

TWO EXAMPLES OF HOW THE HUNGARIAN ASSOCIATION OF RARE DISEASES CAN HELP THE HEALTH AND SOCIAL SITUATION OF PLWRD?

**„Start by doing what's necessary then do what's possible and suddenly you are doing
the impossible”**

Saint Francis of Assisi

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What is HUFERDIS?

- **Rare Diseases Hungary - The Hungarian Federation of People with Rare and Congenital Diseases - (HUFERDIS) was created on 05.05.2006 after several years of preparatory work.**
- **It is a network of 63 Hungarian patient organisations and several individuals active in the field of rare diseases.**
- **The federation is dedicated to helping people with rare diseases and assisting the organisations that serve them.**
- **Our community has a rich knowledge base and experience on listening and capturing the needs and perspectives of people living with a rare disease in different contexts.**



1, Facilitating and encouraging the preparation of Hungarian Plans for rare diseases

First National Plan for Rare Diseases in 2013

8 chapters on 85 pages

1. Main characteristics of the issue, epidemiological data, evaluation of the current situation
2. EU recommendations and obligations
3. Vision
4. Goals, strategic priorities
5. Policy measures in a logical framework matrix structure
6. Interventions - Expected impact - Indicators measuring implementation
 1. diagnostics
 2. centers of expertise
 3. patient registers
 4. graduate and postgraduate training
 5. newborn screening programs
 6. drug supply for rare diseases
 7. research, development
 8. access to social services
 9. civil organizations, patient representation
7. Resource demand
8. Schedule
9. Appendices



Players in the arena:

- medical providers
- public health organizers
- researchers, educators
- drug distributors
- health politicians
- patient organizations

HUFERDIS organized 5 multi-stakeholder conferences to promote the progress of the project and to find consensus.

New roads of the 2nd RDNP until 2030

- **The main changes made to it, in line with point 1.4 of the EESC's 2024 Recommendations:**
 - Holistic cross-sectoral integrated care is needed instead of a mainly medical focus
 - Prioritization to facilitate the work of decision makers:
 - The earlier, faster and more accurate diagnosis,
 - Better access to care, with adequate quality assurance,
 - Integrated care with better coordination, establishment of a Resource Center
 - Better training, education, raising awareness
 - Expanding the number of 9 intervention areas considering the circumstances
 - Detailed description of the adaptation to domestic and international strategies
 - Health-economic analysis of the strategy - value propositions of the National Plan
 - In addition to the framework strategy, development of a short-term action plan with specific actions, responsible persons, deadlines, indicators and budget



2, The training program for RD life path coordinators

Harmonizing with point 1.6 of the EESC's 2024 Recommendations

For people with rare diseases/disabilities and their families

- provided services must be coordinated (health, social, public education, child protection, etc.)
- Implement case management
- Be a cross-sectoral information and coordination hub between health and social care, disability and family, research and education, using the latest digital tools.
- **Key actor: the life path coordinator**



The life path coordinator



- connects families with the services they need.
- as experts and key actors of coordination groups, they ensure access to quality and efficient care.
- its task is cooperation, evaluation, planning, counseling and information about care options,
- communicates widely and facilitates access to the resource.
- case management serves as a means to achieve the well-being and autonomy of those affected, through advocacy, communication, education, identifying service resources and facilitating access to services.

Characteristics of specialized further education

- 4 semesters, 120 credits
- Correspondence training
- Blended education (face-to-face and online)

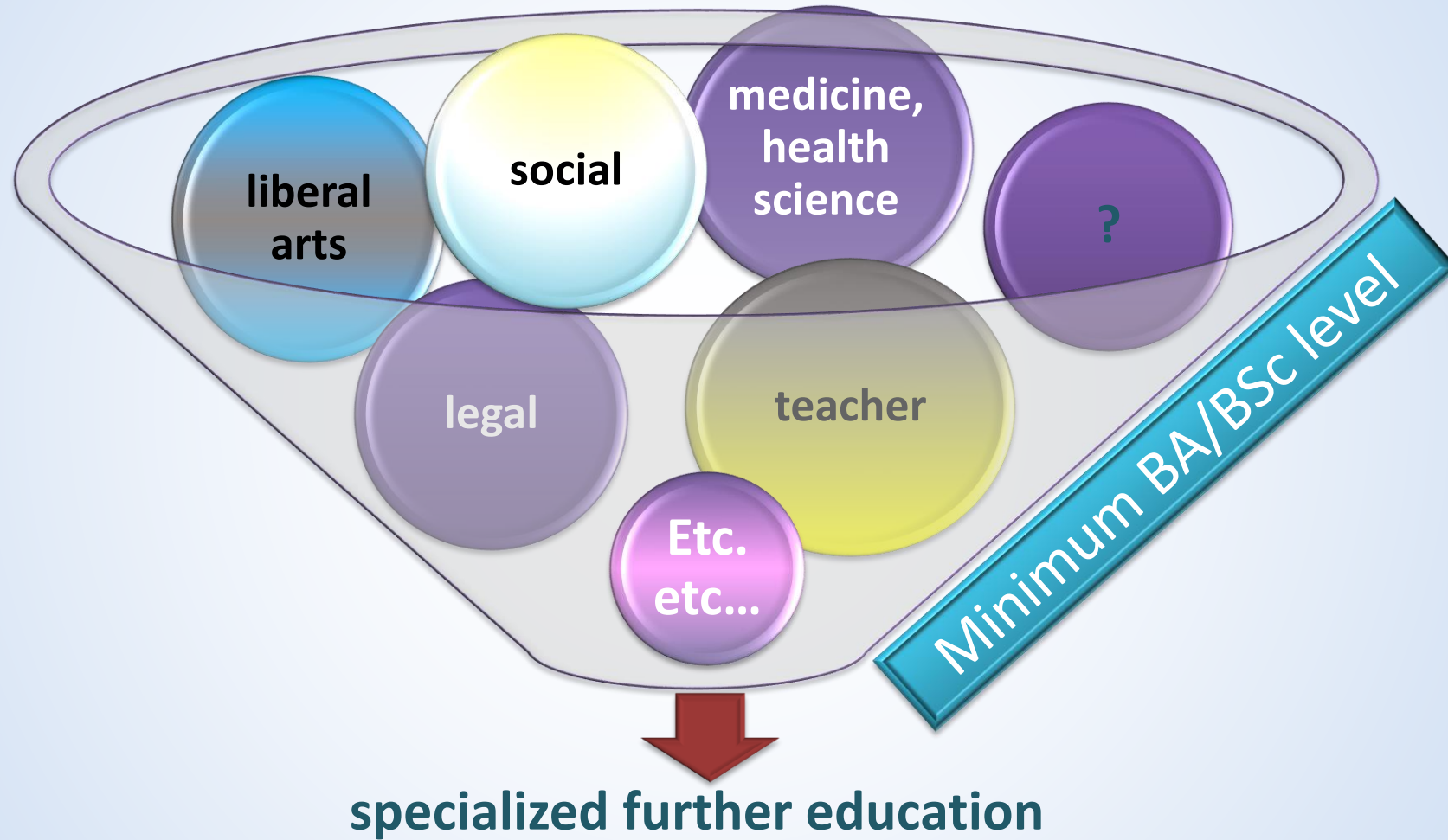
Inter-university cooperation with the patient organization
Several faculties of Semmelweis and Eötvös L. University - HUFERDIS

Practice-oriented, module system, modern teaching methods (interactive, group work, projects)



It is the first serious university training program in Europe where patient representatives participate in the training of healthcare professionals!

Wide input conditions



Modules in training



Case management



"Rare" knowledge



Self-knowledge



Human services
system



Regulation, law,
ethics



Communication



Health / disability
knowledge



Professional
practice

Thank you for your attention!

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