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QUALITY YOUTH MENTORING
FOR INCLUSION: A BIG
BROTHER TO OVERCOME
SHARED BARRIERS





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Authors:

- Fundación Isabel Gemio. Founded in 2008 with the aim of contributing to accelerating research into Muscular Dystrophies, other Neuromuscular Diseases and Rare Diseases, in those biological, physiopathological, genetic or therapeutic aspects that may have an impact on the development and application of curative treatments for those affected, as well as encouraging the exchange of information between experts, patients and their families, and promoting the development of pharmacology. Focuses all its efforts on funding Scientific Research Projects that seek treatment or cure for Rare Diseases.
- Federación ASEM (FASEM). Non-governmental organization created in 2003 that brings together associations and foundations for neuromuscular diseases. It works to strengthen the associative movement and improve the social inclusion, development and quality of life of people and families living with these pathologies.
- Centro Ascolto Duchenne Parent Project aps. Association of patients and parents of children affected by Duchenne and Becker muscular dystrophy. Since 1996, it has been working to improve the treatment, quality of life and long-term prospects of children and young people through research, education, training and awareness-raising.
- Spyros Polyviou. BSc in Social Science & MBA in Cyprus Alliance for Rare Diseases.
- Iro Hadjikyriakou. BA in Social Work in Cyprus Alliance for Rare Diseases.
- Ida Mirković Knaus (RDC). Master's degree in Social Work and is engaged as an expert associate and secretary at the Rare Diseases Croatia.

Partnership of the project:



With a view to greater accessibility, this report is available in accessible electronic format on the project's website: <https://mentoringforinclusion.europeanprojectsfig.eu/>

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Fundación Isabel Gemio

C. de Garibay, 7, 3º Derecha,
Retiro, 28007 Madrid
Tel.: 911 103 158
fundacion@fundacionisabelgemio.com

COORDINATOR

fundación
isabel gemio

Fundación Isabel Gemio was born in 2008 with the aim of contributing to accelerate research in Muscular Dystrophies, other Neuromuscular Diseases and Rare Diseases.

PARTNERS



The Cyprus Alliance for Rare Disorders (CARD) was founded in 2010 counts 20 member associations and more than 250 individual patients.



Rare Diseases Croatia is the umbrella organization that gathers 29 other non-profit organizations as well as more than 900 individual patients with rare diseases.



Parent Project per la Ricerca sulla Distrofia Muscolare (Italy), an association of patients and parents with children affected by Duchenne and Becker muscular dystrophy.



Federación Española de Enfermedades Neuromusculares (Spain), a non-governmental organization that brings together associations and foundations for neuromuscular diseases.

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1

INTRODUCTION

Chapter 1. Introduction

1. Introduction to rare diseases

As an introduction to the project, we are going to provide some key information regarding rare diseases in the European context, as well as in the States involved in the present initiative.

The challenge of defining rare diseases:

In the EU, Rare Diseases are those whose prevalence is below 5 per 10,000 inhabitants. It is estimated that there may be more than 7,000 rare diseases. The 80% has a genetic origin and two thirds manifest themselves before two years old.

The main characteristics:

- high morbidity and mortality rate.
- high degree of functional diversity and dependence.
- their chronicity and diagnostic complexity.
- potentially fatal.
- affected persons specific social and health care needs.

The field of rare diseases in Europe is diverse.



In 2008, the European Commission adopted the Communication "Rare Diseases: A Challenge for Europe". It focused on three main areas: improving the recognition and visibility of RDs; supporting RD policies in Member States; and developing European cooperation, coordination and regulation in relation to RDs.

European Plan for Rare Diseases National Plan Development (EUROPLAN), which goal is to promote the implementation of National Plans or Strategies to tackle RDs.

European Reference Networks (ERNs), which are virtual networks involving healthcare providers across Europe.

Besides, EURORDIS is a non-governmental alliance led by patient organisations and individuals active in the field of RD, dedicated to improving the quality of life of people with RD in the European context. Orphanet is a digital platform specialised in information about RD.

SPAIN:

The first initiative for a systematic, exhaustive and rigorous approach to the situation of people with RD was the work entitled 'Enfermedades raras: Situación y demandas sociosanitarias', published by the IMSERSO in 2001.

ITALY:

Boasts several Centers of Excellence, but the fragmentation due to Title V of Part II of the Constitution which provides, among other things, that the organizational model of rare disease networks be regional in character, results in enormous differences.

CROATIA:

RD began to be mentioned in the public space in 2002 through the activities of the Association of people with Mucopolysarcharidosis (MPS), and from whose work emerged the present-day Rare disease Croatia (RDC), operating since 2012.

CYPRUS:

Cyprus Alliance for Rare Disorders (CARD) is active since 2011. CARD provides a unified voice to 16 patient organisations, as well as 350+ individual patients.

Regarding people living with rare diseases:

SPAIN:

Reported cases for the years 2010-2012 totalled 882,106, or 1.6% of the general population, according to the Instituto de Salud Carlos III.

ITALY:

It is estimated that there are more than one million people affected by rare diseases, while only about 325,000 are surveyed by the National Rare Diseases Registry.

CROATIA:

There is no complete register of people affected by rare diseases, so it is difficult to estimate the number of people living with rare diseases, but some sources state that between 150 and 250 thousand inhabitants.

CYPRUS:

It is only an estimation that there are 60.000-80.000 rare disease patients. These figures correspond to European statistics, indicating that 6-8% of the population per country-member has at least one rare diagnosis.

Young people living with rare diseases show anxiety about the future. They are also concern about whether they will find a partner, have children or find a job.

Research on rare diseases:



SPAIN: There are two major coordinating bodies for biomedical research: Centro de Investigación Biomédica en Red de Enfermedades Raras (CIBERER) and the Instituto de Investigación de Enfermedades Raras del Instituto de Salud Carlos III.



ITALY:
In the Health Chapter of the National Program for Research 2021-2027 (PNR 2021-2027) of the MiUR (Italian Ministry of University and Research), there are some specific articulations for rare diseases.

CROATIA:

Research in the field of rare diseases is poorly developed and few. An additional problem is their dispersion and fragmentation. One of the priorities of the National Program for Rare Diseases 2015-2020 (Ministry of Health, 2015).

CYPRUS:

The main research teams/centres are: (1) Cyprus Institute of Neurology and Genetics (CING) / (2) University of Cyprus / (3) Karaiskaki Institute and the Center for the Study of Haematological Malignancies.

Public initiatives, inclusion and social participation:

SPAIN: on 3 June 2009, the Interterritorial Council of the Spanish NHS approved the Rare Diseases Strategy, updated in 2014. In 2015, it was approved, created and regulated the State Register of Rare Diseases.



ITALY:

Interventions for people living with a rare disease are funded by the National Fund for Social Policies and the National Fund for Non-self-sufficiency.

CROATIA:

The improvement of young people with rare diseases is covered by the National Plan for equalizing opportunities for people with disabilities for the period from 2021 to 2027 (Ministry of Labour, Pension System, Family and Social Policy, 2021).

CYPRUS:

The National Plan for Rare Diseases dates back to 2012 and there has been no formal activity to update it since.



1.1. The project.

The initiative 'Quality Youth Mentoring for Inclusion' aims to create a network of national rare disease organisations to design and implement an empowerment strategy for young people living with barriers, to become mentors and big brothers to other young people and children experiencing the same barriers from all over Europe, in order to guide them in a virtual way to develop their self-confidence, learn about their situation and consequences, and discover mechanisms to achieve inclusion. The partnership has outlined several objectives of the project.

1

**Promote the inclusion of young people
and children
with Rare Diseases
through active participation
and volunteering.**





2

To develop the competences of young people with RD, preparing them for life, as well as teaching them to be protagonists in the inclusion of other young people with barriers.





3

Promote a transformation and change in the field of support for children and young people with disabilities, from being mere beneficiaries to true protagonists of their inclusion.





4

Develop European structures capable of promoting this new vision of working with young people with RD and become a reference in the construction of policies to support research.





5

Promote a more inclusive European culture in which local communities, social partners and governments support children and young people with RD.



2. People that will participate in the project.

The "Quality Youth Mentoring for Inclusion" has developed a mentorship program to support young people across Europe who are affected by rare diseases. It seeks to foster a community of mutual support by establishing mentoring relationships between "Big Brothers" (older or more experienced individuals) and "Younger Brothers" (younger mentees or newly diagnosed individuals) who share similar life experiences and challenges.

The program's core objectives include offering emotional support, promoting social inclusion, and encouraging personal growth and advocacy. By connecting individuals who can relate to each other's rare disease experiences, the program aims to reduce feelings of isolation, provide practical life skills, and empower young people to advocate for themselves and others affected by similar conditions.

In the mentorship structure, Big Brothers take on the role of mentors, providing Younger Brothers with guidance, encouragement, and support as they navigate their unique situations. Big Brothers, who are often further along in their journey of living with a rare disease, are trained to offer advice and companionship while maintaining a sensitive and empathetic approach to each mentee's needs.

Younger Brothers are children or teens, usually new to their diagnosis or those who may be struggling with the daily realities of a rare disease. Matches are carefully made based on shared experiences, personality traits, and, where possible, geographic proximity to maximize the empathy and understanding within each mentoring relationship.

3. Entities that will implement the project

The "Quality Youth Mentoring for Inclusion" initiative is designed not only to support individuals affected by rare diseases but also to engage social entities, organizations, and professionals from within and beyond the healthcare field. The program aims to create a larger support system that recognizes and addresses the unique needs of young people with rare diseases.

This inclusive approach encourages a diverse range of organizations—whether they specialize in rare diseases, mentoring, or have an interest in social impact—to contribute resources, expertise, and perspectives that can enrich the mentorship experience and amplify its reach.

Organizations within the healthcare and rare disease fields, including medical research institutions, hospitals, and patient advocacy

groups, are natural partners for the initiative.

These organizations possess the specialized knowledge and resources that can directly benefit the young participants and provide Big Brothers with valuable insights into best practices in patient care, self-care, and disease management.

The initiative also seeks collaboration with organizations in the mentoring and youth development sectors. By working with established mentoring entities, the program can adopt proven mentorship techniques and leverage the expertise of experienced mentors and trainers. For mentoring organizations, involvement in this initiative offers a chance to broaden their impact by supporting an underserved community, allowing them to extend their mentorship framework to include young people with rare diseases.

Furthermore, the initiative appeals to professionals and organizations outside the realms of healthcare and mentoring who are interested in making a social impact. For example, companies focused on technology, education, or community development might find value in supporting the program by providing digital tools, educational resources, or volunteering programs. For these organizations, involvement in the initiative aligns with corporate social responsibility (CSR) goals and offers an avenue to contribute to a high-impact, values-driven project that fosters inclusivity and resilience in young people.

By inviting this diverse range of partners, the "Quality Youth Mentoring for Inclusion" initiative builds a wide-reaching support network that extends beyond those directly affected by rare diseases. This inclusivity not only amplifies the impact on participants' lives but also fosters broader societal awareness of rare diseases, encouraging a more supportive and empathetic social environment. As the program grows and evolves, the

initiative envisions a society where diverse organizations come together to address the complex challenges faced by young people with rare diseases, ensuring they are supported in every dimension of their lives.

3.1. The network YOU'RE NOT ALONE.

Building on its inclusive approach, the "Quality Youth



"Mentoring for Inclusion" initiative envisions the creation of a robust network uniting organizations from various fields to strengthen collective

efforts in addressing the multifaceted challenges associated with rare diseases.

This network seeks not only to support young people affected by rare diseases but also to stimulate a broader movement that will drive innovation, education, and policy change in this often-overlooked area of healthcare.

This network also enables a powerful model of shared learning and innovation. Organizations from different fields bring varied expertise and perspectives, which can lead to innovative approaches for addressing the challenges faced by those with rare diseases.

Regular conferences, workshops, and digital platforms within the network could serve as spaces for organizations to share insights, discuss new challenges, and devise creative solutions.

By developing a network that harnesses the resources, knowledge, and influence of diverse organizations, the "Quality Youth Mentoring for Inclusion" initiative envisions a future where young people affected by rare diseases receive holistic support, and where rare diseases are met with the research, awareness, and advocacy they deserve. Through collaborative, cross-sector efforts, this network aims to build a lasting, impactful movement that addresses both the immediate and long-term needs of the rare disease community.



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2

THE ROLE OF THE INSTITUTION IN THE MENTORING PROCESS

Chapter 2. The role of the institution in the mentoring process

2.1. The importance of mentoring for people affected by Rare Diseases

There are many challenges that people with rare diseases face, first and foremost getting a correct diagnosis in a timely manner. Patients with rare diseases often wait years before arriving at a definite diagnosis, going through examinations, surgery, and inadequate pharmacological and rehabilitation treatment because the first diagnosis was not the correct one.

This situation inevitably leads to a spasmodic search for a suitable specialist reference point in order to feel truly taken care of, with travel even very far from one's home, generating discomfort on several levels. At the emotional level we find the development of worries, anxieties, instability and uncertainty, at the economic level we find onerous expenses that are not always necessary, at the family-social level complex organisations are structured with parents who have to move away from work, children and young people

who miss days of school and move away from the peer group and social opportunities for inclusion.

In general, rare diseases are frequently underfunded and understudied, leading to limited treatment options and a lack of comprehensive knowledge about many conditions. Other challenges to be noted and not forgotten are certainly:

The possibility of access to adequate treatments and experimental protocols; living with and dealing with the pathological condition that may involve physical and functional problems with limitations in vision, speech, listening and motor skills, deambulatories but also involving the upper limbs. Other relevant aspects relate to any cognitive and emotional comorbidities that may arise. In fact, people with rare diseases may also present, (in a variable percentage of cases),

cognitive problems, language problems in early childhood, and learning problems later on, but also problems in the behavioural and emotional sphere that require specific rehabilitation interventions and the implementation of strategic plans to support, contain and minimise difficulties.

Containing the disinvestment towards the future that is usually structured when living with a rare and complex pathology, exploring and analysing one's own attitudes, interests and passions in order to orient and guide them towards a reorganisation and the possible readjustments needed.

Experiencing confrontation with oneself. In fact, one of the most significant challenges in the experience of disability is represented by the processes of adaptation, elaboration of one's deepest emotions and acceptance of one's condition, supporting the continuous adaptation to continuous changes in one's body and functions, when the rare pathology is also degenerative.

Experiencing confrontation with others in the social context (school, peers, free time, aspects of affectivity and sexuality). The condition of disability, in fact, not only affects the individual, but also the social context and interaction with society can significantly influence the psychological experience. Stigmatisation, discrimination and social isolation can have a negative impact on mental health for the person involved and for the whole family system. In contrast, an inclusive environment, which promotes empowerment and social participation, can foster a more positive psychological adjustment.

Another challenge concerns the family system, which needs to be supported throughout the child's life story. When a child with a rare disease is born, parents are soon engulfed by anxious trips to specialists and hospitals, by deep-seated worries and anxieties. This emotional context can take different forms, conditioning attitudes, life habits and, in general, the way one looks at the world. A typical mode is that of investing to the

maximum in the protection and care of one's own child, leading the parent, over the years, to replace the child, generating relational dynamics marked by emotional-affective dependence, and thus undermining his or her process of differentiation and drive towards autonomy for the person with a rare disease, in fact, the moment must come when his or her problem becomes part of his or her reality and no longer the evil to be fought: only in this way can room be made for other relationships, interests, desires, choices, possibilities.

Precisely because we are talking about persons affected by a disease from birth, symptomatic therapies or standard of care should be complemented by a pathway for coping with life with a disease or disability. Mentoring, in this field, can offer agile and effective tools for sharing strategies to direct the subject's resources towards a better quality of life.

At the same time, it is also proven invaluable for families and caregivers, who may sometimes lose the reins of their own existence in the

course of caring and need both practical information and tools for managing emotions.

Mentoring will play a crucial role in the project, as a tool for supporting individual, educational, and professional growth, and fostering social inclusion. At the same time, the mentoring process will offer guidance and encouragement, helping mentees gain confidence and realize their ambitions while mentors develop leadership and coaching skills.

In the long term, "Quality Youth Mentoring for Inclusion" is expected to make a significant impact on the lives of young people with rare diseases by improving their quality of life, building a supportive community, and fostering inclusivity.

The program not only provides immediate support but also encourages youth leadership, creating a generation of advocates and mentors who can drive awareness and social change. By creating a replicable model for mentoring youth affected by rare diseases, the initiative envisions a network of support that stretches

across Europe, ensuring that young people with rare diseases have the

resources, friendships, and support needed to thrive.

2.2. Key principles in mentoring

 **PARTICIPATION**

 **OPEN MIND**

 **CONFIDENTIALITY**

 **ACCEPTANCE**

 **TAKE CARE OF YOURSELF**

As in every relationship, mentoring youth also has a set of standards, essential principles that act as pillars of mentor – mentee relationship. Below are the main principals which should be followed in the mentoring process.

1. *Voluntary participation.*

Both the mentee and the mentor should voluntarily decide to engage in the mentoring process and to work with one another. This applies throughout the whole mentoring process, that is, if at any point the participation in the process stops being voluntary, ending of the mentoring process should be discussed.

2. *Openness.* The mentee and the mentor have to be open for sharing their experiences, needs, emotions, strengths and weaknesses. They should also be open for taking different viewpoints and approaches, for new ideas, for learning and personal growth. Mentoring should be a process in which both sides learn new things.

3. *Confidentiality.* It is important to agree that what is shared in the mentoring process is confidential and stays between the mentee and the mentor. That way, the mentoring process becomes a safe place to share thoughts, fears and needs. It is important to agree on limits of the confidentiality and on the situations in which it may be necessary to pass around it and inform the third party about the particular situation.

4. *Acceptance.* The mentoring relationship should be a safe place in a way that both sides are accepted with respect to different backgrounds, sets of values, beliefs and experiences. It is probable that there are going to be some differences between the mentee and the mentor, but those should be addressed with respect that there is no “right” or “wrong” way. No side should be judged on the basis of their differences.



5. *Taking care of yourself.*

Even though the mentoring process is a process of learning and growth, it can sometimes become overwhelming both for the mentor or the mentee. In those situations, it is important to acknowledge one's own feelings and share their concerns with the person of trust (such as supervisor), while respecting the agreed confidentiality of the relationship. Keep in mind that the mentoring process should not become a burden, it should be a voluntary relationship between the mentor and the mentee.

2.3. Who is the mentor?

In the mentorship process, Big Brothers take on the role of mentors, providing Younger Brothers with guidance, encouragement, and support as they navigate their unique situations. Big Brothers, who are often further along in their journey of living with a rare disease, are trained to offer advice and companionship while maintaining a sensitive and empathetic approach to each mentee's needs. In the present project, the mentor is:

Someone who has lived with the disease for a long time and who has overcome many barriers through his life. Consequently, it is someone who has developed skills and techniques to overcome those challenges

Someone who has acquired resilience and thus developed a positive view of himself; they are aware of their strengths and abilities, are able to manage his feelings and impulses in a healthy way

Someone who knows how to set realistic and measurable goals and has adequate communication skills. At the same time, the mentor should be a positive role model, an experienced 'friend' who can transfer his or her knowledge.

A person who helps, in a one-to-one relationship, a younger mentee during an important transition period in his/her life, which takes on a much higher value in neuromuscular pathologies where this transition can coincide with a change in the pathology, if for example it is degenerative. At the same time, the mentor helps the mentee realise his/her potential also in the relational/affective sphere

A person who shares his or her life experience with the aim of assisting, supporting, encouraging and guiding the mentee to move safely through the different occasions and experiences of his or her life.

2.4. Who is the mentee?

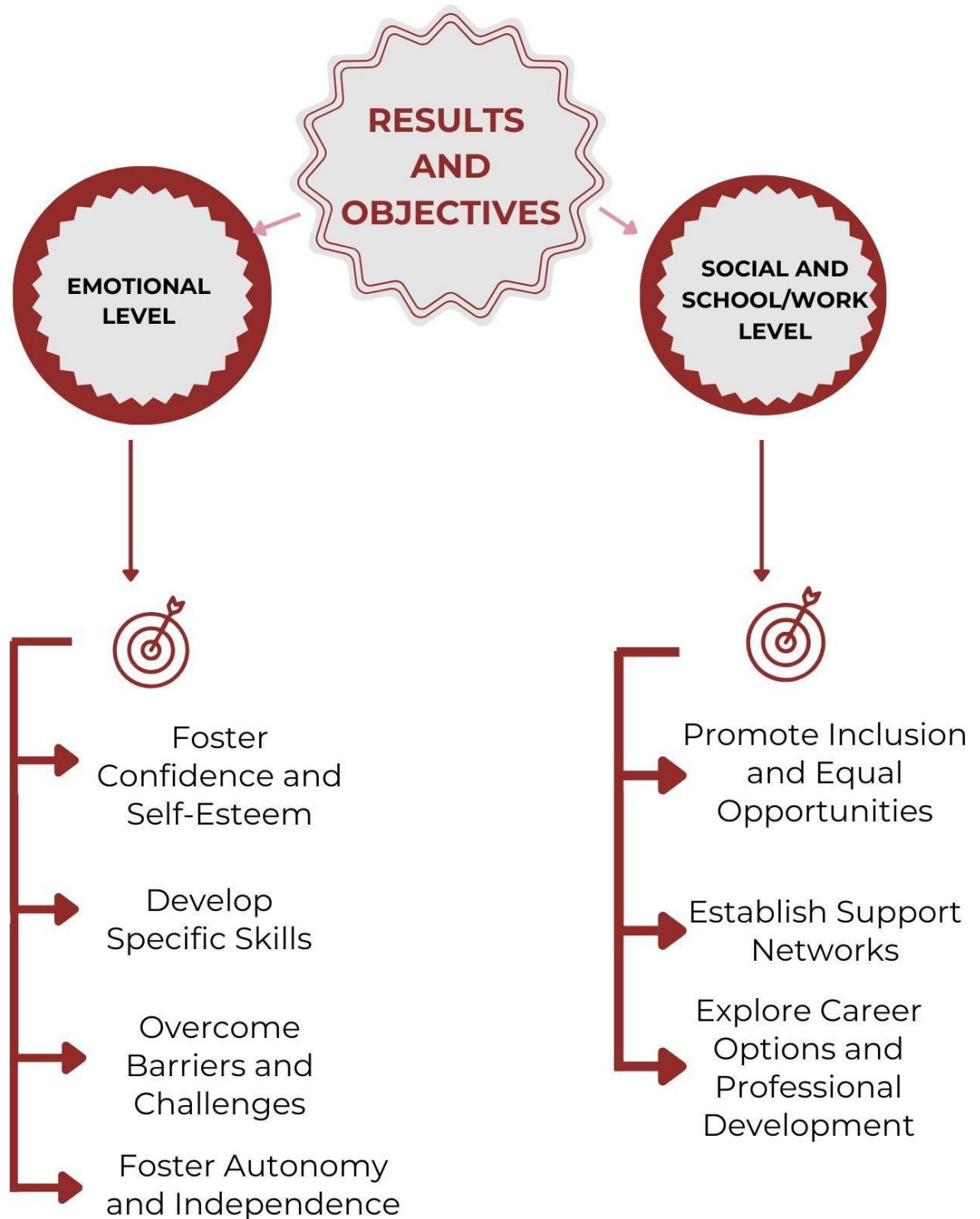
Younger Brothers are children or teens, usually new to their diagnosis or those who may be struggling with the daily realities of a rare disease. Matches are carefully made based on shared experiences, personality traits, and, where possible, geographic proximity to maximize the empathy and understanding within each mentoring relationship. In the present project, the mentee is:

Someone who is experiencing the first symptoms of the disease and thus, with lack of experience and information regarding the disease/diagnosis/symptoms;

Someone who does not know how to face the different barriers related to the disease. Furthermore, the mentee is someone who must acquire resilience, develop a positive view of himself; become aware of his strengths and abilities and learn to manage his feelings and impulses in a healthy way;

Someone who must learn to set realistic and measurable goals and learn to develop appropriate communication skills;

Someone who relies on Big Brother to guide, support and sustain him through the mentoring process.



2.5. Mentoring: objectives and expected outcomes

At the heart of any mentoring relationship is the type of relationship established between mentor and mentee, which depends on both internal and external factors. Internal factors include the personality of the individuals and their ability to enter into positive relationships with themselves and others; external factors include the conditions of the context/territory in which the process takes place.

The skills that make individuals capable of acting positively and effectively both individually and socially are defined as Life Skills. According to the World Health Organisation (WHO), 'Life Skills are the competencies that lead to positive and adaptive behaviour that enable individuals to cope effectively with the demands and challenges of everyday life'.

The mentoring process is in fact decisively influenced by the contexts in which it exists and takes place, and by the countless different objectives for which it is applied. It is therefore important to mark common goals that can be traced back to 2 main levels:

EMOTIONAL LEVEL:

Foster Confidence and Self-Esteem:

Help participants develop confidence in their abilities and strengths, as well as increase their self-esteem to overcome barriers related to Rare Diseases.

Develop Specific Skills:

Identify and work on developing specific skills relevant to the mentee's personal and professional goals, such as communication skills, social skills, technological skills, or specific job-related skills.

Overcome Barriers and Challenges:

Identify and address the specific barriers and challenges faced by individuals with Rare Diseases in their personal and professional development and develop strategies to overcome them.

Foster Autonomy and Independence:

Help participants develop skills for independent living and decision-making, empowering them to have greater control over their own development and well-being.

SOCIAL AND SCHOOL/WORK LEVEL:

Promote Inclusion and Equal Opportunities:

Work to create an inclusive environment that promotes equal opportunities for individuals with Rare Diseases, both in the workplace and in society at large.

Establish Support Networks:

Facilitate the creation of strong and meaningful support networks, both within and outside the mentoring program, that can provide guidance, resources, and additional opportunities for mentoring.

Explore Career Options and Professional Development:

Assist participants in exploring different career options and professional development opportunities that align with their interests, skills, and abilities, taking into account potential limitations related to Rare Diseases.

2.6. The role of the institution in the mentoring process

The institutions and organizations interested on implementing the mentoring process, should be aware that the process is structured with several key components. From our experience, it is essential that the organisation appoints a professional who is responsible for monitoring the progress of the relationship, checking that the basic indications described below are respected.

Contact and recruitment:

Phase in which contact is made with mentors and mentees by registering them on a special platform; it is important to analyse each case individually and avoid rejecting the candidature of anyone who may have shown interest in the project. Next, potential mentors are recruited by providing them with all the necessary information and also specific computer material. It is crucial to inform them about the project, its objectives and the team to be involved also in order to

develop trust with potential participants.

Matching process:

The main objective of this phase is to analyse candidates well in order to ensure the right conditions and circumstances that foster strong relationships of trust between people sharing the same diagnosis, common interests, and thus favouring the mentoring process. At this stage, a careful investigation of the mentor candidate's aptitude traits and motivation to exercise this role, combined with adequate customized training (especially on the side of empathic and effective communication) can make all the difference.

Training and orientation:

The relationship must be the central component of peer mentoring programs, so any disruptive elements must be analysed and ongoing training for the mentor must be planned for the

development of specific skills. Training and orientation were also considered crucial to contribute to the success of the program in order to prepare the mentee to have knowledge and expectations of the program requirements, but also for the parents as their involvement ensures support for the mentee and guarantees positive results. Mentors and mentees should develop skills in active listening, empathy, and mentorship techniques, allowing them to build strong, supportive relationships with their mentees.

Monitoring and evaluation:

Another relevant element is the monitoring of the mentoring process, which must include a standardized procedure for both mentors and mentees in order to solicit information, provide feedback and personalized support. Regular monthly check-ins help maintain progress, allowing both Big and Younger Brothers to discuss goals, celebrate achievements, and address any challenges. The mentorship journey is organized into

phases to support continuous development.

Final evaluation and closure:

Ultimately, a reflection and transition phase allow participants to review their progress, celebrate milestones, and prepare for future goals. The initiative includes methods for evaluating its effectiveness, with regular well-being surveys and goal achievement tracking to assess improvements in mental health, self-esteem, and life skills.

2.6.1. Why to implement the mentoring process?

The further aim of the project is to work for the integration and well-being of children and young people living with Rare Diseases and to support parents in this path. In order to help disseminate knowledge of the psycho-social aspects related to pathologies, it is important to organise training programmes and disseminate specific information material in order to create a network of collaboration between researchers, clinicians, patient associations and the various contexts of life that work with children/young people (e.g. schools and rehabilitation centres, etc.).

For the institution, this mentorship program can enhance patient satisfaction, build a supportive community, and foster trust while also creating opportunities to gather insights that inform care practices, drive advocacy, and potentially contribute to impactful research efforts.

The serious problems related to neuromuscular diseases, muscular dystrophies and rare diseases make it essential to have an integrated social-health intervention useful to ensure multidisciplinary care. In this scenario operate associations which make use of the presence of professionals who are responsible for optimizing the support network for patients and their families, orienting parents with specialist physicians and centres of reference, providing information on a wide range of issues, and ensuring, in addition, comprehensive psychological support for the family unit.

In this panorama, it is important to offer a free counselling service aimed at families living with the different diseases through meetings in person or through telephone contact, to provide information related to pathology, genetic and prenatal diagnosis, and updates regarding research and clinical trials. One of the primary goals should be to

disseminate key information contributing to the spread of increasing awareness both in the scientific-clinical field and in civil society.

The further aim is to work for the integration and well-being of children and young people living with different diseases and to support parents in their interfacing with educational institutions. To help spread knowledge of the psycho-social aspects related to pathologies, it is important to organize training programs and disseminate specific information material in order to create a network of collaborations between researchers, clinicians, patient associations, and the different contexts of life that work with children/youth (for example school and rehabilitation centres, etc...).

2.6.2. How to successfully implement the mentoring process in your organization?

Implementing a mentoring process for individuals affected by rare diseases can significantly benefit institutions by fostering a supportive, informed, and resilient community. This type of program connects patients, families, or caregivers with mentors who have experienced similar health challenges, creating a reliable network of guidance and emotional support. By empowering patients and families through mentorship, institutions can improve patient satisfaction and encourage more active engagement in treatment plans, ultimately contributing to better health outcomes and a more holistic approach to care.

Furthermore, a mentoring program focused on rare diseases enables institutions to build a resource of shared knowledge and experience, enhancing the institution's reputation for patient-centred care. By systematically gathering insights from both mentors and mentees, institutions

can deepen their understanding of rare diseases, potentially informing future research and clinical practices.

Such programs also strengthen institutional ties to the rare disease community, promoting advocacy, increasing awareness, and fostering partnerships that may lead to funding or collaborative opportunities for research and support services.

To foster inclusivity, organizations should develop a public inclusion statement that clearly expresses their commitment to inclusion and prominently display it on their website and program materials. Additionally, they should review and adapt their work methodology to ensure accessibility and support for individuals with rare diseases (RD).

This includes evaluating hiring processes for accessibility barriers. Finally, organizations should enhance anti-bullying and harassment policies to explicitly protect against

discrimination based on RD/disability, alongside protections for race, religion, gender, and sexual orientation.

2.6.3. How inclusive is your organisation?

The approval of the ICF (International Classification of Functioning, Disability and Health) classification by the WHO (World Health Organisation) represented a major change in the concept of disability. The ICF introduced a broader and more holistic perspective on disability, shifting the focus not only on people's physical limitations, but also on their overall functioning and their interaction with the environment. With the ICF, disability is seen as the result of a complex interaction between health conditions, bodily functions, activities performed and the environmental context.

This means that every institution must take into account the different abilities of people and create spaces that enable everyone to participate fully not only physically, but also functionally and socially, as

space is a key element in fostering the integration of all people, particularly those with disabilities. Space teaches and includes, just as it influences cognitive aspects and, therefore, learning; likewise, the physical environment plays an important role in determining and managing disability: it can, in some cases, accentuate it or, on the contrary, facilitate its overcoming.

This condition, in fact, is not exclusively linked to physical characteristics, but is related to a series of variables that derive from the context in which an individual interacts. The place where a person carries out his or her activities is also the place where personal relationships are born and built, which in turn have an impact on his or her growth and development process. Organising the institution's

spaces in an inclusive manner means guaranteeing everyone full participation in mentoring processes and ensuring emotional well-being for all, while respecting their differences.

The institution's objective is to create an absolutely inclusive environment, creating spaces suitable for each individual, regardless of their specific characteristics, following the basic concept of 'Universal Design', a design approach aimed at making spaces usable by all, without discrimination. Bearing in mind that if an environment is accessible, comfortable and enjoyable for everyone, from those with disabilities to those pushing a pram with a child, then indeed everyone can benefit from it.

The 7 principles of Universal Design, defined in 1997, are the foundation of this vision:

- fair use: the environment must be usable by everyone;
- flexibility: it must adapt to different abilities;
- simplicity: use must be intuitive;
- perceptible information: essential information must be communicated effectively, regardless of the user's environmental conditions or sensory abilities;
- tolerance for errors: it must minimise dangers and errors;
- containment of physical effort: use must be comfortable, requiring minimal effort;
- sufficient space and measures for access and use: must provide adequate space and measures for access and use.

So, for the successful implementation of the project, the organisation should carry out a self-review.

ASSESSMENT TEST

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18

The institution welcomes all staff and other members of the community.

- Not at all
- Slightly
- Fairly
- Very much

2. Staff perceive that giving and receiving help is normal practice in activities.

- Not at all
- Slightly
- Fairly
- Very much

3. Relationship and mutual support are actively encouraged.

- Not at all
- Slightly
- Fairly
- Very much

4. The members of the institution interact with each other in a respectful manner, regardless of their role.

- Not at all
- Slightly
- Fairly
- Very much



5. All staff feel adequately valued and supported.

- Not at all
- Slightly
- Fairly
- Very much

6. Staff are confident that they can find effective support for their needs in the managers.

- Not at all
- Slightly
- Fairly
- Very much

7. There is a shared feeling of acceptance regardless of personal history, abilities and disabilities.

- Not at all
- Slightly
- Fairly
- Very much

8. The contact group tries to contain obstacles to activities and participation in every aspect of the institution's activities.

- Not at all
- Slightly
- Fairly

- Very much

9. Inclusion is a fundamental mission of the institution, which significantly guides the activity plan.

- Not at all
- Slightly
- Fairly
- Very much

10. Refresher activities actually help to improve the ability to work cooperatively.

- Not at all
- Slightly
- Fairly
- Very much

11. All forms of inclusion support are coordinated in a way that enhances the institution's capacity to respond to individual needs.

- Not at all
- Slightly
- Fairly
- Very much



12. The institution conducts meetings between staff and experts in order to deal flexibly and effectively with problems that arise.

- Not at all
- Slightly
- Fairly
- Very much

13. All staff are encouraged to give their best.

- Not at all
- Slightly
- Fairly
- Very much

14. Everyone is seen, regardless of ability, as having a contribution to make.

- Not at all
- Slightly
- Fairly
- Very much

15. New resources are helped to settle in.

- Not at all
- Slightly
- Fairly
- Very much

16. Staff skills are adequately employed and enhanced.

- Not at all
- Slightly
- Fairly
- Very much

17. The institution combats all forms of discrimination.

- Not at all
- Slightly
- Fairly
- Very much

18. The institution makes its facilities physically accessible to all.

- Not at all
- Slightly
- Fairly
- Very much



SCORING AND RESULTS ANALYSIS



Attribute each score of

- Very much 3 points,
- Fairly 2 points,
- Slightly 1 point,
- Not at all 0 points.

Scores 54 to 40: Excellent level of inclusion of the institution

The institution has achieved an excellent level of inclusion that guides its activity plan, counteracting forms of discrimination and making facilities accessible to all.

At the individual level, the institution excellently supports and encourages cooperative work as it positively welcomes staff and community members by supporting the practice of helping and fostering relationships and mutual support in a climate of respect; it promotes a feeling of trust and acceptance of all figures by valuing and supporting the individual.

All forms of inclusion support are coordinated to enhance the institution's capacity to respond to individual needs and to deal flexibly and effectively with problems that arise.

Scores 39 to 26: good level of inclusion of the institution

The institution has achieved a good level of inclusion that guides its activity plan, adequately counteracts forms of discrimination and makes the facilities accessible.

At the individual level, the institution adequately supports and encourages cooperative work as it welcomes staff and community members by sufficiently supporting the practice of helping and fostering relationships and mutual support in a climate of respect; it promotes a good feeling of trust and acceptance of all figures by adequately valuing and supporting the individual.

Most forms of inclusion support are coordinated to try to increase the institution's capacity to respond to individual needs and to deal flexibly and effectively with problems that arise.



Scores 25 to 13: Sufficient level of inclusion of the institution

The institution has achieved a sufficient level of inclusion, which partially guides its activity plan, trying to counter forms of discrimination and making the facilities as accessible as possible.

At the individual level, the institution supports and encourages, sufficiently, cooperative work in that it tries to positively welcome staff and community members by trying to support the practice of helping and partly fostering relationships and mutual support in a climate of respect; it promotes a sufficient feeling of trust and acceptance of the figures by trying to value and support the individual.

Some forms of inclusion support are coordinated to try to increase the institution's capacity to respond to individual needs and to deal flexibly and effectively with problems that arise.

Scores 12 to 0: insufficient level of inclusion of the institution

The institution has not achieved a sufficient level of inclusion and fails to orient its activity plan and counteract forms of discrimination by trying to make facilities accessible to all.

At the individual level, the institution fails to support and encourage cooperative work as it does not positively welcome staff and community members; it must try to promote a feeling of trust and acceptance of all figures by valuing and supporting the individual.

Almost no support for inclusion is coordinated, failing, for the majority of situations, to respond to individual needs and to deal flexibly and effectively with problems that arise.



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3

**FINDING AND
TRAINING A GOOD
MENTOR / MENTEE**

Chapter 3: Finding and training a good mentor / mentee

This chapter includes a roadmap of the stages, tools and processes to develop and monitor the relationship between big and younger brothers and measure the outcomes. Sharing about illness, and perhaps even more so when sharing about a rare degenerative one and its consequences, is challenging both for the person living with the disease and their families. In small, closed societies, it is even more difficult.



3.1. Contact, Registration, Recruitment

A combination of methods is deemed particularly important to use in order to inform about the project, its objectives and the team to engage, and develop trust with potential participants. In the cases where the partner is a federation of rare diseases and non a rare-disease specific organization, initial contact is to be made with the national and international rare diseases associations to benefit from their expert knowledge on patient needs for support.

Their expert knowledge will be used to inform the various tools that will be used for the purposes of the current project. Open contact methods to incite registration of interest include:

Websites and other open dissemination venues such as mass mailings, newsletters, and social media posts (including paid ads) explaining the significance of the

project and using welcoming language for mentors and mentees.

Educational events and closed meetings organised by the institutions throughout the year, involving national partners who have direct access to patients. In these sessions, the institution will offer more detailed information about the project, covering the mentorship process, timeline, and participant responsibilities. This will allow them to understand what to expect and make an informed decision about joining the project.

Involving the healthcare professionals: Liaise with key physicians in each country to inform them about the project and ask them to inform their patients handing out relevant material.

Recruitment brochures and other marketing/educational material explaining the significance of the project and using welcoming language for mentors and mentees can also be placed in hospitals / clinics that are visited by patients with Duchenne diagnosis, in agreement with the directors and/or treating physicians.

For a successful recruitment, mentoring programs should clearly outline the requirements, rewards, and potential challenges of mentoring, setting realistic expectations about what mentoring can achieve. Explain that mentors will receive adequate training and support can help prospective mentors feel prepared and competent. Mentees and their families should also be fully informed about the program's purpose and requirements, ensuring alignment on both sides. Other recommendations:

It is recommended that mentoring programs include people with Rare Diseases on their website, flyers, social media, and other marketing materials. Besides, to have staff with Rare Diseases lead recruitment presentations will allow prospective mentors and youth participants to see themselves represented in the program's administration.

It is important that all recruitment materials are accessible and written in Plain Language. Moreover, it is critical to ask about accommodation needs throughout every step of the mentoring process, including during the recruitment stage to ensure that the process is accessible.

Recruit a diverse pool of mentors will help to increase the chances of finding a best fit for each youth within the program's mentee pool. Look for mentors with RD/disabilities who have other meaningful traits that would make them strong mentors, such as prior experience in helping roles or familiarity with the mentee's interests.

Program will recruit mentors whose skills, motivations, and backgrounds best match the goals and structure of the program. For both mentors and mentees, a successful mentoring relationship relies on mutual empathy, respect, open communication, and commitment. Mentors should demonstrate understanding and sensitivity, adapting their guidance to meet the

unique needs of each mentee while fostering a supportive environment that encourages growth. Mentees, in turn, benefit by being open to learning, actively participating, and communicating their needs and goals. Both parties should remain flexible, solution-oriented, and committed to the process, as consistency and dedication are key to building trust and making meaningful progress. Together, they can create a positive, empowering relationship that promotes resilience, autonomy, and personal or professional growth.

The registration of mentors and mentees will be done through the online platform **A BIG BROTHER FOR INCLUSION**. Through this platform, the people interested will fill in a questionnaire with information about their personal characteristics, interests, objectives and needs.

The information received will be saved in the database of the organisation and will be used to guide the matching process. The program will select mentors and mentees whose needs best match the services offered by the program. Nevertheless,

the organizations should consider each mentor applicant individually, avoiding the dismissal of any potential candidates and focusing on recommendations that support inclusivity.

3.2. Interview

After the registration, the institution will conduct in-depth interviews with each of the young participants to further assess his or her level of suitability for the mentoring process. The interviews will be tailored to each participant, and the institution will document all the information, which will be used for the matching process. By listening carefully to their stories, the organisation will gain valuable insights and will be able to guide the matching process following a criteria based on: empathy, communication skills, leadership qualities and compatibility.

The pre-interview questionnaire will start with general questions and move on to more disease-related questions, to identify personality traits and lived experiences with the condition. The tone and layout of the

questions will be neutral and explanatory at all stages. It is recommended to avoid deeply personal questions such as marital or relationship status.

3.3. Matching process

Good relationships develop between people who share common interests and spend time together. Relationships define the outcomes of mentoring programs, which are achieved when mentors and mentees like and value each other and feel they have developed something special and different from what each has with others in the program and school or community. The goal of the project is to create the right conditions and circumstances that will cater for strong trusting relationships between people who share the same diagnosis (muscular dystrophies and rare diseases).

To ensure that the participants are well suited for each other, we will focus on age, lived experiences with the condition and personality traits. We will obtain these data through the questionnaire and interview results, described in section 3 above. The partnership has outlined the following recommendations to conduct the matching process:

Before making a match, ask mentees and mentors with Rare Diseases what information they are comfortable sharing in advance with their prospective match partner. For mentees with Rare Diseases, who often need to build experience with self-advocacy and self-determination skills, listening to their preferences is fundamental to achieving successful program outcomes. The first way a mentoring program can demonstrate that they respect, and value mentee's preferences is to empower them by honouring their preferences during the matching process.

Programs should solicit mentees' opinions about their preferences for a particular mentor and when these preferences are denied, discuss the reasons for the decision about mentor assignment with them directly. Even if a mentor wants to move forward with their mentee, the final decision should come from the mentee. It is always important to take into consideration the participant preferences, but it is also important to encourage them to get out of their comfort zone.

If possible, program host a group event where prospective mentors and mentees can meet and interact with one another in an organized fashion, and then provide feedback to the mentoring program regarding their preferences for matching. This process gives mentors and mentees some “voice and choice” in matching and is based on the idea that this practice will be associated with greater engagement in the program.

Encourage parents or guardians to give feedback about the selected mentor prior to matching. This practice is designed to reinforce parent engagement and parent voice in the mentoring program. Parents may have the greatest insight into the type of mentor that would connect best with their child and thus, their input and feedback can help create a better match.

The matching process should not focus on the diseases or the disability to guide the matching process. Instead, it should prioritize the needs and expectations of the mentee. The most important thing in

the matching process is to listen the preferences and needs of the participants and try to find their match according to this. For that matter, it is essential to conduct individual interviews with the participants.

Experience showed that matching based on shared values and interests (sports, culture, hobbies) is more effective than matching solely based on a shared identity characteristic.

Regarding personality, goals and strengths, experience showed that matching participants with different personal traits (extrovert - shy / self-confident - insecure / organize - messy) may be positive for mentors and mentees.

Ultimately, it is crucial to understand that is the program’s responsibility to determine the best match for each participant and that the process is a positive one. It is essential also to communicate individually to all the participants the results of the matching process and to make sure the participants agree and feel comfortable with their corresponding



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mentor/mentee and explain to them that it is possible to make a change if necessary.



3.4. Training, orientation and goal setting calendar

Organisations will offer pre-match mentor training, because of the increased training demands on preparing effective peer mentors, who are, by definition, youth or young adults, and who need to learn additional information about being a mentor to a peer.

Mentor training is particularly important will benefit both mentors' and mentees' perceptions about the quality of their mentor-mentee relationship, and will have an impact on their feelings of closeness, support, satisfaction, and effectiveness as a mentor. Further, these perceptions of the mentor-mentee relationship are thought to influence the positive outcomes and continuation of the mentor-mentee relationship, suggesting the lasting importance of mentor training for youth outcomes. These are some of the aspects that are fundamental for the training of the mentor:

Program trains peer mentors on how to deliver program activities with fidelity and enthusiasm, especially in programs where mentors are expected to utilize a curriculum or help build specific skills in mentees, including how to facilitate participant interactions and ensure a positive group experience when leading activities and conversations.

Program provides peer mentors with additional training about roles and boundaries. Training topics should include out-of-program contacts; romantic relationships between mentors and mentees; inappropriate conversation topics with their mentee or in the presence of mentees; and always being a role model in the building, because mentees are always watching mentors.

Program trains peer mentors on how to manage the challenges that can emerge when supervising younger peers who may appear to be disinterested, be uncooperative, or misbehave at times. (e.g., active

listening and reflection), especially when the mentoring program includes structured, planned activities.

Training has recently been considered to also be a fundamental method of preparing someone to be in the new role of a protege or mentee. Providing a prospective mentee with both orientation and training is particularly important because having knowledge and expectations about program requirements, as well as about this new type of relationship, can contribute significantly to its success. Program trains mentees about how to participate in the program, including having a positive and respectful attitude and how to provide feedback to their mentor about what they like and dislike about the program, the mentor, and their interactions to help the mentee learn to be a self-advocate.

Parent training is particularly important because parent involvement in and support of the mentoring relationship is associated with positive youth outcomes. Parents need to have knowledge and expectations about program requirements, as well as

about how this new type of relationship can significantly contribute to their child's success. For example, understanding the potential benefits of being mentored and setting goals for the relationship can help build. The training is structured in 5 sessions.

Introduction to mentoring

Brainstorming session, definition of mentoring and discussion on expectations expectations of the process.

Skills of a good mentor/mentee

Open debate, role-playing and active listening

Safety and ethic behaviour

Practical exercises, protocols for protocols for sensitive issues and/or conflict situations

Beginning of the mentoring process

Setting a schedule or diary, understanding of basic rules, commitment agreement, etc.

Goals and activities

Understanding the different steps, objectives, skills and activities of the activities of the process.

3.4.1. SESSION 1. INTRODUCTION TO MENTORING

The objective of this phase is that the participants understand the fundamental purposes of mentoring process- For that matter, we recommend the following activities:

Brainstorming session. Discuss everyone's ideas of what mentoring process is; how it should look like; who

is included and what are their roles; what are some short-term and long-term benefits of participating in mentoring.

Interactive lecture. Description of the mentoring process, roles and responsibilities of the organization, mentor, mentee, parents (if included) and benefits of taking a part in the

initiative (skill development, networking, increased confidence...).

Introspection and discussion on expectations, hopes and concerns. Writing down the expectations, hopes and concerns. Every mentor/mentee should write down what he/she expects his/hers mentoring process to be or look like, what he/she hopes it to be, what are some concerns.

A conclusion should be derived from the brainstorming session as an introduction to the lecture. The conclusion should cover the following:

The definition of mentoring process as a partnership in which a more experienced person (the mentor) provides guidance and support to a less experienced person (the mentee) with the aim of personal growth, developing specific skills or achieving some other personal goal that is set in the process.

The mentoring process include the mentor and the mentee, but also the organization and mentee's parents and other close social circles as a support mechanism.

Benefits of mentoring reflect in personal growth of the mentor and the mentee, advancing communication skills, building confidence, networking, broadening perspectives and other.

3.4.2. SESSION 2. SKILLS OF A GOOD MENTOR/MENTEE









The objective of this phase is to understand and learn the skills which make a good mentor and mentee. For that matter, we recommend the following activities:

Open discussion. What are the skills that every mentor/mentee should have.

Interactive lecture. 10 things every good mentor/mentee should do.

Exercise on active listening skill. In pairs, mentors should try role playing with one telling a story, and the other one responding to it using active listening methods. Active listening is the basic and one of the most important skills which mentor should develop. To listen actively means to focus completely on the mentee with the aim of understanding him/her as well as possible. The mentor can do this by letting the mentee know how he/she heard and understood the mentee's message and leaving space.

TIPS FOR BEING A GOOD MENTOR

-  *Paraphrase to check if the message has been understood*
-  *Reflect on what you have heard*
-  *Paying attention to body language*
-  *Maintain eye contact*
-  *Use open questions*
-  *Do not interrupt the learner during the conversation and do not finish sentences*
-  *Allow silence and feel comfortable with it*
-  *Exercise the ability to give feedback*

This way, the mentor sends a message that he/she is trying to understand the mentee, that he/she is interested in how the mentee is doing, and that he/she accepts and respect the mentee as he/she is.

Exercise on providing feedback skill. In pairs, mentors should think of different situations and give feedback to one another, being mindful of how to give corrective and constructive feedback. Feedback is an important tool for learning and developing. Positive feedback and appraisal of certain actions or behaviours can encourage the mentee and make him/her more confident in their development process.

Apart from the positive feedback, corrective feedback is also important part of learning and growing. Corrective feedback can be given when the mentee is taking a less than desirable path and/or there is a room for improvement. When giving the corrective feedback, the mentor should be mindful of how it can affect the mentee at that moment.

It should not be given from an authority standpoint, but more as a friendly observation or advice. Also, the mentor should be open to receiving feedback and reflecting on it.

Tips on giving corrective feedback:

Discuss if and how does the mentee like to receive the corrective feedback

Give corrective feedback in private

Feedback should be given on specific behaviours or actions

Form the feedback in a positive tone of voice

Offer suggestions of different ways of acting to the mentee to try next time when in a similar situation.

3.4.3. SESSION 3. SAFETY AND ETHIC BEHAVIOUR DURING THE MENTORING PROCESS

The objective of this phase is to ensure that mentors and mentees understand and know how to address health and safety issues within the mentoring process. For that matter, we recommend the following activities:

Practical exercise. Practical dialogues to learn how to manage sensitive issues, concerns, and conflicts.

Action protocols. Presentation of the action protocols developed by the partnership regarding confidentiality, delicate matters, and conflict resolution.

Conclusions and reflection. The group reflects on the conclusions and questions that arose during the previous exercise.

For this exercise the mentors should get into pairs. By taking turns in the role of the mentor and mentee, they should practice communication in cases of sensitive topics and conflicts. Here are some scripts proposed for them to build the conversation around, but they can also come up with their own script that should include discussion on sensitive topic, concerning topic or a conflict.

Sensitive topic:

In the last meeting, you and the mentee touched upon the topic of romantic relationships. Due to his physical disability, the mentee struggles with needing assistance with the bathroom. He feels extremely self-conscious about that aspect of his life and is worried that it will prevent him from ever having a romantic relationship. As a mentor, address the mentee's concerns with sensitivity and provide support and encouragement.

Concerning topic:

As a mentor, you noticed that the mentee has become increasingly introverted, quiet, and reserved over the past few weeks. The mentee, who was previously engaged and communicative, now seems withdrawn and uninterested in activities they used to enjoy. As a mentor, you are concerned about the mentee's mental health and want to address these changes in their behaviour with sensitivity and care.

Conflict:

The mentee has repeatedly been late to scheduled meetings, often without offering any apology or explanation. Additionally, the mentee has been calling you at inappropriate times, such as late at night or during weekends, to cancel the meetings, disregarding the agreed boundaries. As a mentor, you need to address these issues in your mentoring relationship.

The partnership offers the following actions protocols that should be implemented in case of a conflict situation. The mentoring process must respect and protect the privacy and

trust of the mentee, creating a safe and supportive environment for their personal and professional development:

Clearly define and communicate to both mentor and mentee what types of information will be considered confidential (e.g., any sensitive personal or professional information shared during sessions).

Ensure both parties understand that all shared information in the mentoring context should be treated as confidential unless explicitly stated otherwise.

Make sure that the process of breaking confidentiality is handled with sensitivity, transparency, and a focus on the safety and health of the mentee and others:

Clearly communicate to the mentee from the outset that there are specific circumstances under which confidentiality may need to be broken (e.g., threats of self-harm, harm to others, or instances of abuse)

When it becomes necessary to break confidentiality, do so in a

transparent and supportive manner. Explain the steps you will take, who will be informed, and the intended outcomes of the disclosure.

Provide continuous support to the mentee throughout the process, ensuring they understand that the primary goal is their safety and well-being.

Remember to to handle sensitive topics with care, ensuring that the mentoring process is supportive, respectful, and conducive to the mentee's well-being and development.

Establish and maintain a safe and respectful environment where sensitive topics can be discussed openly and without judgment.

Encourage the mentee to set boundaries regarding what they feel comfortable discussing and always respect those boundaries.

Offer appropriate support and resources when discussing sensitive topics to ensure the mentee feels supported and has access to additional help if needed.

In case of a conflict, it is necessary to handle the situation constructively, fostering a positive and productive mentoring relationship.

Address conflicts as soon as they arise to prevent escalation and to maintain a healthy mentoring relationship.

Utilize active listening and empathy to understand the mentee's viewpoint and feelings regarding the conflict.

Develop a clear and actionable plan to resolve the conflict and prevent future issues. Collaboratively identify potential solutions, ensuring both the mentor's and mentee's needs and concerns are addressed.

Contact the organization responsible of the mentoring process to communicate any uncomfortable situation and find a solution.

The end of the mentoring relationship must be handled thoughtfully and respectfully, leaving both the mentor and mentee with a sense of closure and accomplishment.

It is important to define clearly the duration of the mentoring process. At the beginning of the process, discuss the duration, number of sessions and frequency.

Use the final stages of the mentoring relationship to reflect on the progress made and celebrate accomplishments.

Facilitate a positive transition for the mentee, offering continued support and resources as needed.

Express willingness to stay in touch, offering to be a continued resource or point of contact if appropriate, while clearly defining any new boundaries and expectations for post-mentoring interactions.



3.4.4. SESSION 4. BEGINNING OF THE MENTORING PROCESS

The objective of this phase is to understand completely the entering the mentoring process and first steps. In this part, it is essential that the participants understand the mentoring agreement involves several key steps to ensure it effectively evaluates the mentoring relationship and its outcomes:

Timeline/Calendar:

Establishing a clear timeline ensures that assessment activities are conducted at appropriate intervals throughout the mentorship program, allowing for ongoing feedback and *adjustment of mentoring strategies*.

Ground Rules Document:

Setting ground rules helps to establish clear expectations and guidelines for both mentors and mentees, promoting a respectful and productive mentoring environment.

Commitment Form: A commitment form formalizes the mentorship agreement and ensures that all participants understand their

roles and responsibilities within the program.

Authorization of Image Rights:

Obtaining authorization for image rights ensures that participants' privacy and consent are respected when using their images or likeness for program-related purposes.

Skills Assessment Report: The initial skills assessment analyzes the apprentice's competencies at the start of the program. Skill progress is detailed by tracking their advancements.

Finally, recommendations and conclusions are presented, providing suggestions for the apprentice's continuous development and a reflection on the program's effectiveness.

Diary: Both parties involved can develop a journal (writing, audio, video, etc.) where they share reflections on their role and the mentoring process. After each meeting, the mentor/apprentice can review and reflect in their journal about the encounter.



3.4.5. SESSION 5. GOALS AND ACTIVITIES

The objective of this phase is to understand the different steps, objectives, skills and activities of the mentoring process. The mentoring process is divided into 5 phases.

Building the Relationship. The first phase aims to create a strong foundation for a successful and supportive mentoring relationship.

Discovering my role in society. The second phase aims to understand the relationships with family and friends and to help the mentee build up a supportive network and develop an active role in society.

My daily Life. The third phase provides support to overcome the challenges and foster the strengths of individuals, empowering them to navigate daily life with confidence.

Thinking about the Future. The fourth phase reflects about the future opportunities and different career paths for the mentee and develops the critical and analytical thinking.

Talking about my Disease. The fifth phase will focus on the disease. Mentor and mentee will see together

testimonies of people in the same situation and will train mechanism to improve mental and physical health.

Each of the phases outlined above include the following characteristics:

Objectives: Three goals aligned with the topics and activities to be carried out in each phase.

Skills: Three abilities per phase that will be discussed and practiced during the exercises.

Activities: A set of resources, games, and activities that will help the apprentice understand the objectives and skills of each phase.

Workshops: A training activity that delve into some of the most prominent skills such as self-assessment, problem-solving, critical thinking, and communicating about illness.

The closure of the mentoring process is an important procedure that

should be approached with care and respect for all parties involved. Here are some steps that can be included in this process:

Goal Evaluation: Before closure, the mentor and mentee should reassess their initial objectives and evaluate whether they have been achieved.

Overall Review: Conduct a comprehensive review of the mentoring experience, including successes and challenges encountered during the program.

Feedback: Provide open and honest feedback on the mentee's progress, strengths, and areas where improvement may be needed.

Discussion of Future Plans: Discuss future plans and potential options for the mentee's personal development.

Conclusion and Farewell: Establish a definite date for closing the mentoring program.

Exchange of Contacts: Agree on the extent to which contacts will be maintained between the mentor and mentee after the mentoring relationship ends.

These steps can help ensure that the closure of the mentoring process is a thorough and beneficial experience for both parties, allowing for a smooth and effective transition to the next stage in the mentee's development.

3.6. Monitoring

A significant portion of mentoring program work is dedicated to monitoring and supporting mentoring relationships, and there are many reasons why this is crucial for the success of mentoring. Continuous monitoring of a program is vital for improving quality and ensuring an effective mentoring program, as it contributes to more positive outcomes, helps participants stay focused on the project goals, and enables them to address challenges if they arise. Monitoring strategies also inform many other aspects of a mentoring program, such as ensuring effective organizational structure, activities, recruiting mentees and mentors, technology usage, and communication processes.

The program may offer face-to-face or online discussion groups facilitated by a program representative, mentors, and mentees, on topics related to rare diseases as a complement to program activities or training.

This allows mentors and mentees to deepen their knowledge or share their perspectives. During each mentor monitoring contact, program staff should inquire about mentoring activities, mentee outcomes, concerns about safety, the quality of the mentoring relationship, and the impact of mentoring on both the mentor and the mentee using a standardized process. This process can be conducted through meetings of program staff with the mentor, the mentee, and, if applicable, a parent or guardian (Garringer M, Kupersmidt J at al. p. 61-62).

In conclusion, the frequency of monitoring contacts between the mentor and the mentee should take into account any challenges that could lead to closure. Therefore, monitoring and support contacts may need to occur more frequently if such challenges arise (Garringer M, Kupersmidt J at al. p. 62).

3.7. Exit and closure

It is fundamental for an effective matching process and effective monitoring of the relationship to guide and help the participants through the process. To plan for closure, the mentoring program should have a conversation with all members of the match to discuss their interest in continuing the mentoring relationship beyond the original commitment. This conversation allows everyone the opportunity to formally commit to continuing the mentoring relationship for an additional period of time and discuss any challenges they are experiencing that need to be addressed in order for the relationship to continue. Closure of the mentoring relationship may be predictable (e.g., conclusion of the academic year) or

unpredictable (e.g., change of address, illness). Subsequently, it is imperative that agencies plan for both unanticipated and anticipated closures, and have clear policies in place to address and document both of these types of scenarios

Closure activities can take many forms, such as exit interviews, a match meeting with or without agency staff, or a larger group event. Prepare mentors and mentees for the closure experience with as much lead time as possible. Ensure the closure experience offers opportunities for celebration, reflection, and referral. Formal closure meetings between the mentor and youth can help frame the end of the match in a positive light.



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4

**BECOME A MEMBER
OF THE NETWORK
YOU ARE NOT ALONE**

Chapter 4. Become a member of the network you are not alone



Young people are affected by the absence of accessible infrastructures, psychological support, genetic counselling services, low level of teacher and employer awareness, accessible education and employment programmes, disability awareness and acceptance. At a social and institutional level, there are many challenges:

the lack and fragmentation of information;

the lack of research on organizational models and innovative prostheses and aids;

lack of training on rare diseases of health professions;

the diversity of accessibility to services, drugs and aids;

the difficulties of the territorial care system for people with rare diseases.

Building on its inclusive approach, the "Quality Youth Mentoring for Inclusion" initiative envisions the creation of a robust network uniting organizations from various fields to strengthen collective efforts in addressing the multifaceted challenges associated with rare diseases.

By bringing together healthcare institutions, research centers, advocacy groups, educational organizations, and businesses, the initiative aims to foster a collaborative ecosystem that tackles rare diseases on multiple fronts—research, advocacy, patient empowerment, and public awareness. This network seeks not only to support young people affected by rare diseases but also to stimulate a broader movement that will drive innovation, education, and policy change in this often-overlooked area of healthcare.

One of the primary objectives of this network is to facilitate and accelerate research. Rare diseases are frequently underfunded and understudied, leading to limited

treatment options and a lack of comprehensive knowledge about many conditions. By creating a space where research organizations, hospitals, and academic institutions can collaborate, the initiative can promote a shared focus on advancing research for rare diseases. This collaboration could involve funding joint research projects, sharing clinical data, and providing young patients and their families with access to new findings and clinical trials. Such a network also enhances the sharing of best practices in medical treatment and patient care, ensuring that individuals with rare diseases receive the most up-to-date and effective support possible.

Advocacy is another essential area that the network will strengthen. Many rare disease patients and their families face systemic challenges, such as access to healthcare, specialized treatments, and social support. By uniting advocacy organizations, patient groups, and policy influencers, the network aims to amplify the voices of young people with rare diseases, making their needs

heard on a broader stage. Together, these groups can work to influence policy, pushing for increased government funding, improved healthcare accessibility, and policies that support educational and career opportunities for those affected by rare diseases. Advocacy within this network also includes public awareness campaigns that aim to educate the broader population, reducing stigma and fostering empathy and understanding for those living with rare conditions.

Empowerment lies at the heart of this network, with a particular focus on enabling young people affected by rare diseases to become active participants in their communities and advocates for their own needs. The initiative's mentorship program, which pairs Big and Younger Brothers, is a key driver of empowerment, providing mentees with the tools and support they need to build confidence, resilience, and independence. However, empowerment also extends to organizations in the network. By sharing resources, expertise, and support frameworks, network

members can work together to build programs that equip young people with essential life skills, such as self-advocacy, goal setting, and career development. Corporate partners, for example, could develop internship or employment programs tailored to those with rare diseases, helping them gain work experience and skills in inclusive and supportive environments.

Finally, this network enables a powerful model of shared learning and innovation. Organizations from different fields bring varied expertise and perspectives, which can lead to innovative approaches for addressing the challenges faced by those with rare diseases. For example, tech companies could contribute to telemedicine advancements, making healthcare more accessible for young people in remote areas, while educational institutions might develop training for teachers to better support students with rare diseases. Regular conferences, workshops, and digital platforms within the network could serve as spaces for organizations to share insights, discuss new

challenges, and devise creative solutions.

By developing a network that harnesses the resources, knowledge, and influence of diverse organizations, the "Quality Youth Mentoring for Inclusion" initiative envisions a future where young people affected by rare diseases receive holistic support, and where rare diseases are met with the research, awareness, and advocacy they deserve. Through collaborative, cross-sector efforts, this network aims to build a lasting, impactful movement that addresses both the immediate and long-term needs of the rare disease community.

The main purpose of the network is to establish a framework for international cooperation among social entities specialized in rare diseases that are part of a high-impact network at the European level. The parties commit to collaborating in the joint implementation of actions aimed at:

a) Promoting investment in research on rare diseases (RD): To promote and support initiatives that drive funding and the development of scientific studies, clinical trials, and research programs that enhance knowledge, treatment, and care of RDs.

b) Fostering the inclusion and participation of young people with RDs: To implement the project "QUALITY YOUTH MENTORING FOR INCLUSION," aimed at creating mentoring programs that facilitate the social, educational, and labor inclusion of young people affected by RDs, ensuring their full participation in society.

c) Establishing themselves as a recognized advisor on rare diseases: To strengthen the network's capacity to provide expert advice to national governments and European institutions on rare diseases, influencing the development of public policies and healthcare and social care strategies.



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5

**BECOMING A BETTER
MENTOR: STRATEGIES TO
BE THERE FOR YOUNG
PEOPLE**

Chapter 5. Becoming a Better Mentor: Strategies to Be There for Young People

According to the Cambridge Dictionary, “mentor” refers to an experienced and trusted person who gives another person advice and help¹. Being a mentor means carrying a responsible role of helping youth in overcoming various challenges leaning on mentor’s own personal experience and knowledge. Although it is a responsible and sometimes challenging role, being a mentor is also a great opportunity for personal growth, acquiring new knowledge, skills and experiences.

To help mentors navigate throughout their role as easily as possible, in this chapter we presented some skills, strategies and tips which mentors could find helpful in the mentoring process.

5 self-reflection questions for mentors

Before diving into details on what makes a good mentor, here are some self-reflective questions for the mentors. The aim of these questions is to encourage mentors to think about their role. Mentors can also come back to these questions again at any point of the mentoring process, especially if they feel insecure or start to question their role as mentors.

1. What inspired me to become a mentor?
2. What was the situation or time in which having a mentor could have been helpful to me? In which ways could mentor have helped me at the time?
3. What kind of mentor do I want to be?
4. In my opinion, what makes a good mentor?

¹ Cambridge Academic Content Dictionary

5. Which skills and/or characteristics of mine could be helpful in the mentoring process?

5.1. What makes a good mentor?

There are some skills that greatly help in creating space for joint work, collaboration and development in the mentor – mentee relationship. Below are some skills that are important for a mentor to nurture in order to make the mentoring process as successful and productive as possible.

1. Be supportive and positive

Mentor's role is to guide, uplift and empower the mentee. The focus should be on exploring the mentee's abilities and opportunities for growth. As a mentor, acknowledge and celebrate small victories to boost the mentee's confidence and motivation.

2. Listen carefully and show interest for the mentee's experiences and needs

Pay attention to what the mentee is sharing with you - their

concerns, experiences, aspirations. Use active listening to show the mentee that what he/she is sharing with you is important to you. You can use open questions to deepen some topics, but always check and respect the mentee's boundaries.

3. Be honest and authentic

Express your thoughts and feelings honestly. Make sure to align your words, actions and values and be consistent in demonstrating them. Sharing your emotions and experiences will foster mutual trust and connection in the mentoring relationship.

4. Adapt

Be flexible in your approach and keep in mind that despite some similarities, everyone's journey is different and unique. Adjust your

mentoring style based on the mentee's needs, preferences and goals.

5. Create safe space for sharing thoughts, feelings, making mistakes

Validate the mentee's feelings and provide a safe space for open communication. Acknowledge and respect diverse opinions, backgrounds and experiences by making it clear that everyone's perspective is valued and ensuring that your responses are free from judgement.

6. Encourage the mentee to explore their strengths and abilities

Help the mentee identify different skills, knowledges, behaviours or other tools which helped him/her overcoming challenges in the past. Explore different resources available to the mentee while focusing on his/her surroundings (such as family members, friends, school etc.). Provide positive reinforcement and recognition when you observe the mentee utilizing his/her strengths – this boosts confidence and encourages further exploration.

7. Encourage the mentee to take the lead in different activities

Ask the mentee about different activities he/she would like to participate in during the mentoring process. Encourage the mentee to give suggestions and create plan of specific steps that are necessary in order to engage in the suggested activity. Encouraging active participation and independence builds the mentee's self-esteem and the sense of control over his/her own life.

8. Learn

Let the mentee teach you about his/her life and different challenges he/she faces. Even though you are the mentor, the mentee is a crucial informant on his/her everyday life. When asking about it, make sure that the mentee feels comfortable sharing that information with you.

9. Give constructive feedback

Offer constructive feedback in a positive manner, emphasizing areas of improvement while acknowledging the mentee's efforts and progress.



10. Take care of yourself

The mentoring process can also be hard for mentors as well – evoking some past experiences and memories, becoming vulnerable by sharing your story or empathizing with another’s story can become difficult or overwhelming. And that is completely normal. In case you feel something is too much, do not hesitate to talk to the

supervisor or some other person of trust. Your well-being comes before the mentoring process.



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BECOMING A YOUNGER BROTHER

Chapter 6. Becoming a Younger Brother

Being mentored means having someone older and experienced who you trust to give you advice and help. Your mentor is there to support you through tough times using their own experiences and knowledge. While being mentored might have its challenges, it's also a chance for you to grow, learn new stuff, and have cool experiences. In this chapter, we'll share some tips and tricks to make your mentoring journey easier and more fun.

5 self-reflection questions for mentees

Before getting started with your mentoring journey, here are some questions for you to think about. These questions are designed to help you understand your role as a mentee better. You can always revisit these questions whenever you feel unsure or want to reflect on your mentoring experience.

1. What made me want to find someone to help guide me?
2. Can I remember a time when having someone to talk to and learn from would have made a big difference in my life? How do I think that person could have supported me back then?
3. What kind of person do I hope my mentor will be?
4. What do I think makes someone a really good mentor?
5. What can the mentor learn from me?



6.1. What makes a good mentee?

1. Be Curious

Cultivate a genuine curiosity in every conversation and meeting. Don't hesitate to ask questions about things you don't fully understand or areas you'd like to explore more deeply. This curiosity not only enhances your learning but also signals to your mentor that you're engaged and eager to grow. Keep an open mind, and be willing to challenge your own assumptions, as this can lead to valuable insights.

2. Listen Actively

Practice active listening by focusing intently on what your mentor is saying, making mental or written notes, and asking follow-up questions. Show that you value their insights by nodding, maintaining eye contact, and giving verbal affirmations when appropriate. Remember, listening isn't just about hearing; it's about truly understanding and reflecting on their guidance, which will help you apply it more effectively.

3. Share Your Goals

Take time to clearly define and communicate your goals, whether they're related to your career, personal growth, academic achievements, or skill-building. Being transparent about what you aim to accomplish helps your mentor tailor their advice to your specific needs and ambitions. Regularly revisit and update these goals with your mentor, as they may evolve as you grow.

4. Be Respectful

Show respect by valuing your mentor's time and experience. Arrive at meetings prepared, keep commitments, and be considerate of their advice—even when it challenges you. Acknowledge their efforts and insights, and remember that building a respectful, trust-based relationship is essential to making the most of your mentoring experience.

5. Say Thank You

Gratitude goes a long way in any mentoring relationship. Take moments to genuinely thank your mentor for their time, advice, and encouragement. Small gestures, like a thoughtful thank-you message after a meeting or a note to express appreciation, help reinforce the connection and make your mentor feel valued.

6. Be Responsible

Demonstrate accountability by taking your commitments seriously. If you and your mentor set certain goals, tasks, or timelines, follow through on them to the best of your ability. Own your successes and your missteps; showing responsibility in both builds trust and strengthens your reputation as a mentee who is reliable and committed.

7. Learn from Feedback

Accepting and acting on constructive criticism can be one of the most challenging yet rewarding parts of mentorship. Try to view feedback as a pathway to growth rather than as personal criticism. Be open to hearing

where you can improve and take steps to implement your mentor's suggestions, even if they push you out of your comfort zone.

8. Reflect on Your Progress

Periodically assess the progress you've made since starting the mentorship. Reflection helps you recognize how far you've come, identify areas for further growth, and set new goals. Celebrating small wins with your mentor can be a motivating way to acknowledge your hard work and keep your momentum going.

9. Be Patient

Growth doesn't happen overnight, and progress can be gradual. Understand that skills, knowledge, and confidence build up over time. Be patient with yourself and allow space for setbacks or periods of slower progress. Mentorship is a journey, and part of its value lies in embracing the process, not just the outcome.



10. Take Care of Yourself

Mentoring relationships can sometimes bring up personal challenges, emotions, or vulnerabilities. If a conversation brings up difficult feelings or becomes overwhelming, it's okay to pause and take care of your mental and emotional well-being. Seek out additional support

from trusted friends, family members, or professionals if needed. Prioritizing self-care helps you show up as a healthier, more resilient mentee.



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7

THE MENTORING PROCESS

Chapter 7. The mentoring process

In the "Quality Youth Mentoring for Inclusion" initiative, the mentoring process is structured to provide meaningful support within a concise timeframe. Each mentoring match between a "Big Brother" and a "Younger Brother" is set to last **3 months**, creating a focused, impactful mentoring period that encourages strong connections and practical growth for the mentee.

Throughout the match period, the mentor and mentee meet **once every two weeks**, ensuring consistent support without overwhelming either party. These biweekly meetings serve as structured check-ins that allow the mentor to provide guidance, encouragement, and share personal insights, while also allowing the mentee time between sessions to reflect and apply what they learn.



Each meeting is designed to last **between 1-2 hours**, offering sufficient time for meaningful conversation and goal-setting while remaining manageable and respectful of the mentor and mentee's schedules. This timeframe enables a flexible approach, where shorter or longer visits can accommodate the needs of each pair, depending on the depth of discussions or activities planned for each session.

With this regular and focused approach, the program's mentoring process promotes steady growth, building a trusting relationship that empowers the mentee to develop greater confidence and resilience within a structured, supportive framework.

We can imagine how all this affects the ability to process the condition, the compliance of both the parent and the patient who will become an adult and hopefully develop an active role in their decision-making abilities, as well as the development of resilience.

These fundamental aspects can be supported and sustained by the activation of helping relationships in order to develop skills in the training, educational, work and social spheres within a relationship of trust and understanding such as the one that can be structured within a mentoring process, which can really make a difference.



01

Activities

02

Objetives

03

Competencies

04

Habilities





7.1. Building the Relationship

The first phase of the mentoring process aims to create a strong foundation for a successful and supportive mentoring relationship.

The **objectives** of this phase are:

Establishing Trust and Rapport.
Build a foundation of trust and mutual respect between the mentor and mentee. Create a safe and supportive environment for open communication.

Identifying Needs and Goals:
Understand the mentee's specific needs, interests, and aspirations. Set initial short-term and long-term goals for the mentoring relationship.

Developing a Mentoring Plan:
Develop a structured plan that outlines the goals, expectations, and activities for the mentoring process. Agree on the frequency and mode of communication and meetings.

The **skills** to be developed:

Self-awareness. The mentee begins to develop an understanding of their strengths, weaknesses, values, and motivations with the mentor's guidance.

Identifying Needs and Goals.

Encourage the development of effective verbal and non-verbal communication skills. Practice active listening and empathy to ensure understanding and support.

Reflection:

The mentee starts to engage in self-reflection, which involves critically assessing their thoughts, behaviors, and experiences. Through this process, the mentee gains insights into their personal and professional growth.

The **activities** suggested:

Funny Icebreaker Questions:

Ask humorous icebreaker questions to get the conversation flowing. Funny icebreaker questions set a playful tone for the mentoring process and encourage participants to share amusing anecdotes and insights about themselves.

Two Truths and a Lie:

Each person shares three statements about themselves—two truths and one lie. The other try to guess which statement is the lie. This activity encourages light-hearted storytelling and allows participants to showcase their personalities in a playful way.

Animal Traits Game: Describe Yourself :

Game designed to help participants describe themselves by choosing between two options related to animals. Participants will define their characteristics and personality traits by choosing between two animal-related options at each phase.

Workshop. Developing the Mentoring Agreement

This activity involves several key steps and documents to ensure it effectively evaluates the mentoring relationship and its outcomes:

Timeline/Calendar:

Establishing a clear timeline ensures that assessment activities are conducted at appropriate intervals throughout the mentorship program, allowing for ongoing feedback and adjustment of mentoring strategies.

Ground Rules Document:

Setting ground rules helps to establish clear expectations and guidelines for both mentors and mentees, promoting a respectful and productive mentoring environment.

Commitment Form:

A commitment form formalizes the mentorship agreement and ensures that all participants understand their roles and responsibilities within the program.

Authorization of Image

Rights:

Obtaining authorization for image rights ensures that participants' privacy and consent are respected when using their images or likeness for program-related purposes.

Skills Assessment Report:

The initial skills assessment analyzes the apprentice's competencies at the start of the program. Skill progress is detailed by tracking their advancements. Finally, recommendations and conclusions are presented, providing suggestions for the apprentice's continuous development and a reflection on the program's effectiveness.

Diary:

Both parties involved can develop a journal (writing, audio, video, etc.) where they share reflections on their role and the mentoring process. After each meeting, the mentor/apprentice can review and reflect in their journal about the encounter.

7.2. Discovering my Role in Society

The second phase aims to understand the relationships with family and friends and to help the mentee build up a supportive network and develop an active role in society.

The **objectives** of this phase are:

Learn to Navigate Social and Community Settings:

Equip the apprentice with strategies to adapt their approach when interacting with different personality types to improve communication and relationship-building.

Foster active participation in society:

Promote the mentee's active involvement in societal activities to foster a sense of community and civic engagement. Facilitate involvement in social, recreational, and professional groups to foster a sense of community and inclusion.

Use Self-Assessment Tools:

Equip the mentee with self-assessment tools to promote continuous personal and professional growth. Provide feedback on the results, helping the mentee interpret their findings and develop actionable plans based on their insights.

The **skills** to be developed:

Networking:

Building and maintaining relationships. Interacting with peers, colleagues, and authority figures. Resolving conflicts and managing interpersonal dynamics.

Self-Advocacy:

Empower the mentee to express their needs, preferences, and goals clearly. Teach strategies for self-advocacy and self-representation in various settings.

Proactivity:

Approaching challenges with a proactive mindset, focusing on

solutions rather than dwelling on problems. This involves taking initiative and being resourceful in finding ways to overcome obstacles.

The **activities** suggested:

Family and Friends Bingo:

Create bingo cards with different personal traits and characteristics that describe the people that populates your social circles. This can lead to valuable conversations about setting boundaries, communicating effectively, and fostering positive relationships.

Social Circles Map:

The objective of this activity is to map the social circles in one's life and the interaction and proximity among them. This can lead to group discussions on family and friend dynamics and communication strategies.

Workshop. Self-Assessment
Tools:

By using self-assessment tools, individuals can gain insights into their

strengths and areas for personal and professional growth. It promotes self-awareness, fosters positive change, and encourages the cultivation of desired characteristics to enhance relationships and overall well-being.

GROW model: is a simple and effective framework used primarily in coaching and mentoring to facilitate goal-setting, problem-solving, and personal development. GROW stands for Goal, Reality, Options, and Will/Way Forward.

SWOT analysis: Conducting a SWOT analysis involves evaluating their internal strengths and weaknesses, as well as external opportunities and threats related to their personal and professional development.

RADAR chart (also known as a spider chart or web chart) to track progress can be an effective visual tool, especially in mentoring or coaching contexts where multiple dimensions of development or achievement need to be monitored.



Combining the GROW model, SWOT analysis, and RADAR chart into a methodology focused on personal characteristics and role in society can provide a comprehensive framework for self-reflection, goal-setting, and strategic planning. Follow the methodology and the example provided to identify and address the mentee's challenges with a proactive mindset, focusing on solutions rather than dwelling on problems.

7.3. My Daily Life

The third phase provides support to overcome the challenges and foster the strengths of individuals, empowering them to navigate daily life with confidence.

The **objectives** of this phase are:

Overcome Daily Life Challenges: To empower the mentee with practical life skills and strategies to bounce back from setbacks and effectively cope with daily life challenges.

Promoting Emotional and Mental Well-being: Support the mentee in managing emotions and coping with stress. Enhance the mentee's ability to analyze problems, make decisions, and take action in their daily life.

Fostering Personal Development and Self-Improvement: Help the mentee in identifying personal strengths, interests, and areas for growth through self-assessment exercises or reflective practices.

The **skills** to be developed:

Self-Management: Self-management skills foster personal development, resilience, and the ability to adapt to challenges, which are crucial for mentees' overall growth and success.

Problem-Solving: By mastering problem-solving, mentees become more self-reliant and confident in tackling challenges both within and outside the mentoring relationship.

Decision-Making: Assessing options and weighing pros and cons. Making informed decisions based on available information. Taking responsibility for decisions and their consequences.

The **activities** suggested:

Read and solve the riddles with the mentee and reflect on his/her abilities to overcome challenges. They will challenge individuals to analyze information, think creatively, and find unconventional solutions. The Enchanted Forest Crossroads / The

Mountain Summit Challenge / The Desert Oasis Puzzle

Workshop. Learning Problem
Solving techniques

This workshop focuses on
analyzing a personal problem from the
past and learning methodologies to
tackle similar issues if they occur again
in the future, structured into 3 phases:

Phase 1: Problem Reflection
and Root Cause Analysis

The mentee individually reflects
on a personal challenge they have
faced or are currently facing.

Introduction to root cause
analysis methodologies such as the
Fishbone (Ishikawa) diagram or the 5
Whys method.

Discussion to synthesize
findings and explore connections
between root causes and the personal
challenge.

Phase 2: Methodologies for
Solution Development

Overview of problem-solving
methodologies: Mind Mapping.

Practical exercises where the
mentee apply these methodologies to
brainstorm potential solutions for their
personal challenges.

Guidance on setting realistic
objectives, identifying barriers, and
developing actionable steps to
overcome them.

Phase 3: Action Planning and
Commitments

Design an action plan for
feedback and refinement.

Reflection on key learnings
from the workshop and identification of
personal growth opportunities.

7.4. Thinking about the Future

The fourth phase reflects about the future opportunities and different career paths for the mentee and develops the critical and analytical thinking.

The **objectives** of this phase are:

Analyse Inclusion in Society:
Broaden the mentee's awareness of inclusion issues, stimulate critical thinking about barriers and opportunities for inclusion, and empower them to contribute positively to creating more equitable and welcoming environments in their communities.

Educate on Right and Resources: Ensure mentees are aware of their rights and the resources available to them, such as accessibility services, legal protections, and community support networks.

Explore Career Options:
Introduce mentees to different career paths and opportunities that align with their skills and interests. Setting career

goals and planning for professional growth.

The **skills** to be developed:

Confidence and Resilience:
Develop mentees' confidence and resilience to handle future challenges and fight for their rights.

Critical Thinking: Analysing information and evidence on topics such as inclusion and accessibility in the workplace. This will help mentees to evaluate arguments, make logical conclusions and solve problems creatively and innovatively.

Set Priorities: Teach the mentee to determine the order of importance and urgency of tasks or activities, ensuring that the most critical tasks are addressed first and that resources are allocated effectively.

The **activities** suggested are:

Analyse News Articles and Studies on Inclusion: Read and discuss with the mentee news articles on inclusion and facilitate a discussion

by posing open-ended questions that encourage critical thinking and reflection.

Representation on the Media:
The objective is to explore and discuss representation of people with rare diseases and disabilities in the media through recommended movies and series.

Workshop. Learning to set your Priorities

Identifying career options can be a crucial step for individuals at various stages of their professional journey. Here are some activities that can help the apprentice explore and identify potential career paths. These activities will assist them in understanding their interests, skills, and values, which are essential for identifying suitable career options.

MIND MAP: Provides a structured yet flexible approach to identifying and exploring potential career paths, empowering the apprentice to think critically and creatively about their future aspirations.

SKILLS BAROMETER: The apprentice will evaluate and visualize current skill levels in key competencies. Participants will be able to identify their strengths, weaknesses, and development opportunities for personal and/or professional growth.

RADAR CHART: Enables progress tracking with an effective visual tool, especially in mentoring or coaching contexts where multiple dimensions of development or achievement need to be monitored.

7.5. Talking about My Disease

The fifth phase will focus on the disease. Mentor and mentee will see together testimonies of people in the same situation and will train mechanism to improve mental and physical health.

The **objectives** of this phase are:

Experience Sharing:

To create a safe and open environment where the mentor and mentee can share their personal experiences with the rare disease. This objective focuses on building a strong, supportive relationship through mutual understanding and empathy.

Coping Mechanism
Development:

To identify, discuss, and practice effective coping strategies for managing the emotional and physical challenges of the rare disease.

Community Building: To foster a sense of belonging and connection

within the rare disease community. This involves encouraging participation in support groups, connecting with others who have similar experiences, and building a network of support.

The **skills** to be developed are:

Active Listening:

The mentee will learn to actively listen and engage in meaningful conversations. This skill is crucial for understanding others' experiences, providing support, and building empathetic relationships.

Emotional Intelligence:

The mentee will develop greater emotional intelligence, including self-awareness, empathy, and emotional regulation. This skill will help them manage their own emotions and respond effectively to the emotions of others.

Empathy:

The mentee will enhance their ability to understand and share the feelings of others. This skill is crucial for building strong, supportive relationships and providing effective emotional support within the rare disease community.

The **activities** suggested are:

Video testimonies: The videos of the Erasmus+ project YOUTH WITH COURAGE, co-funded by the European Union, show the testimonies of young people affected by rare diseases regarding their social circles, daily challenges and participation in society.

Inspiring Stories:

The inspiring testimonies of the Erasmus+ project THE VALUE OF FACING SCHOOL, co-funded by the European Union, gather the insights of teachers, students and families regarding the inclusion and accessibility of people affected by rare diseases in the school context

TALKING ABOUT MY
DISEASE

The workshop aims to equip apprentices with the confidence and skills necessary to share information about their illness.

Mentors participating in the Erasmus+ **QUALITY YOUTH MENTORING FOR INCLUSION**, cofunded by the European Union, project will serve as a source of inspiration and support by sharing real-life experiences and ideas. Each mentor will explain to the apprentice their challenges, strategies, and success stories in various aspects of life, including education, personal growth, and professional achievements.

Next, the apprentice will engage in a reflective activity with a series of guided questions to help them craft their narrative and share their story.

Both parties discuss the importance of sharing their experiences, exploring benefits such as raising awareness, reducing stigma, and finding emotional support.

Finally, mentor and apprentice summarize the key points, highlighting

lessons learned during the mentoring process and the importance of continuous practice and the benefits of open communication.

closures and have clear policies in place to address and document both types of scenarios.

7.6. Exit and closure

To plan for closure, the mentoring program should have a conversation with all members of the match to discuss their interest in continuing the mentoring relationship beyond the original commitment. This conversation allows everyone the opportunity to formally commit to continuing the mentoring relationship for an additional period and discuss any challenges they are experiencing that need to be addressed for the relationship to continue.

Closure of the mentoring relationship may be predictable (e.g., conclusion of the academic year) or unpredictable (e.g., change of address, illness). Subsequently, it is imperative that agencies plan for both unanticipated and anticipated

Closure activities can take many forms, such as exit interviews, a match meeting with or without agency staff, or a larger group event. Research suggests that if closure is not formally processed, even for mentoring relationships characterized as weak, this may contribute to negative emotional outcomes for the mentees such as feelings of disappointment or anger.

Likewise, mishandling closure procedures all mentoring programs should have a framework in place for handling both anticipated and unanticipated closures, and the various options and decision points around closure should be communicated to mentees, parents and caregivers, and mentors both



during onboarding and at other points as the match progresses.

It's never too early to communicate about closure and set participant expectations on how it is handled. These practices can help ensure that youth with disabilities, and their mentors, are cared for during this time of transition.

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