



Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

Case management for patients with rare diseases and their families - the pilot and current insights

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INNOVCare - Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

INNOVCare Workshop on Scaling Innovative Care Delivery for Rare Diseases and Complex Conditions

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www.innovcare.eu



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Topics to be addressed

- ✓ assessment of possible needs
- ✓ gather insights from the field of rare diseases and current care delivery
- ✓ the way we intend to adapt it
- ✓ develop strategies for improving care delivery at national and European countries

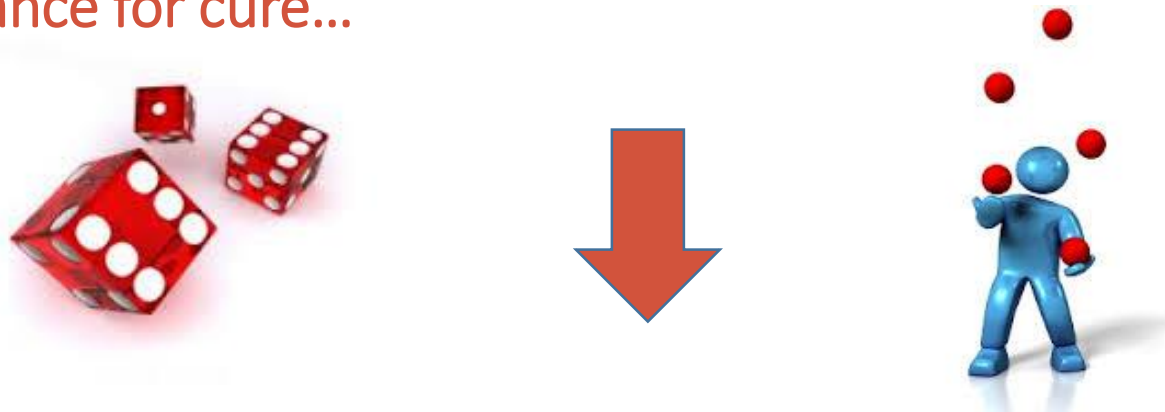


**“helping others” to create
new solutions for their every day life!**



State of the art and needs assessment

- Rare Diseases in Romania: declared a national priority, too often forgotten, considered to be costly and that the patients have NO real chance for cure...



- *The lack of integrated services addressed to those affected by rare diseases, to facilitate the diagnose and to give the power to go forward and look for treatments, therapies, rehabilitation, inclusion in school and community...*

NoRo – Frambu

**Mentoring
Program**



NoRo – a Pilot Reference Centre for RDs



"Scaling innovative care delivery - directions and possibilities"

Services

➤ Medical department:

- ✓ Diagnostic: a part of the patients are oriented to other services and others are included in NoRo services:

➤ Day Care Centre:

- ✓ **Therapies** : Ergo therapy, gymnastic (MIRA), massage, hydro therapy, sensorial therapy, behaviour therapy, speech therapy, electric stimulation and deep oscillation
 - ✓ **Social assessment and Individual Plan for Rehabilitation**
 - ✓ **Patient electronic registry**
 - ✓ **Funded by the Local and County Council**
 - ✓ **Collaboration with kindergarten, schools and families in order to ensure continuity of care**
- ✓ **Working for common goals**
- ✓ **Forum for problem solving**

Teamwork



Services:

❑ 1. **Day care center:** 50 children from Zalau and Salaj county:

- ✓ **Daily intervention program:** ergo therapy for groups, 2 hours / day, 5 individual therapy/ child/ week;
- ✓ **Multidisciplinary evaluation** and yearly re-evaluation (medical, social, kinetic, psychological);
- ✓ **Therapeutic weekends** for families & training for increasing of the family resilience;
- ✓ **Summer camps;**
- ✓ **Connected** with other services at community level to ensure continuity of care;
- ✓ **Home visits of our therapists** (2 weeks/year)

"Scaling innovative care delivery - directions and possibilities"



Services:

❑ **2. Patient groups:** 12-14 patients (and personal assistants x 5 days/group with the same RD)

- ✓ **Multidisciplinary evaluation** (medical, social, kinetic, psychological)
- ✓ **Therapies** (gymnastic , massage, hydrotherapy, speech, sensorial, behavior, electric stimulation, MIRA, occupational therapy)
- ✓ **Therapeutic education and counseling** (first aid, disease information, sharing best practice, meeting professionals, support groups, teleconferences; etc.)
- ✓ **Information** and connection with the social services in their proximity: www.participrare.ro
- ✓ **Patient registry** (*data protection, confidentiality, informed consent*)



"Scaling innovative care delivery - directions and possibilities"

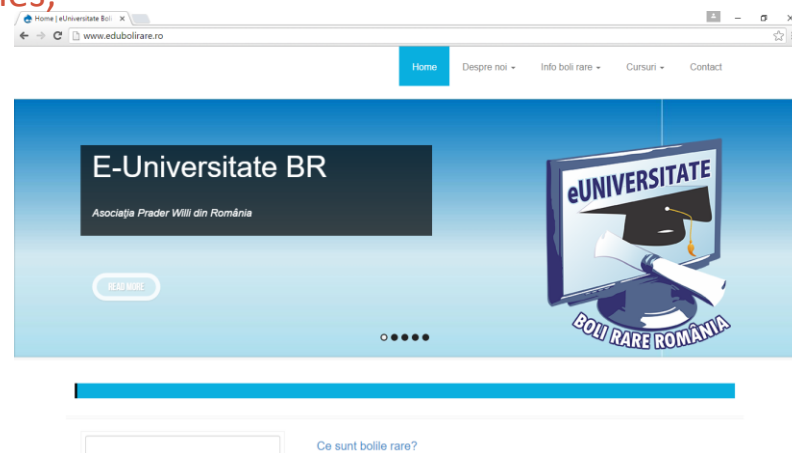


HelpLine

- *Help Line NoRo* : 0260-610033
- or e-mail: office@apwromania.ro și office@bolirareromania.ro

www.edubolirare.ro

- ✓ **Guidelines** for emergency services, integrated care, books, leaflets, guide of services, map of services;
- ✓ **2 magazines;**



NoRo- a Pilot Reference centre for RDs

❑ Opened in June 2011 through a project of the RPWA, funded by Norway grants (Frambu as partner)

❖ NoRo is:

- ✓ a **Resource Centres for Rare Diseases** in Romania
- ✓ recognized as a HCP to participate in ERN & CoE, part of a national consortium;
- ✓ a **one-stop-shop style of service**, specifically designed for people living with a rare disease, **combining medical, social and educational services**;
- ✓ creates a **bridge** between patients/families and various professionals and services involved in patient care;
- ✓ **Involve patients** at local, county and national level in our services;

Pilot care delivery - NoRo centre

- **Country:** Romania, Salaj County, Zalau
- **Target Population:** patients, families, professionals from *Romania*, affected by rare diseases (*give examples or total nr of diagnosis*); all age groups;
- **Type of institution:** *NGO, patient organization;*
- **Origins of funding:** *Local and County Council for the Day Care Center, National Health Insurance for the Medical Department and projects for patient groups and development of the centre;*
- **Total Budget/Year:** **440.000 eur** (*86000 eur provided from Local Authorities to support our services and the rest are from projects, services and sponsors*)

Innovation in our services

Definition: *Creating the new or re-arranging the old in a new way!*

A continuous updating of our services to the needs of patients, in an efficient way,...considering the realities of our environment;

- ❖ Day care center for rehabilitation of children with RDs and autistic spectrum disorders;
- ❖ Pilot center for rehabilitation
- ❖ Center for independent life training
- ❖ Medical Ambulatory (neurology for adults, psychiatry for children and genetics)
- ❖ www.edubolirare & training services (ex. RD school for journalists)
- ❖ Research capacity accreditation

Innovation is needed in RDs as:

- ✓ many questions has no answers yet
- ✓ most of the patients have not accessible treatments
- ✓ we can't talk about social inclusion without **education for all** and **employments opportunities** for patients and families;



Development and sustainability

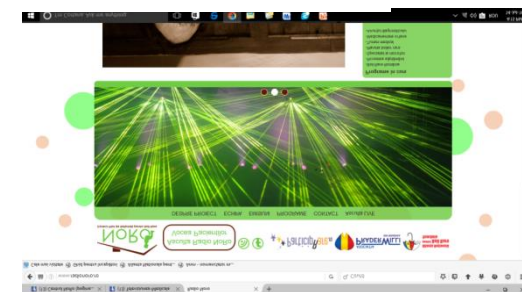
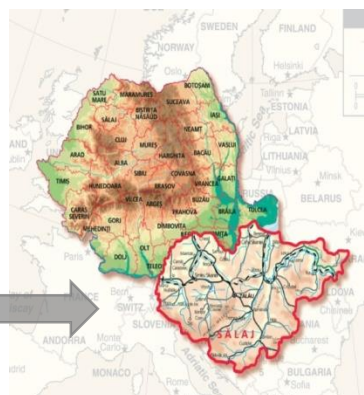
- Established by a Patient Organization
- Partly funded by the Local and County Authorities;
- Accreditation and ISO 9001 quality standards in the management of our services;
- Developed through projects:
- Mentoring program with Frambu;
- ✓ **Cooperation with Professionals;**
- involvement in ***elaboration of national policies***
- **integrated care approach**
- **case management** in child protection system,
- **cooperation** with other social, medical and educational services;
- ✓ <http://www.edubolirare.ro/downloads/ghid2016/#/26>



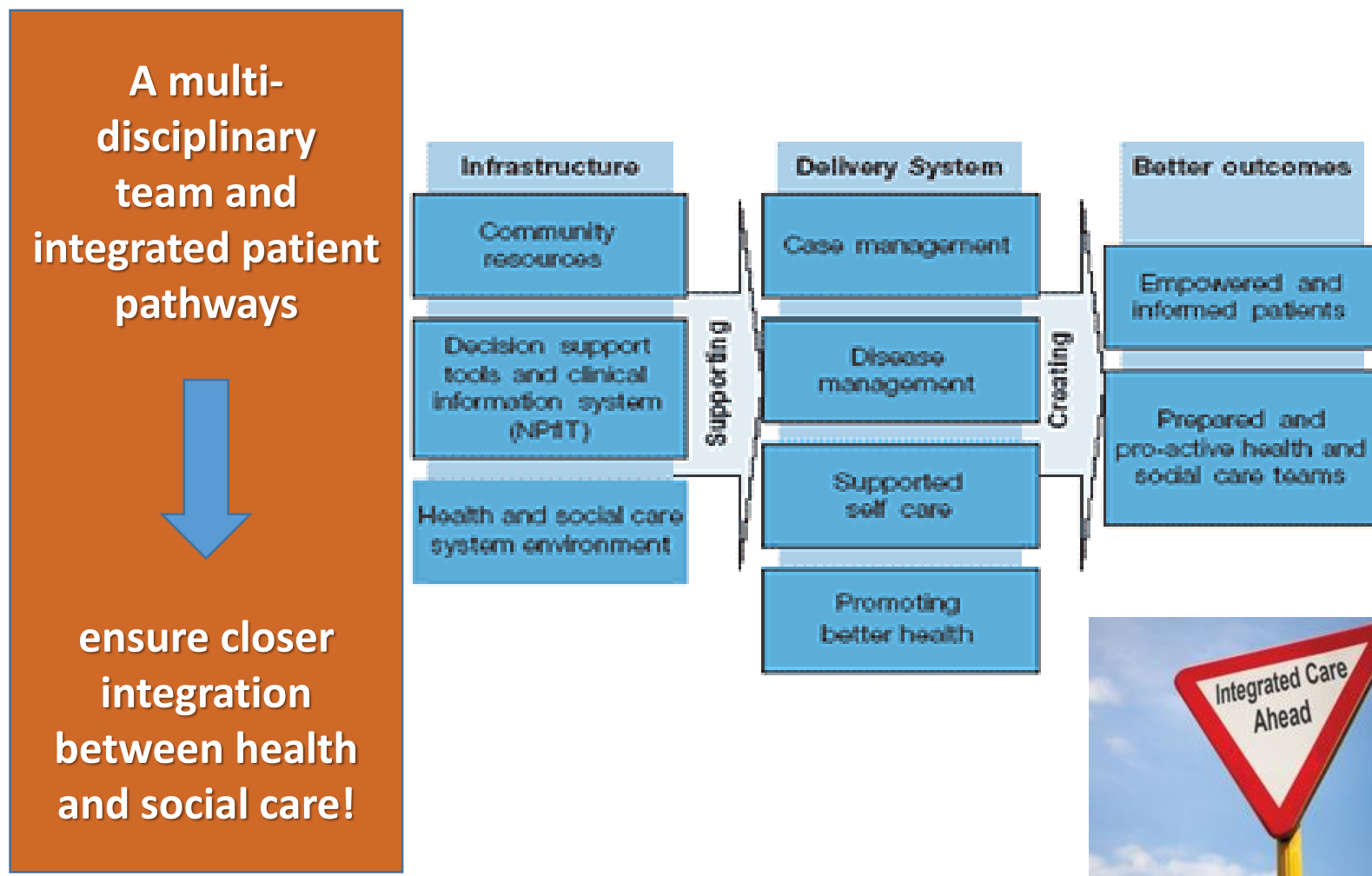
Next steps INNOVCare

- To **give voice** to the social needs of people living with a rare disease
- **Testing** a holistic, personalized care pathway
- Implementation of a **pilot of this pathway** in Romania;

- ✓ www.participrare.ro
- ✓ www.radionoro.ro
- ✓ 2 magazines;



Care pathway and case management



Expected impact

☐ **Beneficiaries:**

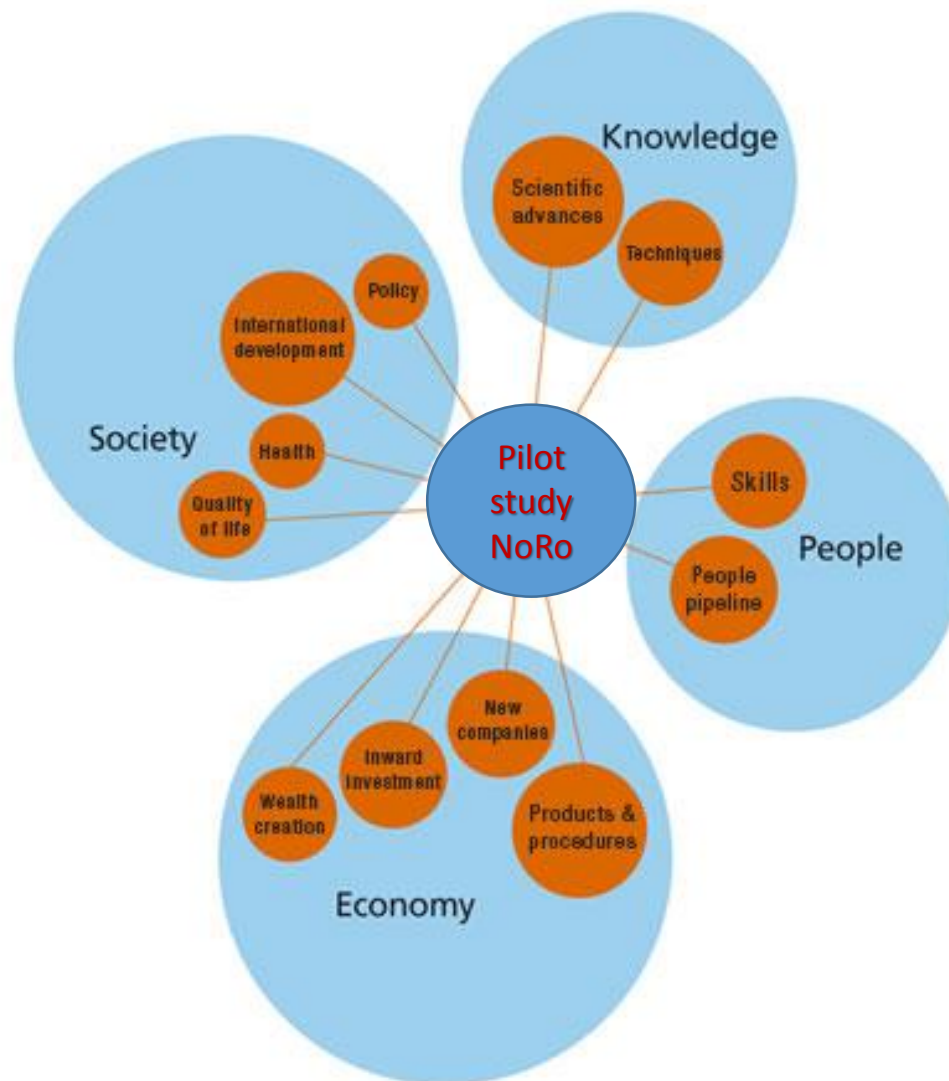
- ✓ **Improved quality of life** for beneficiaries of the project
- ✓ **Longer-term benefits** after 18 months

☐ **APWR – RPWA:**

- ✓ **Organizational capacity & skills** and knowledge development for staff
- ✓ **A better known service provider** (quality and efficiency)
- ✓ **A resource' network** created at county level

☐ **Partners:**

- ✓ **Effectiveness** of interventions proved
- ✓ **Up scaled model** at county, national and international level
- ✓ **Promoted** project



Tools

➤ Impact of rare diseases on daily life and care coordination

- ✓ Preliminary results of study conducted by EURORDIS, via **Rare Barometer Voices**, in European Countries: *1200+ respondents across Europe and diseases: 63% patients, 35% parents, 2% spouses, 2% grand-parents.*



A EURORDIS INITIATIVE



Preliminary results of Rare Barometer

- The **disease impacts fairly/a lot the daily life of 86%** of patients/families;
- **43% of patients/families invest over 4h/day in illness related tasks** (hygiene, house chores, treatment);
- **65% of patients/families find difficult to manage the time that they spend organizing care;**
- **49% have difficulties managing their health related administrative procedures;**
- **53% have difficulties managing the time spent explaining the disease to different experts/professionals;**
- **47% find hard to handle their visits to health and social support services/specialists** in a short period of time; additional 7.2% are not able to handle these visits at all;
- **69% feel that the different service providers communicate/exchange fairly badly/very badly** about the person living with a rare disease (treatments, disease consequences, relevant information);
- **75% consider that professionals from social, local and support services following them know the consequences of their disease fairly/very badly; 70% consider that they are fairly badly/very badly prepared to support the family in dealing with the consequences of the rare disease;**
- **71% consider the costs associated to their disease to be fairly/very high; 64% find them hard to manage.**

Workshops

- Results of **Partners' Meeting** in Madrid and **Workshop** on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions - **Ågrenska**, Gothenburg, 8-9 September 2016.



Recommendations

What matters to patients and their family

- Roles of case manager listed are all important but need to be prioritized: step wise approach -> *start with what you can influence the most*: e.g. patients' attitude and level of information, being the person who is there as a permanent contact for patients;
- Case manager needs to be a facilitator and should not replace other professionals;
- Case manager supports and empowers patients/families, who always have ultimate decision power; case manager should be neutral and independent in providing advice and referral to services;
- Case manager needs to have a visible added value to services already provided: not just be one additional person/service to talk to;

Recommendations

- Need to **organize** activities efficiently;
- Family should **not** feel that it is **one more specialist** the patient has to be in contact with;
- The case manager should design a flexible / adaptable **Case management Plan**, based on the needs assessed and work by it;
- Case manager should **guide/empower patients**: helping the patients in decision making, analysing the options, evaluating the risks (even in cases where the patients' opinion is other than the family's), manage their own services / needs after some time, and maybe re-enter case-management in a new period with new situations/needs;
- Measurement of the **quality of the service** is important, because the management of this type of services is essential;
- Case managers **basis are in communication and networking** with patients and services in the region;
- The case manager should be a person who ensures that the patient knows her/his **rights** and can access these rights and at least, access information.

Suggestions

- **Quality of life of patients**, broadly speaking not health based, must be evaluated;
- NoRo is already providing multidisciplinary approach and various services –case managers will offer a **new service**;
- It's important to connect the role of case manager to **legal framework** in Romania;
- Case managers need to know “everything and everyone” about services, RD's and RD resources – **creating a network is essential**;
- **Training** is very important, information from multiple domains

Focus groups

- **Focus groups** were organized to help with information the work of WP7 and to help design our intervention and training curricula

Questions addressed:

- ✓ Quality of life
- ✓ Autonomy and care management
- ✓ The role of the case manager



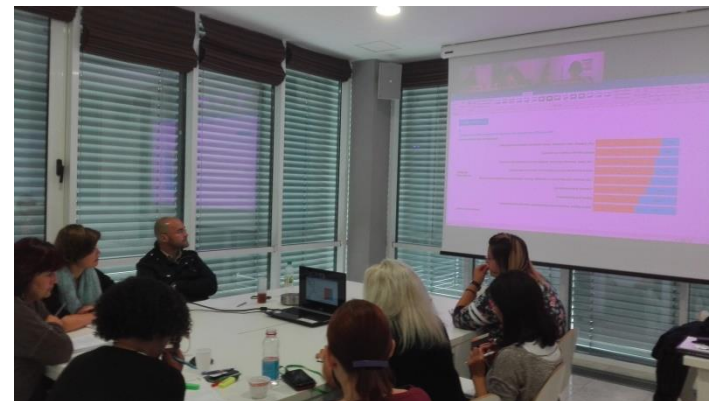
- **General conclusion:** PLWRD have great expectations and need for case managers for having a better quality of life

Field visit of ZSI to NoRo

19-20 september 2016

Topics discussed:

- ✓ Presenting NoRo services
- ✓ Details about the new service provision
- ✓ Designing the pilot intervention
- ✓ Objectives of the Case management
- ✓ Activities of the case manager
- ✓ Necessary topics in the Curricula



Main activities:

- Selection of the case managers
- Development of the curricula for case managers
- Providing the training
- Mapping the main services and resources at county level
- Organizing a meeting with the potential beneficiaries
- Selecting the 60 beneficiaries (outside NoRo)
- Assigning the case managers and the beneficiaries



❖ *Starting case management activity: evaluation of the needs, Personal Development Plans (PDP), creating the network and coordination of the patient and the family to the services they needed, re- evaluation and adjustment of the PDP, ...evaluation of the patient satisfaction of the service provided.*



Resources needed !

➤ Human resources:

- ✓ APWR team: 1 manager, 1 assistant, 4 case managers; (*accountant, therapists, doctors, nurse;*)
- ✓ **Partners - CJSJ:** 1 manger, 1 assistant ;
- ✓ *Volunteers & Advisory committee – creating the network;*
- ✓ *members of CJ Project Unit*

➤ Financial resources: salaries, overheads, traveling

❖ Still challenging:

- ✓ **Lack** of resources for traveling in the county, meeting with people, training?
- ✓ **To find** resources to cover travel costs related to patients' access to services
- ✓ **Printings – information materials and training materials**
 - **budget transfers** possibilities during project implementation?
 - **sustainability** of these arrangements after the project end



Outputs

- 4 case managers trained
- 1 training support material created for case managers
- 1 ~kick-off-meeting~ meeting with the potential beneficiaries organized
- 1 map of services created
- 120 cases involved in case management
- 120 PDP developed and used
- At least 2 group activities and 5 personal meetings with each case
- A communication kit for each case developed
 - ✓ 4 thematic meetings with professionals – doctors, teachers + therapists, nurses + social workers, potential employers ???

Outcomes

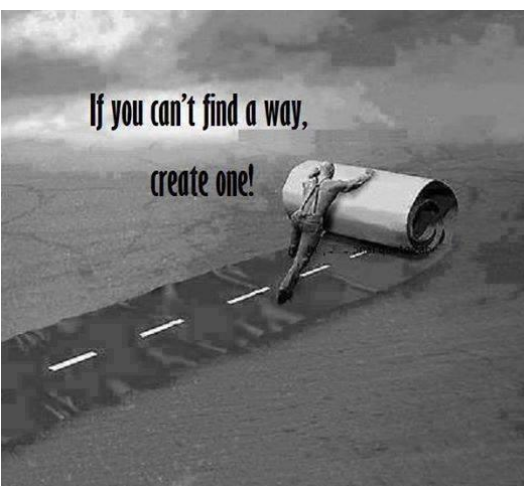
- Improved skills on case management for 4 people
- Better informed people about rare diseases and their rights
- Changed attitude for patients and families – more pro-active in accessing services, better communication skills, better self-management, more autonomy, more peer-support and peer-learning, increased family resilience, better understanding and acceptance in community
- Improved communication among all the stakeholders involved in care
- Better understanding of RD needs at community level and service delivery



❖ Improved access to services for beneficiaries and better QoL

Inter sectorial and international collaboration

- ❑ **Innovative care pathway** bringing together national resource centres for rare diseases and regional case managers, **in partnership with public bodies**;
- ❑ **Evaluation of the socio-economic impact** and a **cost-benefit analysis** of the care model;
- ❑ **Exchange of good practices** & initiate **European network of services**;
- ❑ https://www.youtube.com/watch?v= 2jy_saqxq0



Important QUESTIONS



- What does QUALITY OF LIFE mean for you?
- What do you think QUALITY OF LIFE means for a patient with a rare disease?
- What changes in policies should occur to fulfill these needs?
- What is our role in this?



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Thank you

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