facing SCHOOL

THE INCLUSION OF YOUNG PEOPLE WITH NEUROMUSCULAR DISEASES, MUSCULAR DYSTROPHIES AND OTHER RARE DISEASES IN EDUCATION

PARTNERSHIP

COORDINATOR

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

Universidade de Évora (Portugal), a center for the creation and diffusion of culture, science and technology, which, through the articulation of study, teaching and research, is integrated into the life of society.

Fondation Maladies Rares (France), a private non-profit legal person, promotes research projects and scientific excellence, as well as the sharing and dissemination of knowledge in the field of rare diseases.

C.E.I.P. Clara Campoamor de Málaga (Spain), an early age and primary public school of bilingual education that uses research, experimentation and educational innovation as a fundamental element of teaching practice.

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

Uniamo Federazione Italiana Malattie Rare (Italy), the representative body of the community of people with rare diseases. It has over 150 member associations.

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

INTRODUCTION

Rare diseases currently affect 3.5% – 5.9% of the worldwide population (EURORDIS, 2023a). More than 30,000,000 people in the European Union, which means that 1 in 17 Europeans suffer from a rare disease. (*EURORDIS, 2023*)

It affects
out of every **1**
2.000 inhabitants

3.5% - 5.9% of the world's population

Late diagnosis
5 YEARS ON AVERAGE

UNDIAGNOSED
Most of the people affected by a RD don't find a diagnosis

AROUND
7.000
rare diseases

LACK OF treatments

CHRONIC NATURE
Often disabling with pain, motor or sensory-intellectual deficits

VERY SERIOUS diseases

80%
GENETIC ORIGIN

In general, these diseases are
INHERITED

The treatment of RD requires a
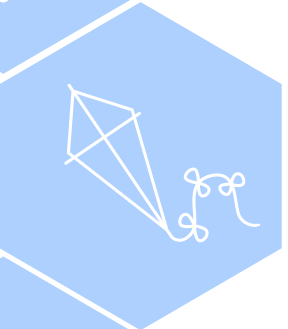**MULTIDISCIPLINARY APPROACH**
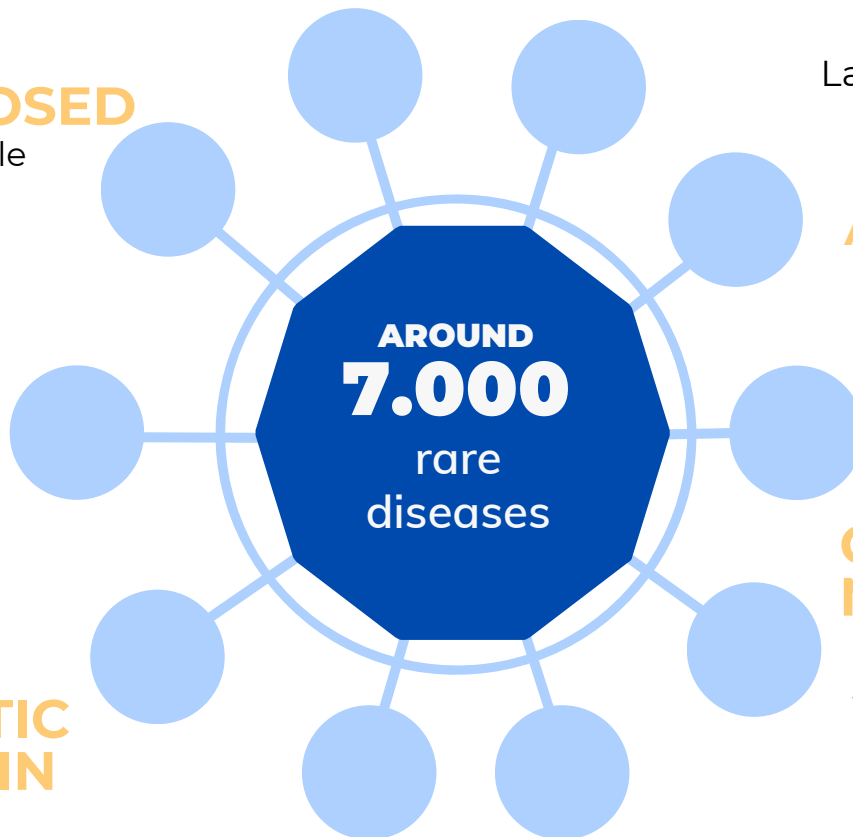
80% hereditary diseases
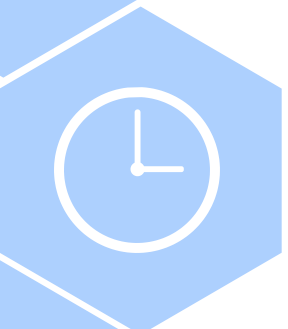
45% neurological origin

decrease in **life expectancy**

2/3 begin in childhood

65% chronic clinical course

delay in the **diagnosis**

expensive **treatments**

DIAGNOSIS

20% of people suffering a rare disease take more than 10 years to be diagnosed; another 20%, between 4 and 9 years.
(*FEDER, 2020*)

PRECONCEPTIONAL DIAGNOSIS

In order to make an accurate diagnosis, a preconceptional diagnosis can be made in some cases for the adequate selection of the affected germ cells.

DIAGNOSIS DURING PREGNANCY

Some diseases that appear during the gestational period may show signs and symptoms of their existence. Some of these symptoms are identified through regular monitoring of the fetus, while other diseases produce distinctive disorders in the mother.

PRENATAL DIAGNOSIS

It is possible to perform an enzymatic or genetic study by examining fetal cells. Example: amniocentesis.
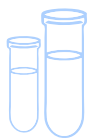
SYSTEMATIC NEONATAL DIAGNOSIS OR NEONATAL SCREENING

It is possible to identify the existence of an inherited metabolic disease (paradigm of a rare disease) or congenital hypothyroidism by analyzing dried drops of blood usually collected from the heel of the newborn ("heel prick test"). The problem is that only 20 to 30 of these diseases are identified.

CLINICAL DIAGNOSIS

For some rare diseases, an algorithm can be established and applied in an average diagnostic protocol. But in many other cases it is necessary to apply thorough examinations in suspicious situations, such as repeated miscarriages, for example.

COMPLEMENTARY TESTS

For their use it is necessary to have a well-defined diagnostic hypothesis and to know what each complementary test is for and what information it will provide. This field is certainly the one with the most rapid and important advances.

TREATMENT OF
RARE DISEASES

HUMAN
GENOME

Since the publication of the human genome in 2003, enormous progress has been made and its results have been implemented in the clinical practice. The genetic diagnosis is useful when it is necessary to confirm or dismiss any clinical suspicion.

CRISPR

The CRISPR gene editing technique is one of the greatest advances in medicine leading to numerous findings since its discovery. Currently, there is a first new version of this technique that edits RNA, instead of DNA, in human cells. This method can alter gene expression without changing the genome.

ORPHAN
DRUGS

The current framework of rare diseases fosters research and development of the pharmaceutical industry, and underlines the therapeutic benefits of new orphan drugs, medicines that are intended to treat rare diseases, but are often unattractive to sponsors due to their low cost-effectiveness and therefore require additional support for their development.

The transmission of a disease follows Mendel's laws:

(Baldellou, 2019)
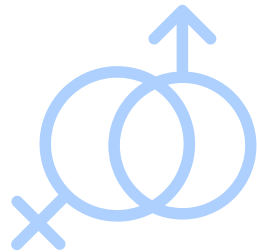
A person is **homozygous** if he/she inherits one gene from the mother and one gene from the father with a mutation.

A person is a **healthy heterozygote** if he/she inherits only one of the mutated genes from the mother or the father. He or she is a carrier but is apparently healthy because the other healthy gene is capable of performing its intended function.

On the contrary, in dominant inheritance it is sufficient to inherit a mutated gene from the father or from the mother for the disease to be expressed (we are **heterozygous sick**) because the mutation of the "sick" gene dominates over the "healthy" gene.

When the **mutated gene** is located in one of the 44 chromosomes that do not determine the sex of the embryo (autosomes), we speak of autosomal inheritance (recessive or dominant).

If the mutated gene is located on one of the two sex-determining **chromosomes (X or Y)**, we speak of sex-linked inheritance.

CONTEXT

In Spain, 94% of patients with RARE DISEASES had their care interrupted by COVID-19 in:
(*FEDER, 2020)*
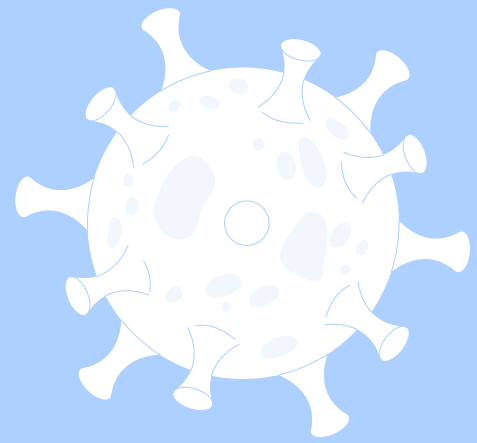
HEALTH CARE

SOCIAL SERVICES

EDUCATION APPROACH

LABOUR APPROACH

Necessities of people affected by rare diseases and their families:

ESTABLISH OBJECTIVES

Decide the objectives that the family plan to achieve and those that can actually be achieved, according to the family's own resources and that of the community.

PRIORITIZE TASKS

Determine and organize the priorities for the achievement of objectives. Help them to decide which are the main goals and which ones are secondary.

RAISE AWARENESS

Provide information and resources to the society and the community that surrounds the family that suffers the rare disease.

1 Dialogue, integration and participation with the family, school and social environment.

2 Free, universal and equal opportunities.

3 Interdisciplinary and high qualified professional teams.

4 Coordination with and the rest of agents involved for an optimal development of the situation.

5 Remote, which means that it can be integrated into the family home, school, or other contexts.

6 Sectorization, due to the need to narrow the field of action.

Six basic principles for the early attention
(GAT, 2005)

SCHOOLING

The schooling of people affected by rare diseases is a right and must be granted with equal opportunities. First, because education is necessary for intellectual and personal development, regardless of any health circumstances.

How to grant a succesful education for students affected by RARE DISEASES?

- EXTRACURRICULAR LINKS
- PERSONALIZED EVALUATION
- INNOVATIVE METHODOLOGIES
- MOTIVATION TECHNIQUES
- SOCIAL AWARENESS
- CURRICULAR ADAPTATIONS

KNOWLEDGE ACQUISTION

School education provides students with the opportunity to acquire knowledge in various disciplines, such as mathematics, science, history, literature and many others. This allows them to develop a solid foundation of knowledge and understanding of the world around them.
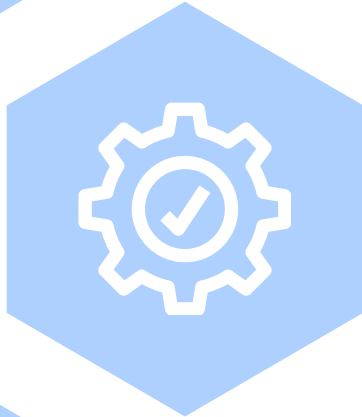
SKILLS DEVELOPMENT

Schooling is also about developing practical skills. Students learn to read, write, solve problems, communicate effectively and work in teams. These skills are essential for personal and professional success in adult life.

SOCIALIZATION

School is an environment in which children and young people interact with their peers, learn to socialize, and relate to people from different backgrounds and perspectives. This social interaction is crucial to their emotional and social development as they learn to collaborate, respect others, resolve conflicts and develop leadership skills.

EQUAL OPPORTUNITIES

Schooling gives all children and youth, regardless of socioeconomic background, gender or ethnicity, the opportunity to receive a quality education. This helps reduce inequalities and provides all students with the tools they need to succeed in life.

ACTIVE CITIZENSHIP

Promotes the formation of informed and committed citizens. Students learn about their rights and responsibilities, democratic values, civic participation and the importance of contributing positively to society. This fosters active and conscious citizenship, preparing young people to be responsible members of the community.

DIGITALIZATION

Digitalization in education is not new, but it has gained considerable momentum in recent years due to the COVID-19 pandemic. In general, the introduction of technology in schools has kept pace with the technological evolution of society.

The European Commission (2020) highlights several benefits of digital transformation in education:

Learning can take place in a fully online or blended mode at a time, place, and pace that suits the student's needs.

Personalized, flexible, and student-centered learning at all stages of education and training.

Development of collaborative and creative learning.

Increased ability to access, create, and share digital content by students and teachers.

RECOMMENDATIONS FOR THE INTEGRATION OF DIGITAL DEVICES IN CLASSROOMS

GOOD PHYSICAL CONDITIONS

Creation of good physical supporting conditions (e.g., arrangement of materials, access to a power supply, and wifi).

TRAINING AND SUPPORT

Training and support of teachers for the use of technological resources and development of learning activities.

WORK AND DEDICATION

The notion that the successful integration of technology implies work and dedication of both teachers and students.

FAMILIARIZATION WITH TECH

The importance of having a good initial familiarization with the use of technologies. This enables the later development of advanced learning activities and scenarios.

(Bock & Probst, 2018, citado por Schimdt & Hang, 2020).

LEARNING

THROUGH PROJECTS

(Niza, 2005; Vasconcelos, 2011)

STARTING POINT

- Identification of a problem, interest or need
- Formulating a question
- Formation of groups with diverse competences
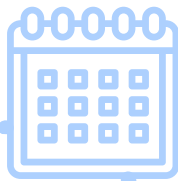
PLANNING AND DEVELOPMENT

- Definition of the tasks necessary for the preparation of the project
- Identification of the necessary means
- Division of tasks
- Definition of the project's socialization mode
- Construction of a table with planning
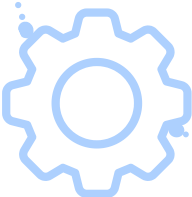
EXECUTION

- Research through digital means
- Adequacy of accessibility
- Teacher support to groups
- Process documentation

DISSEMINATION & EVALUATION

- Communcating of the group learning
- Presentation via digital platforms
- Sharing in the education community
- Book production
- Blog production
- Evaluation with teacher and class feedback

UNIVERSAL DESIGN FOR LEARNING

(CAST, 2018)

Universal Design for Learning Guidelines

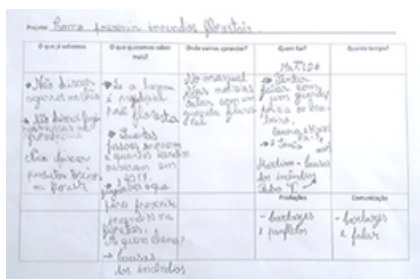| Provide multiple means of **Engagement** →	Provide multiple means of **Representation** →	Provide multiple means of **Action & Expression** →
Affective Networks The "WHY" of learning	Recognition Networks The "WHAT" of learning	Strategic Networks The "HOW" of learning

Access

Provide options for **Recruiting Interest** (7) →	Provide options for **Perception** (1) →	Provide options for **Physical Action** (4) →
• Optimize individual choice and autonomy (7.1) › • Optimize relevance, value, and authenticity (7.2) › • Minimize threats and distractions (7.3) ›	• Offer ways of customizing the display of information (1.1) › • Offer alternatives for auditory information (1.2) › • Offer alternatives for visual information (1.3) ›	• Vary the methods for response and navigation (4.1) › • Optimize access to tools and assistive technologies (4.2) ›

Build

Provide options for **Sustaining Effort & Persistence** (8) →	Provide options for **Language & Symbols** (2) →	Provide options for **Expression & Communication** (5) →
• Heighten salience of goals and objectives (8.1) › • Vary demands and resources to optimize challenge (8.2) › • Foster collaboration and community (8.3) › • Increase mastery-oriented feedback (8.4) ›	• Clarify vocabulary and symbols (2.1) › • Clarify syntax and structure (2.2) › • Support decoding of text, mathematical notation, and symbols (2.3) › • Promote understanding across languages (2.4) › • Illustrate through multiple media (2.5) ›	• Use multiple media for communication (5.1) › • Use multiple tools for construction and composition (5.2) › • Build fluencies with graduated levels of support for practice and performance (5.3) ›

Internalize

Provide options for **Self Regulation** (9) →	Provide options for **Comprehension** (3) →	Provide options for **Executive Functions** (6) →
• Promote expectations and beliefs that optimize motivation (9.1) › • Facilitate personal coping skills and strategies (9.2) › • Develop self-assessment and reflection (9.3) ›	• Activate or supply background knowledge (3.1) › • Highlight patterns, critical features, big ideas, and relationships (3.2) › • Guide information processing and visualization (3.3) › • Maximize transfer and generalization (3.4) ›	• Guide appropriate goal-setting (6.1) › • Support planning and strategy development (6.2) › • Facilitate managing information and resources (6.3) › • Enhance capacity for monitoring progress (6.4) ›

Goal

Expert Learners who are…

Purposeful & Motivated	**Resourceful & Knowledgeable**	**Strategic & Goal-Directed**

GAMIFICATION

Authors van Roy and Ziman (2017) propose that educational game environments should possess the following qualities:

- Students have autonomy in the choices made.
- Activities are both challenging and perceived as achievable.
- Feedback mechanisms are integrated that inform students about their progress in acquiring skills.
- Interaction and collaboration among students and a sense of belonging to a group are facilitated.

The authors also emphasize the importance of flexible and adaptable gamification systems to align with individual preferences and needs. This is one of the crucial aspects of achieving inclusive gamification.

COLLABORATION

Building trusting partnerships between school and family - especially parents - is indispensable for successfully including children and youth with disabilities or learning difficulties in regular school.
(Mazon et al., 2022; Muntaner et al., 2014)

How to achieve good collaboration between families and the school?

Communication

Communicate in a timely manner; show honesty and openness; include positive comments along with negative comments; use the most appropriate communication methods for each family (e.g., phone calls, emails, face-to-face); avoid using technical jargon.

Respect

Respect the characteristics of each family (e.g., language, ethnicity, culture); be understanding of families' other commitments; set positive expectations for students; be punctual.

Confidence

Demonstrate care and affection toward students; be discreet in using private and sensitive information.

Equity

Recognizing that families are knowledgeable about their children; showing openness to learning and accepting when one does not have a specific answer or skill; working as a team, engaging in common goal setting and strategies.

Important characteristics of collaboration for educational inclusion

(Solone et al., 2020.)

Parity

Valuing the contribution made by all team members and everyone should be involved in decisions.

Mutual goals

Stakeholders must have similar goals, where the learning and development of the student(s) are at the center of priorities.

Sharing of resources

Team members should share time, knowledge, educational materials, and other educational resources.

Sharing responsibility for results

All participants are responsible for both the positive things and the negative things.

Synergies

Collaborative work fosters high-quality educational services, where "the whole is greater than the parts."

Models of co-teaching

(Paulsrud & Nilholm, 2020; van Hover et al., 2012)

Sharing knowledge and working together among teachers substantially increases the responsiveness of schools (Solone et al., 2020; Strogilos et al., 2023). Most studies show that co-teaching has several advantages, including the development of meaningful professional relationships, learning between teachers, the definition of new teaching strategies, and the involvement of students (with and without special educational needs) in activities (Paulsrud & Nilholm, 2020; van Hover et al., 2012).

One teacher, one assist

Usually, the regular education teacher takes the lead in leading the class teaching activities, while the other teacher assists, monitoring the students and giving individualized attention to students with difficulties.

Station teaching

The two teachers divide the teaching tasks between them and intervene at different learning stations where the students "rotate".

Parallel teaching

The class is divided into two groups. The two teachers simultaneously teach the same or similar content.

Alternative learning

This involves grouping students according to their specific needs and then giving them specialized instruction.

Team teaching

Co-teachers share teaching responsibilities and lead joint teaching activities.

Individualized Education Plans (IEPs)

IEPs are comprehensive plans designed for students with special educational needs. They outline specific goals, accommodations, and support services tailored to the individual student's needs. IEPs involve collaboration among educators, parents/guardians, and sometimes specialists.

Learning Support Materials and Resources

Additional learning materials, resources, and aids can be provided to support students' learning. This may include modified textbooks, visual aids, assistive technology, and supplementary educational materials tailored to the student's needs.

Small Group or One-on-One Instruction

Students who require more individualized attention and support may benefit from small group or one-on-one instruction. This allows for personalized instruction, targeted feedback, and a focus on specific learning goals.
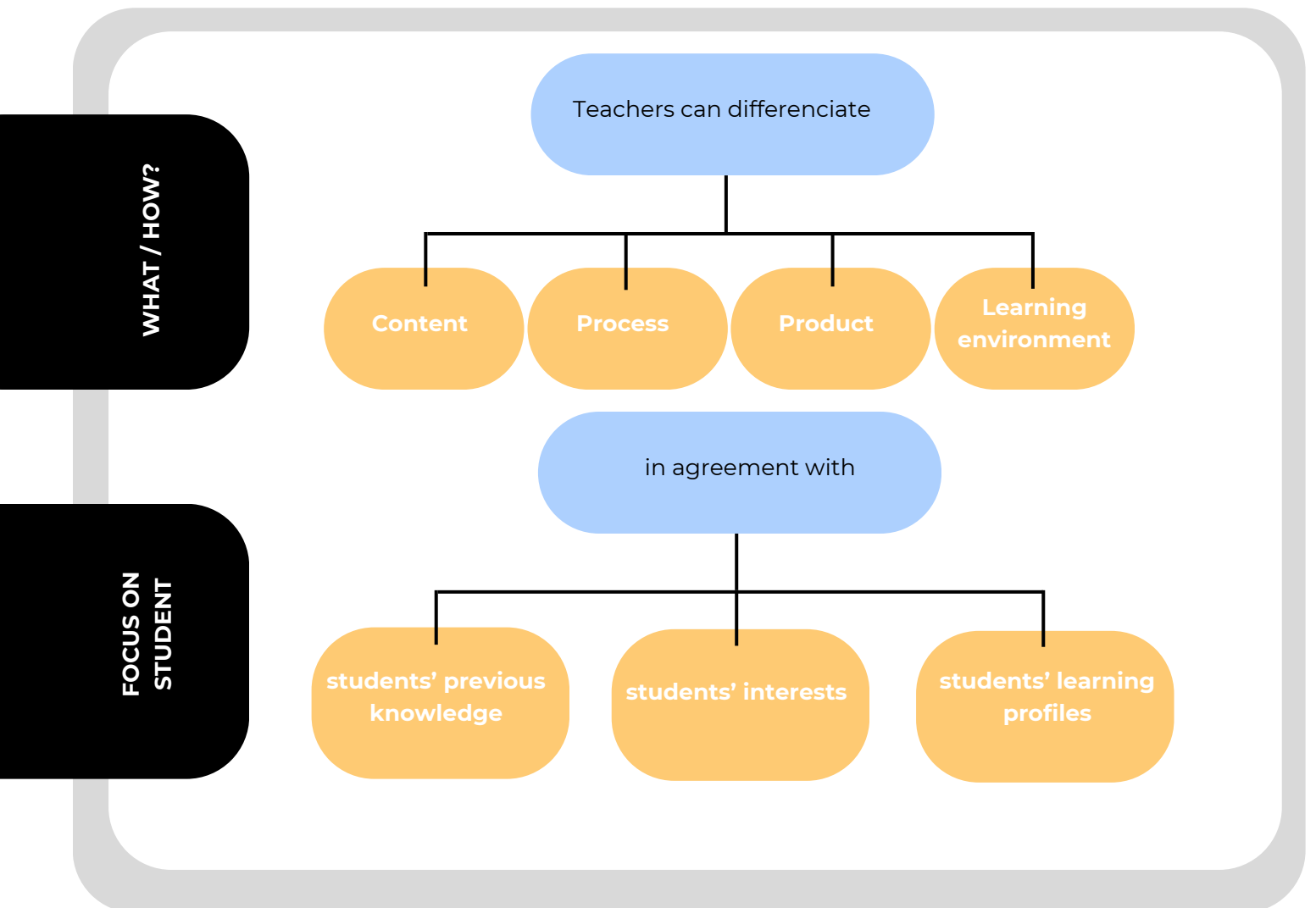
Peer Tutoring or Mentoring

Peer tutoring involves pairing students, where one student provides academic assistance to another. Peer mentoring programs pair older or more experienced students with younger or less experienced students to provide guidance, support, and encouragement.

Measures to support learning

Individual curricular adaptations refer to modifications or adjustments made to the curriculum for students with diverse learning needs. These adaptations are constructed to accommodate the unique strengths, challenges, and learning styles of individual students in order to promote their meaningful participation and progress in the classroom. Although some adaptations are for the needs of individual children, they must consider the whole group of pupils and the general curriculum so as not to create a parallel curriculum.

Pedagogical differentiation scheme

(Tomlinson y Allan, 2002)

WHAT / HOW?

FOCUS ON STUDENT

Teachers can differenciate

- Content
- Process
- Product
- Learning environment

in agreement with

- students' previous knowledge
- students' interests
- students' learning profiles

3 factors to be considered:

Readiness

Readiness refers to the level of competences and background knowledge of the learner. They can be identified through observation and pedagogical documentation.

Interest

Interest refers to topics or issues that learners may want to know about and that motivate them. Students can be asked questions and given the opportunity to participate in planning activities.

Learning profile

The learning profile of learners includes learning style (e.g. is the learner a visual, auditory, tactile or kinaesthetic learner?), preferences about who likes to work in groups or small groups or in pairs.

INCLUSIVE SCHOOLS

WHAT CAN/SHOULD BE DONE TO BUILD AN INCLUSIVE SCHOOL ENVIRONMENT THROUGH THE CONSCIOUS EFFORT OF ALL THESE ACTORS?
HERE ARE SOME RECOMMENDATIONS:

Promote Diversity and Inclusion:

Schools should celebrate diversity and cultural, ethnic, religious, linguistic, and other competence differences, fostering an environment where everyone feels respected and valued. It is important to promote a positive school culture that values diversity, equity, and inclusion. This can be achieved by celebrating diversity through events, curricular and extracurricular activities, encouraging positive interactions among students from different backgrounds, and promoting a sense of community identity and common belonging.

Provide Accessible Learning Materials:

School stakeholders should ensure that all students have access to learning materials and technological resources that meet their needs and make adaptations to educational resources and physical spaces to ensure equal access to education for students with disabilities. This may include physical modifications to the school environment, such as access ramps, accessible restrooms, and adapted furniture. The use of assistive technologies, such as alternative communication devices and mobility aids, can help students fully participate in school activities.

Make the best of information and communication technology (ICT) and related assistive technology:

Schools should identify the equipment and technology that works better for each student. Possible ICT Equipment and software include laptop computers, tablets, bjoy ring, switch technology, eye-tracker systems, e-reader apps, screen reader, voice-activated programs, voice-recording apps, bluetooth lightweight keyboard, ergonomic/split keyboard, and app that enables writing on the screen. The device's accessibilities option (e.g., keyboard changes, options for mouse control, visual adaptations, voice activation) should be used to adjust to the children's needs. ICT training should be provided not only for students but also for teachers and families. Specific postures, positioning, and wrist supports could facilitate the use of assistive equipment. Installing a tray on a wheelchair or setting a height-adjustable table correctly to support the student's arms could be very helpful.

INCLUSIVE SCHOOLS

Create Safe Spaces:

It is important to create a safe and welcoming environment in school organizations where students can express their thoughts, feelings, and difficulties without fear of judgment or discrimination and establish anti-bullying policies. To create quality inclusive environments for students with muscular and rare diseases, it is essential to consider that these diseases can present a wide variety of symptoms and challenges, such as mobility difficulties, fatigue, and the need for regular medical assistance.

Provide Professional Development:

Schools should design and implement a training plan for their teachers and staff (e.g., therapists, psychologists) on how to work with students with special educational needs, muscular diseases, and other rare diseases. Schools should create appropriate conditions for maintaining education professionals updated with the best inclusive practices and related research. Collaborative work, project-based learning, using digital and other technological tools, and implementing universal design for learning principles are essential resources that should be worked on regularly. Meetings with experts, reflective sessions, workshops, online courses, etc, should be promoted regularly.

Foster an Inclusive Curriculum:

Schools should seek to incorporate diverse perspectives and experiences into the curriculum to enable personally meaningful learning for all.

Encourage Parental Involvement:

As mentioned earlier, parents and families should be involved in school activities and decision-making processes, particularly regarding measures that can promote a more inclusive environment for students with muscular dystrophy and rare diseases. In trusted partnerships, the various stakeholders see each other as allies, and parents/families have diverse opportunities to participate meaningfully in their children's education and school life.

INCLUSIVE SCHOOLS

Create an accessible physical environment:

Space organization and support equipment should maximize independent mobility and facilitate the participation of children in learning and other school activities (Muscular Dystrophy UK, 2016).The school environment should be prepared to respond to the needs of children that are ambulant, but also of children that enter the school in a wheelchair or will begin to use a wheelchair during the school years. Classrooms, playground, sports zones, toilet, and canteen and other school facilities should be accessible and safe. Lifts could be necessary for maximizing accessibility in all school buildings, and it is necessary to check if they are suitable for a wheelchair. Children with low muscle strength/function may need help with moving around the school and transfers within the building, including hoisting and transfers between chairs.

The classroom organization:

The organization of seating plays a crucial role in creating an environment that supports the diverse needs of students where all feel valued, supported, and empowered to actively participate in the learning process. Seating arrangements should be designed to promote collaboration, engagement, and accessibility for all learners, foster social interactions and facilitate peer support (Adderley, Hope, Hughes, Jones, Messiou, & Shaw, 2015). Thus, the organisation of seating in the room should be flexible and allow for the creation of different groupings from the large group (in a circle or amphitheatre) to small group organisation and in pairs, depending on the teacher's intent. Placing students with muscular dystrophies or rare diseases near their peers, can encourage inclusive conversations, cooperative learning, and the development of positive relationships. Teachers must consider grouping students with complementary strengths and abilities, which can promote mutual assistance and create an inclusive classroom community (Hoekstra, Van den Berg, Lansu, Mainhard, & Cillessen, 2023). Additionally, the classroom should be equipped with assistive technologies and tools such as ergonomic keyboards, speech recognition software, or alternative communication devices to support students with mobility and communication challenges. Individualized support plans should be developed in collaboration with the students, their families, and relevant specialists to address their specific needs, such as modifications in assignments, additional time for completing tasks, or assistive devices. Flexibility in scheduling and instructional methods can also enhance inclusivity by accommodating learning styles.

INCLUSIVE SCHOOLS

Provide Student Support Services and encourage student relationships:

Schools should offer support services such as counseling and tutoring to meet the individual needs of each student, including those with disabilities or impairments. Teachers, staff, and technicians should encourage students to interact with all their peers, regardless of their background, socioeconomic status, or condition. Students should feel that their opinions are valued and taken into consideration by the school staff (Schwab et al., 2018).

Encourage Collaboration between Teachers and Multidisciplinary Teams:

Many studies show that an inclusive school can be identified by its ability to work as a cohesive team (Ainscow & Sandill, 2010). This broad collaborative work between teaching and non-teaching staff, including technicians and healthcare professionals, both within and outside the school, is essential to ensure comprehensive support for students with muscular and rare diseases, as it requires adapting teaching strategies, sharing information about students' needs and abilities, and promoting social inclusion. Having teacher consulting with other teachers, enables confidence and competence, especially for those with less experience (Boyle et al., 2011).

Ensure Good Collaboration between School and Extracurricular Services:

Collaborative work between the school and healthcare services can ensure access to physical and occupational therapies, adapt the school environment to meet accessibility needs, and offer emotional support to students and their families. Furthermore, collaboration with research centers can help identify best practices and educational strategies to meet the specific needs of these students. In fact, it is crucial for schools to rely on evidence when adapting the curriculum, using assistive technologies, and implementing differentiated teaching strategies.

INCLUSIVE SCHOOLS

Evaluate and Improve:

Schools should regularly self-assess their inclusion policies and practices (Schurig, Weiß, Kiel, Heimlich, & Gebhardt, 2020) to identify areas for improvement and ensure that they are inclusive and welcoming to all students, including those with rare diseases and muscular dystrophies.

For developing more inclusive teachers:

According to the European Agency for Special Needs and Inclusive Education (EASNIE, 2023), inclusive teachers are those who are committed to providing high-quality education to all students, regardless of their background or abilities. There are four key points in the work of teachers that are particularly important in inclusive education:

- Valuing learner diversity - Learners' differences are viewed as a resource and an asset to education. Learner diversity refers to the differences among students in a classroom. These differences can include race, ethnicity, socioeconomic status, age, gender identity and expression, religion, language, physical and mental abilities, and learning styles.

- Supporting all learners – Teachers must have high expectations for all learners' achievements. It means teachers' beliefs influence how they organize learning and attend children with different needs. The higher the expectations the better the support provided to learners. This approach is based on the belief that all students can learn and succeed, regardless of their background or abilities.

- Working with others: Collaboration and teamwork are essential approaches for all teachers. It means that teachers should work together with other teachers, parents, families, and other educational professionals to support the academic and social learning of all learners. This approach is based on the belief that collaboration and teamwork can help teachers provide more effective support for students. By working together, teachers can share ideas, resources and strategies to help students succeed

- Personal professional development: Teachers engage in ongoing professional development to improve their practice. It means that teachers must take responsibility for their own learning and development to engage in ongoing learning and professional development to improve their knowledge and expertise. This approach is based on the belief that teachers who are committed to their own learning are better able to support the learning of their students.

A) Determining the need for intervention:

By involving healthcare specialists, schools can adopt a collaborative and multidisciplinary approach to include students with muscular dystrophy and rare diseases. This collaboration between principals, teachers, inclusion teams, parents/guardians, and healthcare experts enables a comprehensive understanding of students' needs, facilitates the exchange of relevant information, and promotes teamwork to achieve the best educational and health outcomes for students.

Through individual assessments, specialists can identify students' abilities and limitations in areas such as knowledge, motor skills, language, and social interactions. Based on these assessments, specialists can provide recommendations for reasonable adjustments and support strategies to meet the students' specific needs. For example, a specialist may suggest implementing a personalized education plan that outlines goals and necessary support resources for the student to achieve academic and social success.

B) Providing additional knowledge (assessment and guidance):

Healthcare specialists possess specific knowledge about muscular dystrophy and rare diseases, including their nature, symptoms, treatments, and required care. This expertise allows them to provide accurate and up-to-date information to principals, teachers, inclusion teams, and parents/guardians, promoting an in-depth understanding of the needs and challenges faced by these students.

Healthcare technicians such as occupational therapists or physiotherapists can identify strategies to adapt the school environment (classrooms and other educational settings) to students' physical needs, such as ensuring classrooms, bathrooms, and common areas are appropriately accessible to maximize students' independence. This may include guidance on seating, wheelchairs, standing or movement techniques, both at school and at home (Muscular Dystrophy Canada, 2011, p. 5). Physiotherapists can prescribe specialized equipment and aids, such as orthopedic shoes, wheelchairs, and standing supports, as well as provide guidance on movement and transfer issues (Muscular Dystrophy Canada, 2011, p. 5). Nutritionists can provide guidance on specialized diets, weight loss or gain, and nutritional needs. Speech therapists can assist students with speech, language, and communication difficulties, working closely with nutritionists and other therapists to provide helpful guidance in situations where a child may have difficulty biting, swallowing, or chewing (Muscular Dystrophy Canada, 2011, p. 5).

Therefore, healthcare experts can help parents/guardians better understand their children's conditions, enabling them to become active partners in promoting students' inclusion and their academic and emotional development. The clinical team or therapists working with these students can engage with the educational team, discussing the students' conditions and explaining how they can be better included in school (Muscular Dystrophy UK, 2016, p. 19).

C) Providing emotional and psychological support:

Experts can offer emotional and psychosocial support to students, parents, and guardians by providing guidance on the emotional impact of rare diseases and muscular dystrophy, appropriate coping strategies, support resources, and referrals to specialized services when necessary. School psychologists, in particular, can assist students in dealing with issues related to self-esteem, anxiety, or social interactions.

D) Providing training and empowerment:

Experts in inclusive education can provide training and empowerment to teachers and other school staff. They can conduct formal and/or informal training sessions for principals, teachers, and the educational team (Tristani & Bassett-Gunter, 2019; Horne & Vianne, 2009), addressing topics such as the characteristics of muscular dystrophy and rare diseases, best pedagogical practices, inclusive teaching strategies, curriculum adaptations, and communication skills, with the aim of promoting an inclusive school environment.

Through training, specialists can play a decisive role in identifying and implementing appropriate educational resources, such as assistive technologies, adapted teaching materials, specialized pedagogical support, occupational therapy, and physiotherapy. Specialists can provide guidance in selecting and using these resources, ensuring their effectiveness in facilitating students' learning and participation.

E) Establishing mechanisms to monitor students' quality and progress:

External specialists can collaborate with the school's educational team to develop assessment criteria and indicators that are relevant to the specific student. They can assist in the continuous monitoring of the health of students with muscular dystrophy and rare diseases. This may involve identifying warning signs, monitoring medical progress, adjusting medications, making referrals to specialized consultations, and providing specific care. This information is crucial to ensure that health needs are met during school attendance. Specialists can also help in observing the school environment to verify the proper implementation of adaptations and support resources and their effective promotion of the student's inclusion.

There are different mechanisms for monitoring the quality and progress of inclusion in schools for students with rare diseases and muscular dystrophy that can be implemented with the help of specialists. Here are some examples:

- Create and implement individualized education plans for each student with a rare disease or muscular dystrophy. These plans should be developed in collaboration with specialists, teachers, and parents, and include personalized goals and strategies to promote inclusion and academic progress.
- Conduct regular assessments to monitor students' academic progress and social and emotional development, considering their specific needs.
- Regularly monitor and evaluate the adaptations and supports provided to students with rare diseases and muscular dystrophy, such as accessibility devices, specialized pedagogical support, therapies, and emotional support, while providing guidance on the effectiveness of these interventions.
- Conduct direct observations in the classroom and other educational contexts to assess the implementation of inclusive strategies and students' progress.
- Establish partnerships with healthcare services, specialized clinics, and healthcare professionals to share relevant information and obtain ongoing support in monitoring the quality and progress of inclusion in school.

Recommendations for the future:

Conduct longitudinal studies to track the long-term academic, social, and emotional outcomes of students with diverse needs. This research can provide insights into the effectiveness of inclusive education over time.

Using qualitative approaches to listen to the teacher needs, perspectives, and recommendations. This should inform the continuous training of teachers and other educational personal to address the specific needs of children with muscular diseases, neuromuscular dystrophies, and other rare diseases, including the use of information and communication technologies.

Fostering strategies for developing collaborative teamwork in school settings. The use of information technologies (e.g., mobile platforms) should be stimulated for communication and coordination between parents, school staff, and health professionals, including monitoring the measures and goals recommended in the Individualized Education Programs (IEPs). These strategies should be complemented by regular face-to-face meetings among team members.

Evaluation and Monitoring: Effective implementation of the recommendations presented in this guide requires ongoing evaluation and monitoring of progress towards inclusive practices. Such feedback is of major importance for adjusting and adapting inclusive schools' practices.