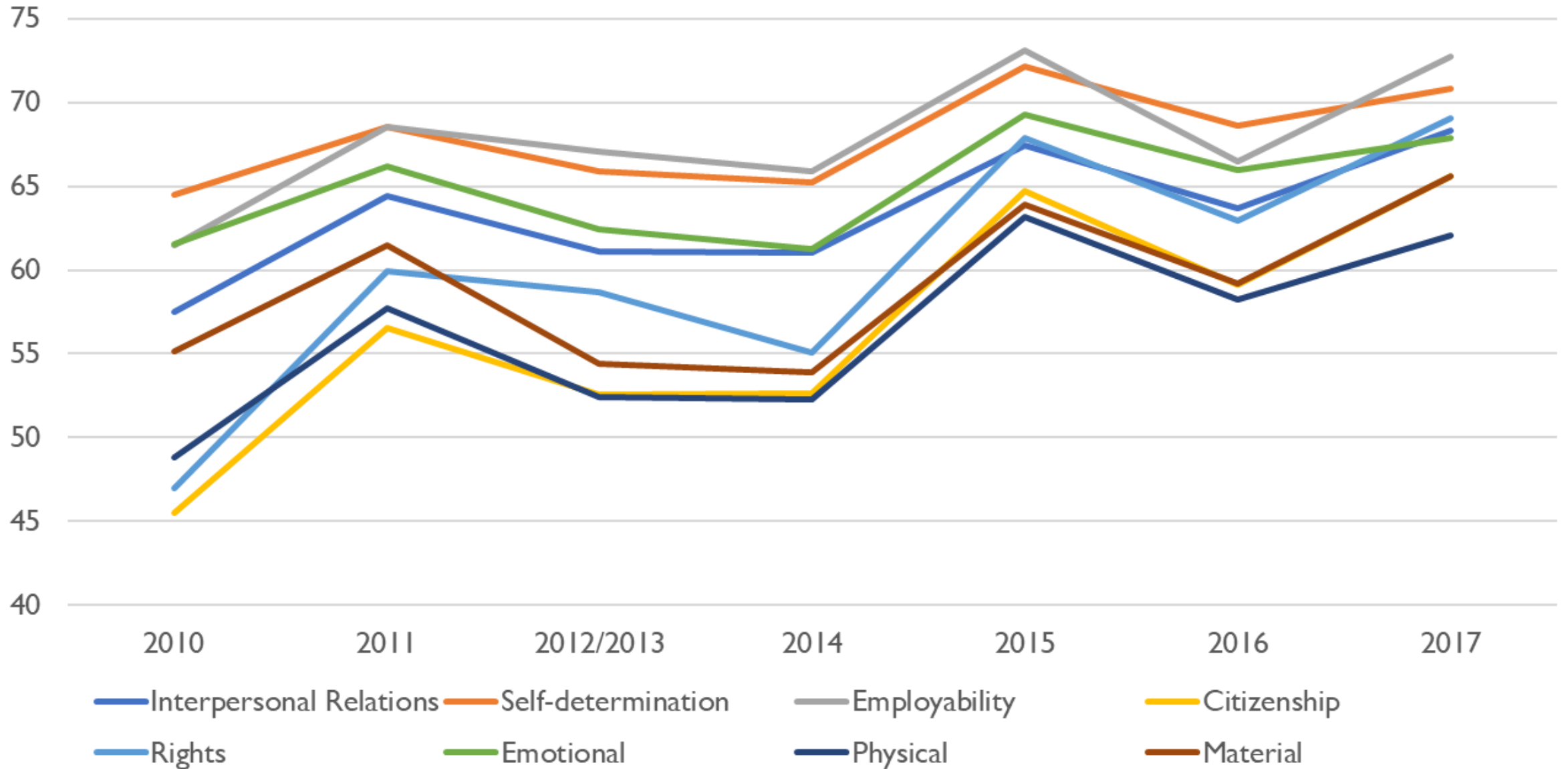 - Process – Scaffolding, Experiential Learning

Rights Promoting Service Mechanisms

- Advocacy & Self-Advocacy

- Rights Education

- Highlighting Rights Success Stories

- Adult Education Approach (Friere)

- Action Learning and Collaborative Enquiry

Rights Promoting Service Mechanisms

- Integrating self-determination and decision making into procedures

- Creating Opportunities to Self-Assert

- Signposting Supports

- Community Outreach and Attitude Change

- Staff Training and Awareness Raising

- Organisational Ethos and Culture

QoL Impact of Services – Trends Domains 2010-2017

Legend: Interpersonal Relations, Self-determination, Employability, Citizenship, Rights, Emotional, Physical, Material

Comparison of QoL Impact Benchmark 2011-2012/13 – 1

	54			60			66			72			78	80
2011									Int Relation					
12/13										Int Relation				
2011										Self-Determine				
12/13											Self-Determine			
2011									Employ					
12/13											Employ			

Comparison of QoL Impact Benchmark 2011–2012/13 – 2

		54			60				66				72				78		80
2011		Citizenship																	
12/13							Citizenship												
2011			Rights																
12/13											Rights								
2011									Emotional										
12/13											Emotional								
2011				Physical															
12/13								Physical											
2011		Material																	
12/13								Material											

Key Service Activities with High QoL Impact

	Activities Consistently Associated with High QOL Impact Ratings
Person Facing Processes	• Capacity building, rights and self-advocacy • Learning to learn, incidental and experimental learning • Mentoring, life coaching or counselling • Stress management
Environment Facing Processes	• Providing support to families and volunteers • Staff training
System Facing Processes	• Project management • Research, data collection and evaluation

McAnaney, D & Wynne R. (2016). Linking user and staff perspectives in the evaluation of innovative transition projects for youth with disabilities. Journal of Intellectual Disabilities, 20(2):165-82. Available at: http://www.ncbi.nlm.nih.gov/pubmed/26912504

The Challenge in Creating QoL Promoting Services

Assessing Organisational Ethos

	User Centred	Profession Centred	Organisation Centred
Priority	Subsidiarity	Professional Integrity	Legacy
Investment	Rights	Disciplinary Boundaries	Precedence
Application of Solutions	Holistic	Diagnostic/ Prescriptive	Existing
Precedence	Participation	Methodology	Viability
Ethos	Consultation	Collegiality	Loyalty
Empowerment of Status	Customer	Accredited	Institutional
Structure	Team	Vertical	Hierarchical
Aspiration	Informed Choice	Clinical Excellence	Market Leader

McAnaney, D. & Craddock, G. (2003). The Challenge of Creating 'User-Centred' Organisations. In, G. Craddock, L. McCormack, R. Reilly & H. Knops (Eds.) Assistive Technology-Shaping the Future. IOS London, 49-60.

- **Guideline 1**: QoL is a fundamental impact of both community care and VET

- **Guideline 2:** QoL is multidimensional and influenced by personal and environmental factors

- **Guideline 3:** QoL has the same components for all people

- **Guideline 4:** QoL principles must underpin interventions and outcomes for persons with disabilities

- **Guideline 5:** QoL needs to be measured using both subjective and objective indicators

QOLIVET Partnership (2022). QOLIVET Partnership. (2022). Enhancing the Quality of Life Impact of Services: Good Practice Guidelines. European Platform for Rehabilitation, Brussels, Belgium.

- **Guideline 6**: Enhanced QoL impact is an essential key performance indicator for services

- **Guideline 7**: Enhanced QoL implies respect, dignity, equality, inclusion, participation and rights

- **Guideline 8**: Staff need to be equipped with the competences that impact on the QoL of participants through mandatory training

- **Guideline 9**: Meaningful participant involvement in service development leads to better QoL impact

- **Guideline 10:** Participants need to be actively involved in setting QoL goals and evaluating outcomes

- **Guideline 11:** Collaboration with communities and other agencies enhances QoL impact

- **Guideline 12:** Synergies between community care and VET are central to improving QoL impact

- **Guideline 13:** Community-wide awareness of QoL principles need to be promoted

- **Guideline 14:** QoL impact must be supported by system policies, processes and training

- **Guideline 15:** QoL outcomes can be enhanced through inclusive and person-centred strategies

EU and EPR activities on quality
Questions for discussion

Current activities at EU level

ESRPD: The Commission will present, by 2024, a specific framework for Social Services of Excellence for persons with disabilities, to improve service delivery for persons with disabilities and to enhance the attractiveness of jobs in this area including through upskilling and reskilling of service providers .

LONG-TERM CARE QUALITY PRINCIPLES – European Care Strategy:

Respect, Prevention, Person-centredness, Comprehensiveness and continuity, Focus on outcomes, Transparency, Workforce, Facilities

Will help making the principles on access to good quality and affordable care of the European Pillar of Social Rights a reality

EPR paper on quality 2021

Intro, what do we mean by quality & excellence in services?

EQUASS principles & approach

Leadership, Staff, Rights, Ethics, Partnership, Participation, Person-Centred Approach, Comprehensiveness, **Result-Orientation,** *Continuous Improvement*

Measuring and benchmarking

EPR paper on quality 2021

Recommendations & key elements for a Framework of Excellence

- Recognition
- Funding
- Regulatory framework
- Some key principles

Expectations from regulators & trends in quality certification

Some examples of good practices

Discussion

What are your main challenges in providing quality services/what do you think are the main challenges to service providers?

Do you have experience in quality of life being measured? How was this done and what did you learn?

What 3 things could help improve the quality of services?

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