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facing SCHOOL

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

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This project has been funded with support from the European Commission. This publication reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

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Partnership of the project:

Spain ISBN: 978-84-09-59030-8

You may cite this publication as follows: Romo, M., Alonso, C., García, B., Artur, A., Silva, C., Marmeleira, J., Saragoça, J., & Casanova, R. (2024). Inclusion and Equity in School: A Digital Methodological Guide for the Inclusion of Young People with Muscular Dystrophies and Other Rare Diseases in Education. Madrid, Spain.

With a view to greater accessibility, this report is available in accessible electronic format on the project's website: www.facingschool.eu

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INTRODUCTION

1.1. Project and partnership

The INCLUSION AND ACCESSIBILITY IN SCHOOL guide has been made possible thanks to the Erasmus + program THE VALUE OF FACING SCHOOL, which main objective is to promote a strategic partnership between specific entities of rare diseases, neuromuscular and muscular dystrophies (along with schools and other institutions), to facilitate the process of schooling of children and young people affected by these pathologies. For this matter, the project will also generate stable channels of communication and collaboration between the education centres themselves, as well as expert entities in rare diseases.

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.

Figure 1. Partnership Erasmus+ THE VALUE OF FACING SCHOOL.

1.2. Why this guide?

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, 2023b).

Behind the statistics, there are thousands of individuals with stories full of strength, courage and perseverance. The daily life of these families is affected by the consequences of a pathology that has a profound impact on their lives, especially when the symptoms manifest in young children, something that occurs in most of the cases.

Finding a diagnosis is often a complex and exhausting process for rare diseases. There are between 4,000 and 5,000 of these pathologies for which no specific treatment is available yet, or it is not as effective as expected, which makes the life of patients even more difficult. (Orphanet, 2023).

Fortunately, society and public administrations are no longer unaware of these realities. In the last decade, rare diseases have gained visibility due to the promotion of research, networking, direct and comprehensive care programmes, and emotional support for people affected and their families.

Nonetheless, there are still many challenges to be addressed. One of them is inclusion and accessibility in school, which plays a crucial role in the lives of children and young people with rare diseases. The school period is key for socialization, and teachers should encourage positive attitudes in families to facilitate close collaboration between both parts, fostering honesty and ongoing communication. This collaboration requires a joint effort among families, experts, and the education institution itself. Furthermore, the myriad of competencies and skills of these young individuals must be enhanced, because they will shape their future opportunities.

In recent years, different factors have contributed to widening the gap for the people affected by these pathologies. The COVID-19 crisis highlighted a pre-existing crisis in education. It made inequalities more visible (UNESCO, 2021), and became a reason for systemic change in education worldwide. Prior to the COVID-19 crisis, Ainscow and Haile-Giorgis (1999) explained the meaning and importance of systemic change in

education to promote more inclusive approaches:

> *... methodological and organizational changes made in response to pupils experiencing barriers to their learning are, under certain conditions, likely to benefit all children, thus linking together the pursuit of equity and excellence. it involves a continuous process of school improvement aimed at using available resources, particularly human resources, in order to support the participation learning of all pupils within a local community. In this way, those pupils seen as having special needs come to be regarded as the stimulus that can encourage developments towards a much richer overall educational environment (1999, p. 106).*

Besides, in the last decade, education systems worldwide have adapted to unprecedented circumstances due to the on-going digital transformation of social life. Something that has been increased considerably since the COVID-19 pandemic. While there have been rapid and comprehensive steps towards a digitalisation of education, access to learning remains a challenge.

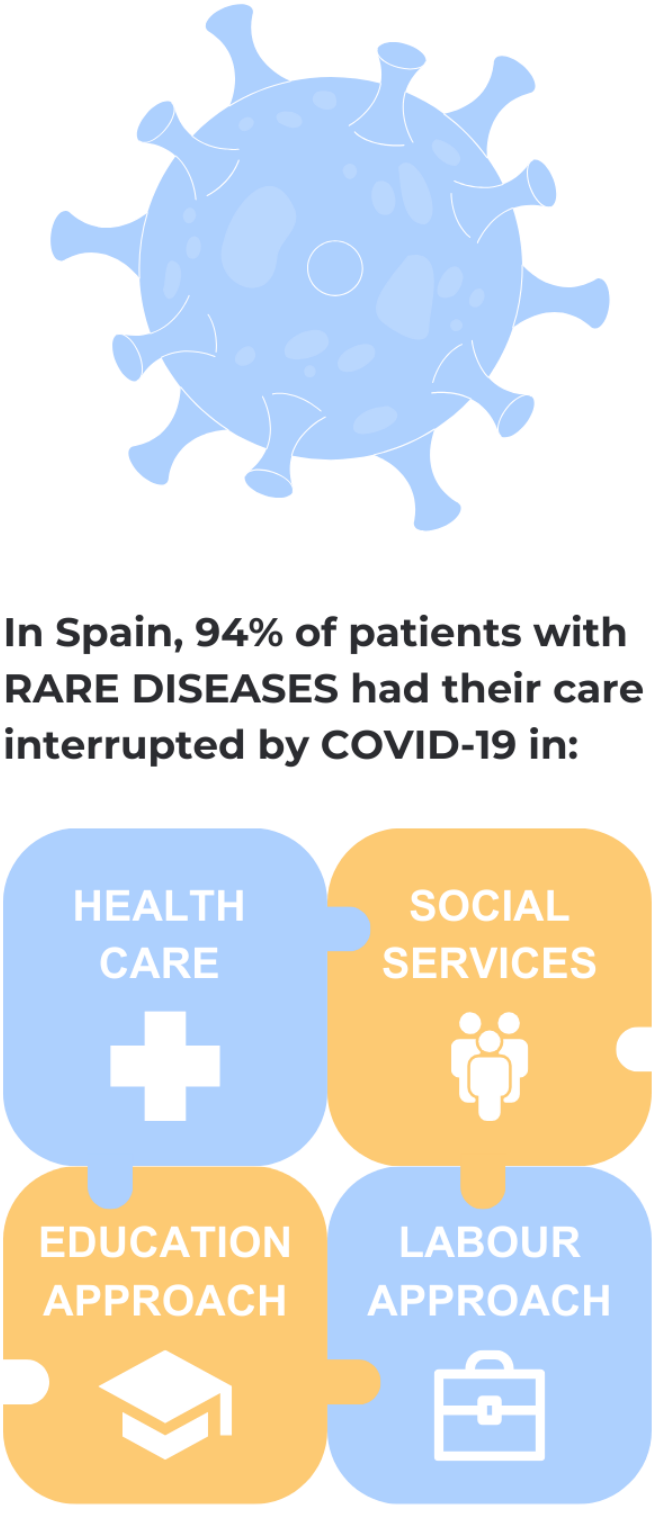

Figure 2. Impact of Covid-19 in rare diseases treatment in Spain (Feder, 2020)

New barriers to participation in society and in education are emerging. At the same time, the increasing use of digital media and technologies for teaching and learning opens new opportunities to overcome exclusion.

The present guide aims to offer a simple and direct tool for schools and teachers to approach these pathologies, along with a set of resources that may be put into practice in the classroom and its context. Besides, the present document will provide a better understanding of the problems, difficulties, suffering and uncertainties of affected persons and their families.

We hope to contribute to reduce exclusion and indifference towards people affected and their families. We also hope to reduce the uncertainties and doubts that education professionals may have when they approach a student with a rare disease. This type of condition unfortunately requires a lot of effort in the different fields of science (where, of course, the educational sciences are also included).

1.3. Which are the objectives?

This methodological guide aims to assist schools and teachers in including students with rare diseases into their classrooms, regardless of the stage of their condition. The objective of this guide is not only to provide information about the disease and the possible symptoms that these persons may experience, but also to provide methodological guidelines, curriculum adaptations, and evaluation mechanisms adapted to the student's reality. This will promote a quality education adapted to their educational needs which takes into consideration the different stages of their personal development.

This guide is created to successfully help schools and teachers to support students with rare diseases, fostering their inclusion and optimizing their learning experience. By implementing the necessary tools, adaptations, and support mechanisms, we will ensure that these students receive a comprehensive education that meets their specific needs and promotes their academic and personal growth.

To achieve these objectives, we have divided the methodological guide in two different parts:

DIGITALIZATION: In this part, we will provide information on digitalization, how it is transforming school environments and its potential in the field of inclusion. We will also review and discuss relevant inclusive methodologies such as learning through projects, gamification, multilevel teaching, and universal learning design. And we will highlight the importance of fostering collaborative work between parents, teachers, and experts.

INCLUSIVE SCHOOLS: In this part, we will explain how schools can create good inclusive environments. One of the main issues to be discussed is the collaboration between different school and out-of-school services (e.g., social and health systems, research centres). Another relevant issue will be the school organization, focusing on the role of leadership and of intermediate structures.

1.4. Who is this guide for?

The project is primarily aimed at:

- TEACHERS
- PARENTS
- STUDENTS

But is it also targeted for all the education context, and society as a whole. It is necessary more training and education in this field. People affected and their families need to be understood. When this process of understanding is real, education and schooling are more inclusive and more effective.

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2

CONTEXT

2.1. Necessities of people affected by rare diseases and their families

People with rare diseases face many difficulties that leads to the delay or failure of the diagnosis, also increased by the lack of information and guidance by professionals in the field. Consequently, patients and their families must explore a difficult path that take them to multiple medical consultations. In the treatment phase, the lack of information on the pathologies and symptoms makes difficult to get proper care. Some rare diseases have as many variants as people affected, which means that each patient has a specific diagnosis and specific symptoms. Therefore, families ask for clear and early information, along with proper advice and guidance, which help them to choose the right information for the improvement of their quality of life. If this situation takes place in the health sector, we can only begin to understand how difficult must be to obtain information in other contexts for people affected and their families.

For this reason, it is a priority to offer training and information on the characteristics and necessities of these diseases to professionals that are closer to this reality. If it is difficult to access clinical information, it must be extremely exhausting to find support on other aspects of these pathologies, such as psychological needs, financial support, education, work, social, etc. The ignorance and lack of knowledge hinder the communication with patients and their families, adding unnecessary pain to those already in distress.

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.

Figure 3. Necessities of people affected by rare diseases and their families.

Patient associations have become an effective tool to gather the claims and necessities of this people. They also became an important source of information and professionals for families and patients, providing support, caring for their social background, raising awareness about their rights and duties, promoting and strengthening collaborative activities, fostering volunteering in health and education, and giving advice on social and community resources.

MODULE 8. ACTIVITY 1
YOUTH WITH COURAGE

The disease can generate anxiety and uncertainty in your child. They are likely to cope with difficult conflicts and doubts. At times, they may find it difficult to communicate their situation. These inspiring stories from young people in a similar situation may help them identify their problems and express their concerns.

It is vital to have qualified professionals in the field of rare diseases, which will add value and incorporate a comprehensive and multisectoral vision. Their professional approach should be different, innovative, daring, agile and imaginative, effective beyond the health field and able to undertake a transversal journey that benefits the coordination, collaboration, search for resources and fulfilment of the needs of each affected person in their daily lives.

Regarding education, teachers and educators become an important identification agent when the child attends preschool. At this stage, health issues can be detected in basic abilities and behaviours for learning: motor skills, socialization skills, language skills, attentional and perceptual difficulties, and cognitive or emotional limitations that had not been detected earlier. The conditions and interactions that take place in the school context, different to those of the family environment, allow, in most cases, to identify the presence of deviations in the evolutionary process, imbalances in the psychosocial/affective development of the child and/or alterations in his behaviour. These symptoms can easily go unnoticed by the parents and health professionals, given their nature or the less severity of the disorder. Consequently, they are only identified when the child initiates his education.

When the educator or teacher finds a possible disorder, they must inform the family. Then, they will jointly coordinate and plan some monitor and observation guidelines following the data gathered by the school and the family environment. At the same time, they will visit the paediatrician of the child and the Centre for Child Development and Early Care, aiming to establish a complete diagnosis that allow to initiate an appropriate therapeutic intervention. Situations of social risk, inadequate care, affective deprivation, and suspicion of child abuse can also be identified in the school context. In those cases, it must be coordinated with Social Services professionals.

Finally, there is a great gap between the dissemination of scientific research information concerning the disease and the management and application of this knowledge and progress in the school context. For this reason, it is essential that society receives training and education in this field, thus increasing the quality of life and the visibility of those affected by rare diseases. Hence,

their rights are fully understood and respected in every context of their lives and the professionals that treat them have the knowledge and qualification to overcome every possible outcome.

Figure 4. Six basic principles on early care (GAT, 2005)

2.2. The importance of social awareness and education on rare diseases

Families normally must cover an important part of the caregiving due to the deficiencies of the social health system. This situation has a tremendous impact on the social integration of people affected by rare disease and their relatives, which produces changes in the family routine concerning their abilities and quality of life (Puente Ferreras et al., 2011) such as: loss of employment or educational opportunities, increase of family spending due to accessibility necessities and special food products (Elosegui et al., 2012).

Both parents and educators underline the lack of educational resources developed to cover the specific needs of these patients (Ramírez, 2004). Children affected by these diseases need support and special educational conditions adapted to disability degree in order to achieve the highest quality in their education (Barrio & Castro, 2008). The emergence of a rare disease provokes psycho-emotional alterations, due to the uncertainty for the future development and the consequences of the disease, as well as the feeling of impotence that arises when you are not able to

manage the situation (Salinas et al., 2012), which must be overcome to adapt to it (Prisma Social, 2017).

It is essential to guarantee quality, easily accessible, and updated information on rare diseases for professionals and citizens, in the health, education, social and labour fields. This will have a positive impact and will empower patients in self-care and all agents involved in the process of decision-making. The use of information and communication technologies (ICTs) is also important to achieve this objective and to raise awareness in relation to rare diseases (Guillén, 2018).

It is also necessary to increase the knowledge of rare diseases in undergraduate and postgraduate education in health, social and education sciences; as well as in the specialized health training programs and in the continuous training of the professionals involved.

Likewise, it is essential to inform and raise awareness on rare diseases in the education community and to improve the information available on the specific needs for schooling, as well as the social and health aspects of students with rare diseases. The final goal is to provide a more personalized and adapted approach, coordinating and implementing educational, social and health actions in the school context.

In the *Manual Ilustrado de Enfermedades Raras* (Cruz & Bosch, 2004) the authors claim that collaboration is necessary in the psycho-pedagogical approach that must be adapted to each person, especially in the paediatric age, but also in university, and in all educational stages. There must be sources of aid available for families and primary and secondary education centre, to help them select and implement the most appropriate education methodology. In primary education, the norm is to integrate the child in an ordinary school so, in later stages as high school and university, he or she can participate accordingly despite the sensory, motor or psychological disabilities. (Cruz & Bosch, 2004).

All actions must aim at the acquisition of the best possible quality of life in rare disease, from family to school and social integration. The problem is complex and only a greater education of parents, teachers and students in favour of inclusion and equality will make it possible (Posada, 2016).

The quality of teaching obliged us to pursue a teaching-learning process where numerous variables and elements that represent school life come together.

2.3. The role of the education system

Society demands from education the ability to create and transmit knowledge and promote its active participation in society, as a centre of innovation that prepares students for the future. For this matter, we must have a methodology based on research, that brings closer teacher and student towards a more practical and comprehensive teaching progress, always with the appropriate infrastructure and innovative teaching materials and methodologies.

One decisive point for the change consists of the modernization of the educational centre. This must incorporate the advances and developments of society, analyse the role and quality of teaching, the assessment and evaluation of its infrastructure, and the relationship with their natural and community environment. And at the centre, we find the main protagonists: teachers, school staff and students.

MODULE 3. ACTIVITY 1
TESTIMONY OF SARAH SALMONA'S SCHOOL EXPERIENCE

What does it mean for a student to live with a rare disease? In addition to having to face the practical difficulties caused by the illness, the child often finds himself confronted with the judgment that others (children and especially teachers) bring about him, or rather about his illness. This activity consists of a reflection activity built around the story of the school experience of a high school teacher affected by a form of myopathy.

The quality of teaching depends on the teaching methodology and on the teacher itself, among other factors. Not only knowledge is important, but also the teaching methodology. For this reason, the suitability of teaching professionals and their impact on the aptitudes of students at the end of their education are life changing.

Teachers must get special qualification. Besides the extensive basic training, it is necessary an appropriate theoretical-practical pedagogical training. It is also essential to reflect on teaching methods and techniques and to participate in courses and activities where they can

acquire knowledge on curricular programming, but also motivation techniques, personalized evaluation, and new didactic methods.

Teacher should also feel motivated. The involvement in the process and the feeling of content they will experience with the results will trigger the participation of teachers in new courses, congresses, sessions of pedagogical and seminars and debate tables, as well as conferences. They will feel extremely rewarded with the human relationship they build with the students, the intellectual commitment and science applied, and, most importantly, with the progress they will observe in their students with special needs.

It is necessary to foster a more personalized education in the teacher-student relationship that allows a greater knowledge of the needs and capacities of each one, promoting a continuous evaluation of the progress, needs and challenges that arise every day.

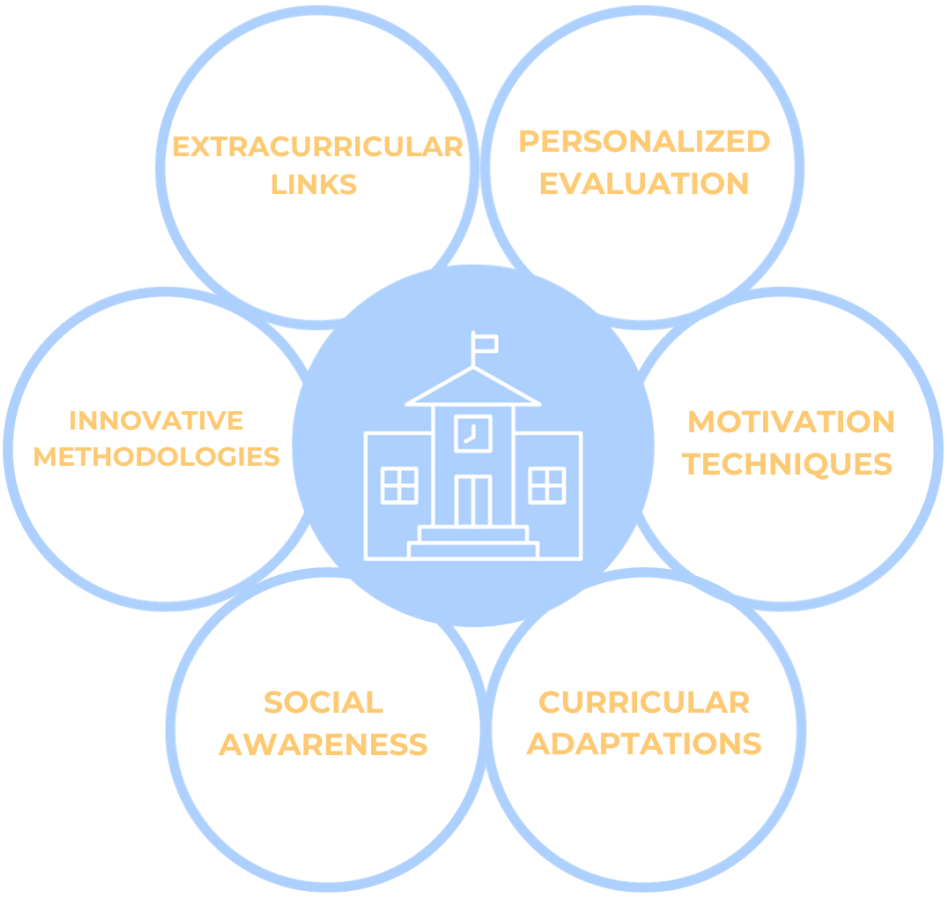

Figure 5. Characteristics of a successful education for people affected by rare diseases.

MODULE 1. ACTIVITY 3
ROLEPLAY - EXPLORING CLASSROOM ENVIRONMENT

Roleplay is the implementation of activities in which the participants, in this case teachers, take on the role of others, as if they were playing a 'make believe' game. It's a planned learning activity where teachers take on the role of learners. As you know empathy is stronger and more effective when we truly put ourselves in the "other person's shoes".

Students should also feel motivated through the principle of co-execution between teachers and students that will encourage and prepare them as training agents. This will allow them to be useful to society applying an attitude of dialogue and functionality from the teacher to the student. A more active and autonomous participation of students in the reshaping and understanding of the contents of agendas and programs will benefit people affected by rare diseases.

In this context, it is also recommendable to build extracurricular links with people affected by these pathologies in cultural and recreational activities aiming for the integration of the student.

If the objective is to improve the life of students in the education context, we must develop awareness campaigns and remedy the lack of material, human resources and technical means. The success of teaching for these people lays on the degree of information, motivation and collaboration of all members of society.

In turn, teachers and school centres must establish an internal evaluation system, a constant and thorough analysis of their different constitutive parts. The centres should also elaborate a general report of the different evaluations which will provide an overall image of the institution that focuses on inclusion and integration. This ongoing practice would be a solid basis to improve the quality of education in general and, more specifically, of students with special needs.

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facing SCHOOL

3

RARE DISEASES: MUSCULAR AND NEUROMUSCULAR DYSTROPHIES

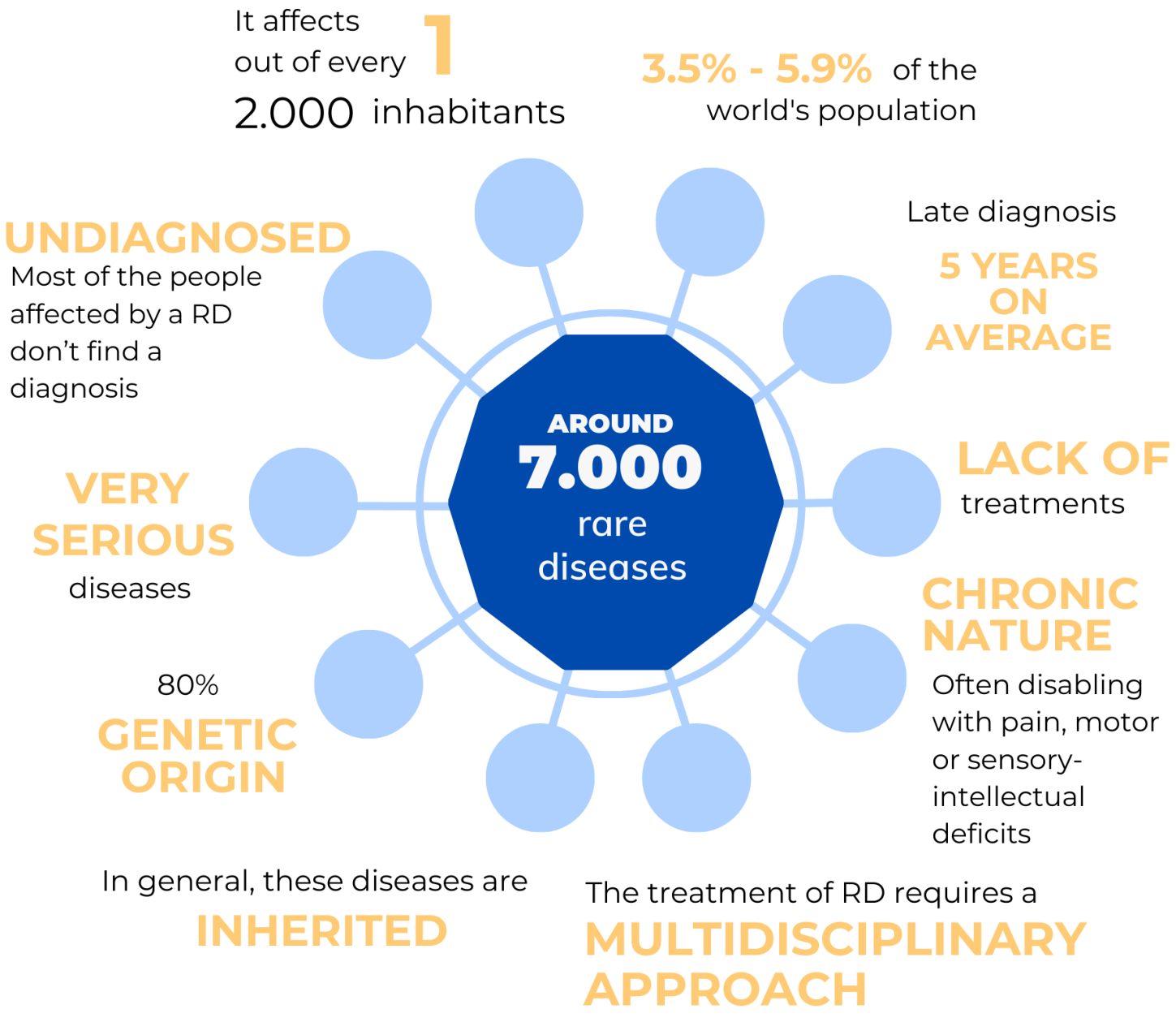


Figure 6. Facts on rare diseases.

3. Rare diseases: muscular and neuromuscular dystrophies

3.1. Introduction

When we talk about rare diseases, the adjective "rare" should be interpreted as "infrequent". The definition of rare diseases in medicine started to be used 50 years ago. It was coined in 1978 to refer to hereditary metabolic diseases, in a scientific publication of the American Journal Paediatrics. (Palau, 2018).

Regarding the paradox of rarity (EURORDIS, 2005) (the peculiarity of the low prevalence of individual rare diseases with the large number of existing rare diseases, leading to a very low probability of suffering from a specific rare disease, but not so much from any of them), we may affirm that, given the prevalence figures or proportion (1 out of 2000 people), there are many patients affected by rare diseases although the diseases are rare, so it is not completely uncommon. Despite the low prevalence of each disorder, rare diseases are very numerous and, taken together, constitute a major public health problem in many countries (Taruscio & Cerbo, 1999). It is also frequent to be affected by one of these diseases when one member of the family has suffered a similar condition. In the contrary, it is infrequent to suffer one when there are not similarities in the medical record of the family.

It should be noted that each person is, statistically speaking, a carrier of six or eight genetic variants, which are generally, but not always, recessive in their transmission. These variants generally have no consequences, but if two individuals carrying the same genetic variant have offspring, they may be affected.

Although not all rare pathologies are congenital (manifestations from birth), most of them (75-80%) are of genetic origin and can be inherited, which undoubtedly increases their impact and the need to provide genetic counselling to the affected person and his/her family.

From a medical perspective, rare diseases are characterized by the large number and wide diversity of disorders and symptoms that can vary from disease to disease, but also when we refer to the same disease. The same condition can have very different clinical manifestations from one affected person to another. For many syndromes there is a great diversity of subtypes. Besides, "two patients with the same disease can have a different degree of condition and evolution", explains Jordi Gascón (Menéndez, 2017).

The lack of knowledge of rare diseases responds to a problem of data dispersion. It is difficult to effectively collect quality aggregated data because the patients are few and are poorly characterized. For many years, the dispersion of patients has been an obstacle for scientific research on rare diseases, but with the breakthrough of new technologies the scenario is slowly changing. Years ago, patients with rare diseases had to deal with problem of isolation, as well as the intrinsic problems of the disease. Nowadays, the Internet allows groups of patients with rare diseases to be more connected than ever.

PRECURSORS

1630 - WILLIAM HARVEY

The best mechanism to learn about nature is studying rare forms of disease.

1866 - MENDEL'S LAW

Statements about the way certain characteristics are transmitted from one generation to another in an organism.

1902 - ARCHIBALD GARROD

Application of Mendelian genetics to an alteration that he describes as an inborn error of metabolism in 1908. Anticipating the concept of the enzyme gene, coined in the 1950s by Beadle and Tatum.

1902 - ASBJORN FOLLING

A Norwegian biochemist and physician, discovers phenylketonuria, which leads to the first neonatal screening in the 1960s by the American microbiologist ROBERT GUTHRIE.

Figure 7. Precursors on the research of rare diseases.

3.2. The impact of rare diseases

As mentioned above, rare diseases affect 3.5%-5.9% of the world's population. This means that there are around 300 million people in the world affected by a rare disease, as stated by a study published in the European Journal of Human Genetics and carried out by the reference portal on rare diseases Orphanet, the European Alliance of Associations of Patients with Rare Diseases (EURORDIS) and Orphanet Ireland under the coordination of the National Institute of Health and Medical Research of France (INSERM) and the Global Gene Project (Nguengang Wakap et al, 2020).

MODULE 12. ACTIVITY 5
DIRECTORY OF RELIABLE WEBSITES AND RESOURCES

Finding reliable information on rare diseases, whether it is information about the disease, treatments, clinical trials or support organisations can be challenging. It is sometimes difficult to discern the serious professional website from others that might not contain up-to-date information that has been reviewed by professionals. Therefore we provide a list of the most prominent and active websites that provide reliable information on RD.

Most rare diseases (89.1%) are extremely rare, 1 case per 100,000 people (Rath, 2021). This means that most diseases affect a very low number of people, located in different countries of the world, which makes rare diseases a global challenge. For this reason, it is necessary for scientists and patients to collaborate beyond their borders.

Experts estimate that the number of rare diseases in the world is around 7,000. However, recent analysis suggests the figure could be up to a 50% higher (Monarch Disease Ontology, 2023). For example, the Instituto de Salud Carlos III (ISCIII) lists 22,851 diseases, although some are variants of the same syndrome.

3.3. Classification of rare diseases

The International Statistical Classification of Diseases and Related Health Problems (ICD) includes thousands of diseases. This system has evolved since its creation by the end of the 19th century. ICD-11 uses anatomical divisions as a classifying axis, although it has been expanded with more transversal classifications such as neoplasms, endocrine and metabolic diseases or causes of morbidity. But there is a factor that is substantially altering the way in which new diseases are discovered and, therefore, classified: genetics.

Rare diseases naming is based on a more or less complete description of the pathology (for example, retinitis pigmentosa), or the name of the doctor or group of doctors that first-described the symptoms of the disease (for example, Lennox Syndrome-Gastaut). It is a descriptive naming in which either the most important symptom or the name of the discoverer is used to identify the disease.

However, the breakthrough of genomics has originated an unprecedent change. Currently, most of the rare diseases identified receive the name of the gene that originates

them. Now, for the first time in the history of medicine, the classification of diseases is carried out following a functional analysis.

Nonetheless, this classification still fails to reflect the enormous diversity of individuals. One of the main problems that patients with rare diseases must overcome is the lack of a diagnosis. It is difficult to find out the number of rare disease patients that are undiagnosed. The problem may be that the traditional classification system used in medicine does not apply on rare diseases and, because when the number of patients is very low, it has problems to classify them.

Specialists keep trying to find a solution. As Palau (2020) claims, "when you approach a disease, there is data available according to synonymous terms, causative genes, coding of related diseases in the International Statistical Classification of Diseases and Related Health Problems or the coding of the catalogue of phenotypes and OMIM (Online Mendelian Inheritance In Man) genes. Besides, one of the main purposes of Orphanet is the creation and maintenance of an encyclopaedia of rare diseases to classify these pathologies in a hierarchical and multidisciplinary way. Each disease is now assigned a unique ORPHA code that is non-transferable in time".

MODULE 11. ACTIVITY 3
CLASSIFICATION OF NMD

Neuromuscular diseases (NMD) are considered rare diseases, and are a group of more than 150 diseases that all involve injury or dysfunction of peripheral nerves or muscle. Due to their low prevalence, NMD are often difficult to diagnose and unknown to the general population and even doctors that have not specialised in these conditions. Therefore there is a need to gather all these diseases and their main symptoms into a brief guide that can be used to quickly browse through all the diseases and get an overview of every condition.

3.4. Characteristics of rare diseases

Although they vary greatly (no two patients are alike) there is a set of common characteristics:

- Around 80% are hereditary diseases that are caused by an anomaly in the person's DNA. Less frequent are the diseases that result of infectious, immunological, degenerative, proliferative and other unknown causes that may be the origin of a rare disease and which leads to the random appearance of the disease. Although rare diseases do not constitute an official nosological group, they are a heterogeneous group with a common factor which is low prevalence (Cortés, 2015). Only the 50% of the causes are identified.

- 45% have a neurological origin and, when the origin is different, 50% present neurological manifestations. Rare diseases can affect patients both in their physical and mental, behaviour and sensory capacities. Different disabilities can coexist in the same individual.

- Those affected suffer a decrease in life expectancy (EURORDIS, 2005).

- Two thirds of them begin in childhood, even before the age of two, and many from the time the foetus is formed. But they can appear at any stage of life. The most common are

Infantile Spinal Muscular Atrophy, Neurofibromatosis, Imperfect Osteogenesis, Rett syndrome and most metabolic diseases, such as Hurler, Hunter, Sanfilippo, Mucolipidosis Type II, Krabbe diseases, and Chondrodysplasia. In some cases, the first symptoms of diseases, such as Neurofibromatosis, may occur in childhood, but this does not prevent more severe symptoms from its later appearance. Other rare diseases, such as Huntington's disease, Spinocerebellar ataxias, Charcot-Marie tooth disease, Amyotrophic Lateral Sclerosis, Kaposi's Sarcoma, and thyroid cancer, are specific to adulthood. While many diseases cause symptoms in childhood, these symptoms may not translate for years to a specific rare disease diagnosis (EURORDIS, 2005). On the other hand it should also be noted that relatively common conditions can hide underlying rare diseases, e.g. autism (in Rett Syndrome, Usher syndrome type II, Sotos Cerebral Gigantism, Fragile X, Angelman, Adult Phenylketonuria, Sanfilippo...) or Epilepsy (Shokeir syndrome, Feigenbaum Bergeron Richardson Syndrome, Kohlschutter Tonz Syndrome, of Dravet...). In fact, a rare disease can be masked by a multitude of other conditions, which can lead to a misdiagnosis.

- Due to its minority nature and little-known symptoms, diagnosis usually takes many years.

- 65% have a chronic and progressive clinical course, with serious and debilitating conditions, which generate high rates of disability and decreased quality of life. In fact, it is considered that rare diseases are responsible for 25% of chronic diseases (Cortés, 2015). Most of them are quite serious and disabling (65% of those affected have some degree of dependency, and more than 80% physical or emotional disability), degenerative, chronic (85%). One out of five patients suffer from chronic pain (more than 20%) and in 50% of cases the vital prognosis is compromised.

- Most of them require complex and expensive treatments, which must be assumed by multidisciplinary teams. 8 out of 10 Spaniards consider that rare diseases have fewer resources and tools than the more well-known or general pathologies, according to data from the Federación Española de Enfermedades Metabólicas Hereditarias (FEEMH), which makes treatment difficult: 42.68% of the people affected do not have one and if there is one, it is not the correct one or the adequate one.

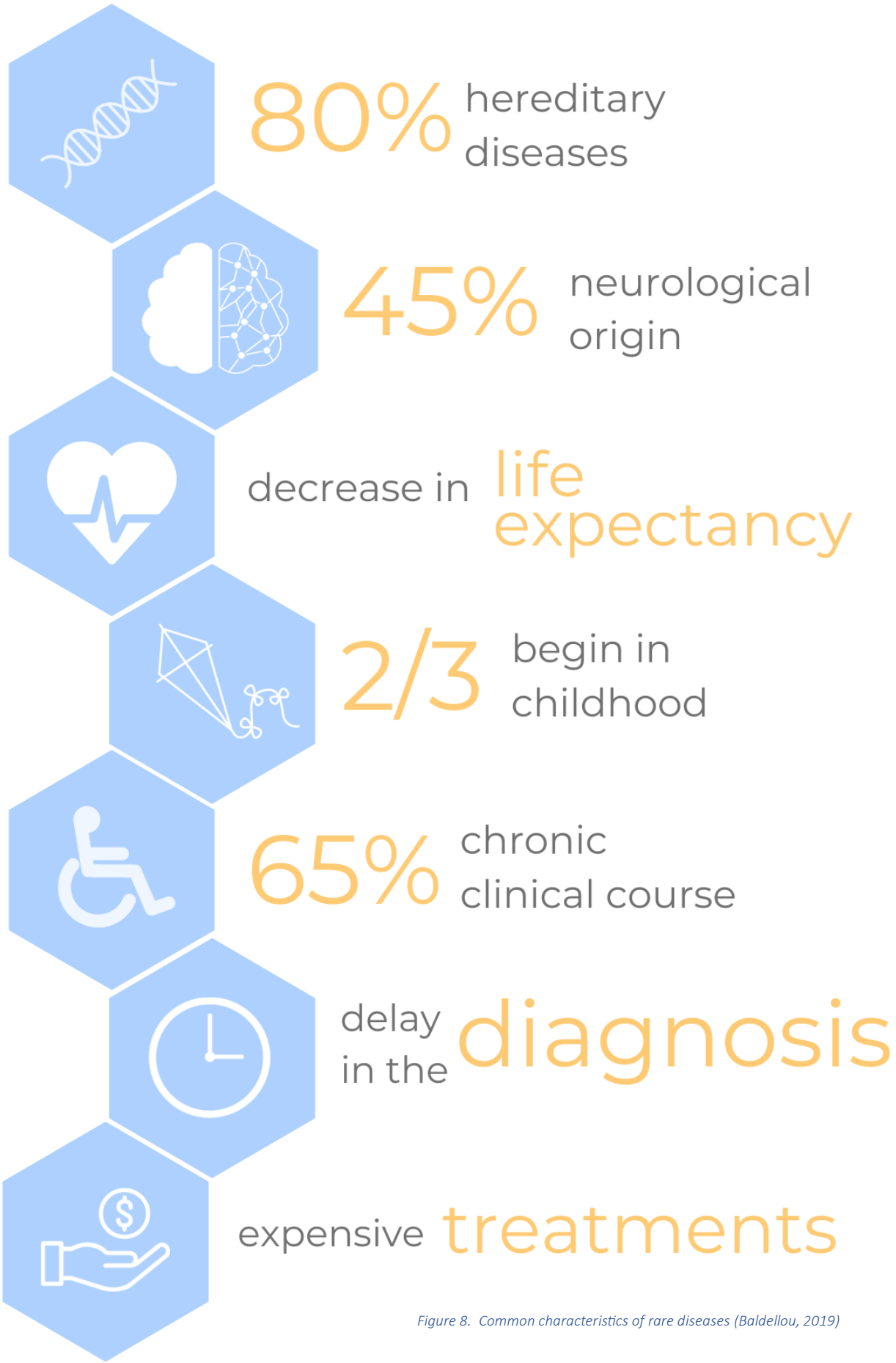


Figure 8. Common characteristics of rare diseases (Baldellou, 2019)

3.4.1. Characteristics from the origin of rare diseases

Baldellou (2019) makes the following distinction regarding the origin of rare diseases:

-ACQUIRED DISEASES

They represent the 20% of rare diseases, and their origin is usually a very rare infectious, parasitic, or toxic agent, as mentioned before.

-HEREDITARY DISEASES

As stated by genetics, most of our genes are in the 46 chromosomes (23 pairs) located in the nucleus of cells. Twenty-two pairs are formed by two homologous chromosomes, one from the father through the spermatozoon and another from the mother's ovule.

MODULE 4. ACTIVITY 1
FIND OUT MORE ABOUT DMD AND BMD

The proposed activity aims to broaden knowledge about DMD and BMD by presenting the pathology and the aspects that characterize it, from diagnosis to its evolution, passing through hints on comorbidities and emotional aspects (developed in depth in activities 2 and 5 of the same module), and of clinical and rehabilitative caretaking.

The transmission of a disease follows Mendel's laws:

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.

Suffering a rare disease is a matter of probabilistic risk and professionals (doctors, educators, physiotherapists, educators, teachers, etc.) must communicate this to the family. See a detailed explanation in Montoliu (2023).

As already mentioned, 80% of rare diseases are hereditary due to genetic disorders of nuclear or mitochondrial origin. The other 20% are acquired diseases and are usually caused by infectious, parasitic or toxic agents.

Genetic pathology of nuclear origin

- Chromosome disorders: These are variants in the number (excess or deficiency) or in the shape (translocations, deletions, etc.) of any of the nuclear chromosomes.
- Point genetic mutations: They are due to the variant of a nuclear gene. Because of this, there is an mutation in the structure or in the function of the protein encoded by this gene leading to the outbreak of the disease.
- Polygenic inheritance: there are diseases that are due to the simultaneous occurrence of mutations of different genes, that triggers the appearance of the disease. They do not follow Mendel's laws and the risk of recurrence of the pathology is 3%.

Genetic pathology of mitochondrial origin

The mitochondria in the cytoplasm of cells also have their own gene endowment. Consisting of 37 genes arranged in a circular DNA, they are responsible for the control of functions essential for the life of the organism and their abnormalities give rise to important clinical manifestations. Of the two germ cells, the egg cell is rich in mitochondria and therefore in mitochondrial DNA, whereas the sperm cell has very few copies of mitochondrial DNA and these are not passed on to the offspring. Therefore, the embryo receives only the mitochondrial genes from the mother. The inheritance of diseases caused by a mitochondrial DNA mutation is therefore a so-called "maternal" inheritance. It is passed on by mothers but can be passed on to both sons and daughters. However, the calculation of risk in offspring is very complicated, as it is an inheritance conditioned by the biological characteristics of the mitochondria and empirical predictions should not be made, but rather a careful case-by-case analysis.

3.5. Diagnosis of Rare Diseases

20% of people suffering a rare disease take more than 10 years to be diagnosed; another 20%, between 4 and 9 years (FEDER, 2020). Besides, there is "a painful percentage" without a diagnosis that it is recognized in the health system as "rare disorder without a determined diagnosis", which increases the ignorance about the evolution of the pathology (Orphanet, 2023).

Many of the patients do not even know what disease they are suffering. There are two main reasons: the difficulty to find the right diagnosing and the lack of professionals with specific training in their hometown. This situation hinders the possibility of receiving personalized care once the disease has been identified.

The management and genetic counselling of patients affected by rare diseases require an accurate etiological diagnosis. This precision diagnosis is most often based on a molecular analysis of the specific gene associated with the disease under study or of panels that include the different genes that may be responsible of a certain phenotype and that allow to identify the underlying molecular disorder, as we have specified.

As mentioned before, rare diseases are very heterogeneous pathologies that involve different organs and systems and hence must be treated by different medical specialties and subspecialties. We need to understand that these diseases are related to multiple genes and multiple mutations responsible of the disorder, and also to other mutations and polymorphisms that regulate their manifestation. Only afterwards could we comprehend the great complexity associated with the study of the molecular mutations behind the different pathologies from the technological point of view.

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.

Figure 9. Typologies of tests to find out the diagnosis of a rare disease (Baldellou, 2019)

The improvement of the diagnostic performance regarding rare diseases also relies upon the accessibility of patients to genetic diagnostic services and to the access of these services to different diagnostic technologies. But regardless of the technical approaches used, improving the diagnosis of rare diseases requires the close collaboration of researchers and institutions, through consortia and patient focus programmes. The International Rare Diseases Research Consortium claims that, when the diagnosis is not obtained after initial sequencing, the data should be transferred to a global network of experts who will apply the knowledge in further studies and will provide feedback of the outcome. (Knoppers, 2014).

MODULE 11. ACTIVITY 1
TWO FACES OF A DIAGNOSIS

It often takes years for families to receive the correct diagnosis of a neuromuscular disease. The road to diagnosis is an odyssey filled with tests, different specialists, uncertainty and anguish. This poster aims to illustrate this journey to diagnosis and to do so in such a way that the family's part and the specialist's part can be seen simultaneously, in order to generate more empathy.

The consequences of a delay in diagnosis can be life-threatening for the patient, who is deprived of early therapeutic options with the consequent clinical worsening and side-effects that could have been avoided. "This occurs to 27% of patients, despite the fact that in recent years the diagnostic delay has been progressively reduced", explain Jordi Gascón (Menéndez, 2017). The consequences of a late diagnosis are very adverse:

- Other children born with the same disease.
- Inappropriate behaviour and inadequate help from family members.
- Clinical worsening of the patients' health in terms of intellectual, psychological, and physical condition, leading even to the death of the patient.
- Loss of confidence in the healthcare system.

One of the goals of the International Rare Diseases Research Consortium by 2027 is that all patients for whom there is suspicion of a rare disease are diagnosed within one year if their disorder is known in the medical literature. Without a correct diagnosis, emergency units are not able to treat the patient appropriately (EURORDIS, 2005).

MODULE 11. ACTIVITY 2
COMMUNICATING A DIAGNOSIS

Both giving and receiving the diagnosis of a child with a rare disease can be challenging and difficult. Multiple emotions collide, which might make that moment difficult to manage. It is important that professionals communicating the diagnosis do it in a manner that facilitates assimilation of the situation and eliminates unnecessary suffering.

Fortunately, as the amount and complexity of genomic data increases, researchers are turning to artificial intelligence (AI) and machine learning (ML) to reanalyse existing data and answer health and research questions. Rapid advances in bioinformatics and genomics make it possible to discover the genetic causes of about 30% of known rare diseases (Setty et al, 2022).

3.6. Treatment of rare diseases

Scientific research is important to develop effective treatments that increase the quality of life of those affected. There are multiple treatments for rare diseases and, in many cases, they are specific to each disease. In general terms, these therapies can be divided into five main groups: small molecules, protein therapies, antibodies, oligonucleotide therapy, and cell or gene therapy.

Given the genetic origin of most of these diseases, these treatments are often aimed at recovering lost function or restoring an abnormal gain in function caused by a genetic alteration. In addition, the recent outbreak of genome editing techniques adds a new paradigm to the therapeutic landscape, opening up the possibility (yet to be realized) of a permanent cure for some diseases (Tolosa, 2023).

3.6.1. Human Genome, progress on rare diseases

Since the publication of the human genome in 2003, enormous progress has been made and its results have been implemented in the clinical practice. “But we still need to analyse the effects of what we are doing, study the costs and organize accordingly”, explain Doctor Carmen Ayuso (Landín, 2017).

In the field of rare diseases, genetic diagnosis is useful when it is necessary to confirm or dismiss any clinical suspicion. The family receives genetic counselling afterwards preventing the appearance of new cases and avoiding the use of unappropriated treatments. Regarding

rare diseases, it is necessary to continue making progress with certain technologies because, and although a lot of analysis has been done, the effects still must be measured.

3.6.2. CRISPR

In 2013, the gene editing technique known as CRISPR made the leap from bacteria to animal models, sparking a revolution that is still in its early stages.

To cure a genetic disease is necessary to generate the defective gene product in the damaged cells. One of the ways to meet this objective is gene therapy, which consists of introducing the healthy gene into the patient's cells. A few years ago, this potential treatment was out of reach for many diseases, and it was completely unbearable to many cases due to the problems that may arise by the permanent insertion of new genes.

In 2005, while working on a line of research on bacteria, the Spanish researcher Francisco Mojica discovered a type of proteins capable of cutting specific DNA sequences. This method is used by bacteria as a defence mechanism against viruses that may introduce their DNA as infectious agents. In this process, the bacteria detect and destroy the invading DNA.

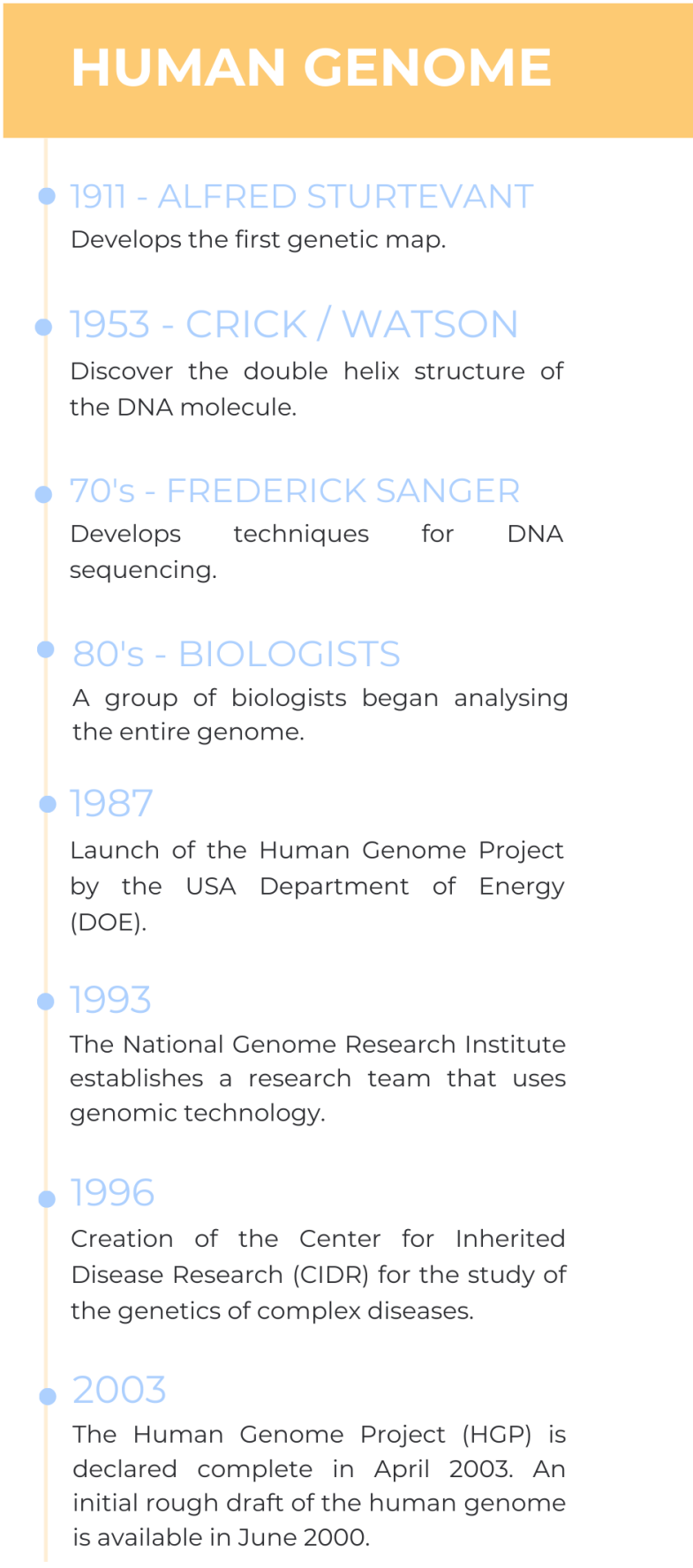
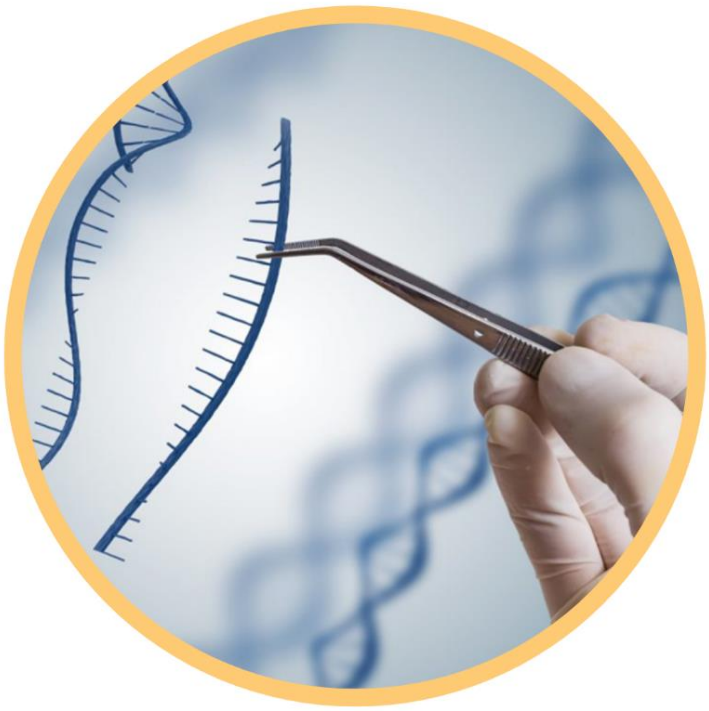


Figure 10. Sequencing of human genome.

It was later, in 2012, when researchers Jennifer Doudna and Emmanuelle Charpentier figured out that this technique could have an important application in biomedicine (Mojica, 2005)

"It is versatile, effective and universal", explains Montoliu (2023), a researcher at the Spanish National Centre for Biotechnology and one of the main experts in this technique. "It will be a structural technique for all the laboratories at the preclinical level", he claims. At the clinical level there is still some progress to be made, but it has already shown its efficiency "in a dozen rare, such as restenosis, Duchenne muscular dystrophy or Huntington's disease", congenital pathologies that have been experimented in laboratory mice (Montoliu, 2023).

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, which holds great potential for both research and disease treatment. This system is capable of correcting mutations in different time windows, even during key development periods. Besides, this new version of CRISPR for editing RNA may avoid ethical concerns associated with the traditional method. "Until now we could modify the genes, but not so easily the transcripts, that is the molecules that exist between the genes and the proteins. With this new tool, it will be possible to edit them without altering the genome", adds Montoliu (2023).



3.6.3. Orphan Drugs

The lack of an accurate diagnosis hinders the possibility of finding the appropriate treatment. In fact, most undiagnosed patients receive symptomatic treatment until they find their diagnosis, as mentioned in previous pages. However, to find a diagnosis does not guarantee a correct treatment. There are two main factors that constrain the options of getting an optimal treatment: the ignorance of the disease and the lack of effective medications.

According to the 2017 reports of the U.S. Food and Drug Administration (FDA) and the European Medicines Agency (EMA), 40% of all medicines approved in both territories containing a new active principle are assigned to the infrequent pathologies study (EMA, 2022).

ORPHAN DRUGS

1960

The concept of "rarity" is coined with the KEFAUVER-HARRIS amendment, which mandates pharmaceutical companies to conduct clinical trials to evaluate the efficacy and safety of drugs.

1960

Approval of the ORPAHN DRUG ACT in the United States, the first orphan drug law.

90's

New orphan drug laws in Singapore, Japan and Australia.

2000

Regulation on orphan medicinal products of the European Union and creation of the Committee for Orphan Medicinal Products at the European Medicines Agency.

Figure 11. Legislation on Orphan Drugs.

In the case of Europe, 40% of the 35 medicines with a new active principle that received a positive evaluation from the EMA, are classified for the treatment of rare diseases. The agency explains that 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 (AEMPS, 2017). In this group we find medicines against rare pathologies such as neurotrophic keratitis, neuroblastoma or carcinoid syndrome, among others.

There are around 1,500 orphan drugs, but the data is constantly changing because of the monthly meeting of the Committee for Orphan Drugs of the European Medicines Agency. This organism holds interviews with nearly 60 experts about 20 to 35 medicines candidates to enter this classification. Every year, between 6 and 8 drugs obtain the require authorisation. Hence, the data is constantly changing. It should be remembered that substantial evidence of clinical safety and efficacy is necessary to obtain approval of an orphan drug (Haffner, 1998). During financial year 2022, there was 195 products with a trade name and positive orphan designation by the European Medicines Agency, of which 146 have authorisation for community marketing.

3.7. Conclusions: difficulties for people affected by rare diseases

Suffering a rare disease, in addition to the specific circumstances of each pathology, implies many other problems: ignorance about the origin of the disease, bewilderment and disorientation at the time of diagnosis; often social rejection and loss of self-esteem; misinformation about care, treatments and technical aids that can make life easier; isolation and lack of communication with other affected people; misinformation about specialists or reference medical centres; lack of study and follow-up protocols; lack of financial aid; lack of recognition in health policies and services; lack of specific drugs to treat the disease; lack of legal coverage to promote research on genetics, clinical trials and new treatment, among others. For further information, see Hoja de Ruta de las Enfermedades Raras (2022).

On the other hand, these pathologies affect multiple body systems, and their approach requires the participation of different specialists. However, few centres offer a coordinated, comprehensive and multidisciplinary care. Health care and examinations are usually frequent

when patients seek a diagnosis. This scenario is in addition to the need for specific treatments, special care and rehabilitation that most patients require throughout their lives. These services are not appropriately organized into packages or programs and many patients must overcome the lack of support by regular health insurance, which leads to abandoned treatment and scarce follow-up. Despite the vast number of patients diagnosed every year with rare diseases, the low number of patients with each disease makes difficult to achieve significant progress.

According to the Chiese study (2022) the costs for patients with rare diseases come from different sources. The most pressing issue is related with the lack of treatments. Rare diseases set a substantial financial burden that is only reduced when treatment is available:

- The burden of rare diseases is approximately 10 times higher than common diseases per patient and year.
- Lack of treatment for a rare disease is associated with a 21.2% increase in total disease costs.
- The costs of care associated with the selected rare diseases were explored using published data, patient advocacy associations, key opinion leaders, and data from the U.S. Bureau of Labor Statistics. The cost burden was classified in three categories:

1. DIRECT COSTS. It includes the cost of treatment, medical procedures, hospitalizations, doctor visits, health care and other medical expenses.

2. INDIRECT COSTS. It includes loss of productivity of both, patient and caregiver, loss of work, changes of residence, travel, and accommodation for medical visits.

3. MORTALITY COSTS. It is based on the value of statistical life and the difference between average life expectancy and that for people with a rare disease.

In summary, beyond the great diversity of conditions, patients with rare diseases and their families are confronted with many similar difficulties, which arise directly from the low frequency of these conditions (Cortés, 2015; EURORDIS, 2005).

However, it is not only the people affected who encounter these difficulties, there are infinite problems such as the lack of national registers, the lack of Reference Units, biobanks, etc. These issues could be analysed in further studies.

Lack of access to a correct diagnosis

The period between the appearance of symptoms and the appropriate diagnosis implies an unacceptable and high-risk delay; as well as a misdiagnosis can lead to inadequate treatments.

Lack of information

Both, regarding the disease and the right services where to find support and qualified professionals.

Lack of scientific knowledge

this implies difficulties in the development of therapeutic tools, definition of therapeutic strategies and a deficit of therapeutic products, either medicines or medical accessories.

Social consequences

Living with a rare disease affects multiple contexts: schooling, work, recreational activities, affective life. It can lead to stigma, isolation, exclusion from social activities, discrimination in cover insurance (health, travel, life) and often reduced job opportunities.

Lack of adequate and quality health care

In addition to medical care, patients with rare diseases require support of specialized experts in multiple contexts. Patients can live for many years in precarious conditions due to the lack of specialized medical attention and rehabilitation.

High cost of the few existing medicines

The additional cost of dealing with the disease, combined with the lack of social benefits and reimbursement, produces a global impoverishment of the family. This increases the inequity of access to the general health care required by patients with rare diseases.

Inequity in the availability of treatment and care

Innovative treatments are often unevenly available, due to high cost, poor availability of reimbursement, inexperience of treating physicians, and lack of consensus treatment recommendations.

Figure 12. Conditions that difficult the live of families affected by rare diseases (Cortés, 2015; EURORDIS, 2005)

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4

THE IMPORTANCE OF SCHOOLING

4.1. Introduction

The concept of schooling refers to an institutionalized educational practice that emerged in Western culture, the product of a specific combination and construction of subjects, technologies, resources (human, temporal, spatial, material, etc.), knowledge, intentions and effects. According to this perspective, the school is a specific, artificial form of education, developed for centuries in a specific geographical and historical space -the European West between the sixteenth and nineteenth centuries-, which expanded in a very short time -from the late nineteenth to the early twentieth century- around the globe and managed to become the hegemonic form of education throughout the world. This involved a special combination of elements that were assembled to build it, often in a conflictive and contradictory manner. In short, the product of a process that was neither harmonious nor "natural" -the only possible point of arrival of the "evolution" of humanity and its educational evolution-, but the result of strong quarrels and oppositions.

Although it is a term of long use in the pedagogical debate, it can be stated that one of the most rigorous academic approaches was made by David Hamilton in 1989, in his book “Towards a Theory of Schooling” (1989). In this work, the author distinguishes between education and schooling and understands the latter as an elaborate and complex human institution, socially constructed and historically situated, which began to take shape towards the end of the Middle Ages, and which has been reformed several times up to the present day.

In the concept of school and schooling, the idea of progress is important, as well as that of evolution and economic and social context. Besides the evolution of these theories, we are very interested in the idea of an institution that has a direct impact in society.

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.

Figure 13. Main characteristics of the impact of school in students.

4.2. Education as a human right

Everyone has the right to receive an inclusive and quality education. The right to education is guaranteed in several international instruments.

Article 26 and Article 29 of the Universal Declaration of Human Rights (1948) recognise free and universal primary education as a fundamental right.

In Article 26 of the UDHR, we find the right to the "full development of the human personality", which also appears in Articles 22:

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 26

1. Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. [...].
2. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms [....].
3. Parents have a prior right to choose the kind of education that shall be given to their children.

Article 29

1. Everyone has duties to the community in which alone the free and full development of his personality is possible.
2. In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others [...].
3. These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

4.3. Schooling and rare diseases

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. And second, because through education, people acquire knowledge, skills and competencies that prepare them to overcome the challenges and benefit from the opportunities that may arise in their lives.

In addition, schooling can also have a positive impact on the health and well-being of affected individuals and their families. By participating in educational activities, patients stimulate their brain, keep a routine, and follow a purpose, which can contribute to their quality of life and better management of their disease.

MODULE 6. ACTIVITY 1
STORIES OF THREE RARE CHILDREN

A little book that tells 3 stories of children living with rare diseases. Each of them talks about their daily life, their dreams and their relationship with other children and teachers.

Education also fosters social inclusion and interaction with other individuals, which can be especially relevant for patients who may feel isolated or excluded due to their health condition. Schooling provides them with the opportunity to interact with peers, build friendships and become part of an educational community.

The rights of children and people with disabilities, such as tolerance, respect, non-discrimination, equal opportunities and the value of differences, should be recognized and guaranteed among children with rare diseases. Bringing the implications of rare diseases closer to the educational context is essential to ensure their

MODULE 3. ACTIVITY 2
VIDEO INTERVIEW OF CAROLINE DESOMBRE

Text developed by Caroline Desombre, professor of social psychology at the University of Lille about the needs raised by the preoccupation of the illness and how teachers should respond to them.

inclusion. Only this way will be possible to create a truly inclusive society where professionals such as doctors, politicians, and entrepreneurs are aware of the issues concerning with rare diseases.

4.3.1. The consequences of misunderstanding rare diseases in school

Ignorance of rare diseases leads to misunderstanding, rejection and isolation of the students affected by these pathologies and this brings important consequences in socio-affective development and school performance. Consequently, it is necessary to implement innovative actions to promote the recognition and guarantee of their rights.

Psychosocial consequences

- Hospitalization, activity restrictions, dietary restrictions, medication, and absence from school.
- Disability of various kinds.
- Uncertainty and fear regarding different aspects related to the disease.
- Feelings of loneliness and isolation, especially when the disease prevents participation in daily activities.
- Lack of understanding and social rejection.
- Feelings of loss of control due to being unable to fulfil age-appropriate roles and potential physical changes.
- Feeling unique, helpless, disoriented, and powerless.
- Hypersensitivity, impatience, irritability, and high expectations.

Consequences in the educational context

- Some parents are hesitant to have their children interact with the child due to fear of contagion or aggressive reactions.
- Teachers may interpret the child's behavior as a lack of discipline, unaware that it is associated with a behavioral disorder caused by the illness.
- Teachers may question their own professionalism out of fear of not knowing how to respond appropriately.
- Peers may experience rejection or jealousy due to the attention and support the child with the illness/disability receives, as well as their frequent absences for treatments and surgical interventions, etc.

Figure 14. Consequences of misunderstanding rare diseases in school (FEDER y Fundación SANOFI, 2021)

The people affected and their families need to be understood. When this process of understanding is real, education and schooling is more inclusive and more effective. However, to understand and empathize with these conditions is complicated without some previous knowledge.

4.4. The necessities of people affected by rare diseases in school

Schooling children with rare diseases can present unique challenges due to the specific medical and support needs they may have.

It is important to emphasize that the schooling of children with rare diseases requires an individualized approach, effective communication, educational adaptations and comprehensive attention to their health. For this matter, education systems and education professionals should provide an inclusive environment, whether through curriculum adaptations, additional pedagogical support, or school-based health services.

The approach to these conditions is complex because they manifest themselves as syndromes. Therefore, the teacher must make decisions (didactic, pedagogical, socio-affective, etc.) that not always have a clearly defined map. In the end, it will be the teacher, together with the family and the rest of the educational community, who will have to adapt his itineraries to the diversity of situations and contexts of the classroom. Collaboration among all the actors involved is fundamental to guarantee a successful and satisfactory educational experience for these children.

MODULE 2. ACTIVITY 1
QUESTIONNAIRE FOR TEACHERS WITH RD STUDENTS

In a class where there are students living with a rare disease, teachers face different situations every day. The questionnaire is designed to understand what objectives have been achieved and what needs to continue working.

Equal access

People living with rare diseases have the right to access education on an equal basis with others. This implies removing physical, cognitive, social and economic barriers that may prevent their full and effective participation in the education system.

Inclusive education

An inclusive educational environment that values diversity and ensures the participation of all students, regardless of their medical condition, must be fostered. This implies providing the necessary adaptations and supports so that students with rare diseases can access the curriculum and participate in all school activities.

Individualised planning

In order to meet the specific educational needs of people with rare diseases, it is important to develop individualised education plans (IEPs) that consider their abilities, limitations and educational goals. These plans should be developed in collaboration with students, their families and education and health professionals.

Appropriate support and resources

People with rare diseases may require additional supports and resources to make the most of their educational experience. This may include support services, curricular adaptations, assistive technology, support staff and specialised training for education professionals.

Awareness raising and training

It is essential to promote awareness and understanding in educational communities about rare diseases. This will help to create an inclusive school environment, free from discrimination and stigmatisation, where diversity is valued and appropriate support is provided to students with rare diseases.

4.5. Conclusions

It seems clear that, in terms of educational levels, the participation of students with disabilities in pre-school education and in compulsory education is much lower. The most important problems begin to manifest in secondary education, due to the difficulty of implementing inclusive education (Ganxenüller and Escudero, 2005). Therefore, although more and more young people with disabilities finish compulsory education, it is necessary to ensure that all of them follow suit (Ganxenmüller and Escudero, 2005).

The Lisbon European Council (March, 2000) called for a general reflection on the precise future objectives of education systems, to which the Member States contributed in their replies to a questionnaire from the European Commission. The five objectives which can now be applied to inclusive education are:

1. To improve the quality of learning in Europe by improving the training of teachers and trainers.

2. To facilitate and widen access to learning at all ages.

3. Updating the definition of basic skills in line with the knowledge society, making information and communication technologies available to all, and paying attention to vocational skills and personal aptitudes as well as specific skills.

4. Open up education and training to the local environment, to Europe and to the world.

5. Making the best use of resources, introducing quality assurance systems and adapting resources to needs.

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facing SCHOOL

5

THE IMPORTANCE OF DIGITALIZATION

5.1. Digitalization and Digital Transformation

In recent decades, the use of digital technologies has expanded significantly and impacted multiple aspects of society. Replacing analogue information with digital information has revolutionized access to information, structuring social life around digital communication and related technological infrastructures (Vlies, 2020). Furthermore, in employment and economy, the growth of automation and digitalization imply new development models associated with sustainability and green economic transition (European Commission, 2020).

Digitalization can be understood as a process of transition to the storage, processing, and transmission of non-physical information through the use of digital technologies (Schmidt & Tang, 2020). Digitalization is inseparable from digital transformation, understood as the comprehensive application of digital technologies in various domains of society to improve and extend products and services and create new digital alternatives (Schmidt & Tang, 2020). Digitalization and digital transformation have changed the development model of societies, and their social, educational, and economic relevance is increasing (European Commission, 2020).

In this guide, when we refer to digitalization, we refer to the technological component associated with it, but above all, to the transformative value of digital technologies in individual, organizational and social contexts and in education and educational systems.

5.2. Digitalization and Technology in Education

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. For example, television was one of the first technological devices to be incorporated into educational settings, with computers and the internet following (Blackwell et al., 2014; Schmidt & Tang, 2020). More recently, technology, especially laptops, tablets, and smartphones, has spilled over into schools, making communicating and sharing information easier (e.g., Nikolopoulou, 2020).

MODULE 10. ACTIVITY 6
BETTER INTERNET FOR KIDS

The Better Internet for Kids portal provides information, guidance and resources on better internet issues from the joint Insafe-INHOPE network of Safer Internet Centres in Europe, and other key stakeholders. The objective is to create a safe environment for children online, and fight against child sexual abuse and child sexual exploitation.

The challenge posed by new information and communication technologies is one of the most current debate topics among teachers and educational experts. This debate includes aspects such as the readiness of teachers and organizations for digitalization transformation, the coordination between digitalization-based teaching and traditional teaching, and how effective digitalization is across curriculum areas and grade levels (Blackwell et al., 2014; Nikolopoulou, 2020; Tamim et al., 2011).

Fleischer (2012) lists several challenges regarding using new technologies in the classroom, including:

- Encouraging (and training) teachers to change their beliefs and teaching methods.
- Reconciling more independent and flexible student study with the need for teacher guidance.
- Designing curricula and teaching models adjusted to digitalization.

Scientific evidence shows that technology has positive effects on student learning. Tamim and colleagues (2011) conducted a synthesis of results from 25 published meta-analyses (1055 studies, 109 700 participants) over 40 years in which they studied the impact of using

technology in the classroom compared to school settings without its use. The results confirmed that technology positively affects primary, secondary, and tertiary students' learning. However, the effectiveness of technological resources occurs mainly when it is used as a support for instruction and not as a form of direct instruction (Tamim et al., 2011), highlighting the role of technology and digitalization as a pedagogical tool and not as a tutor replacing the teacher (Schmidt & Tang, 2020).

Another meta-analysis concerning the use of mobile devices (e.g., tablet computers, laptop computers, and smartphones) in educational settings (from preschool to university level) also reported a benefit on learning (Sung et al., 2016). The authors highlight that mobile devices can promote innovation in education in several ways, including the support they provide for teacher presentation of information, and by promoting innovative teaching methods, among them collaborative learning, exploratory learning outside the classroom context, and game-based learning. In addition, the authors cite the work of Warschauer (2007) to emphasize that the benefits are not limited to the academic level but include the development of communication, creativity, and problem-solving skills.

Some qualitative studies have directly surveyed teachers regarding the use of digital media in school, particularly in the classroom setting. In a recent study, the main benefits found were the level of student engagement/motivation, the pleasant and interactive classroom climate, more accessible access to information, and students' familiarity with the use of technology (Nikolopoulou, 2020). The most significant barriers identified were the lack of technological equipment and current legislation (in some cases constraining the use of mobile devices in schools). Teachers' main concerns related to difficulty managing student behaviour, including agitation, noise, and distraction.

MODULE 1. ACTIVITY 4
EXPLORING WINDOWS ACCESSIBILITY

The Windows operating system often available on classroom computers or tablets offers a menu of accessibility tools that can be used by students. However, in order to them to be used in the classroom, to enhance students' learning, for example during research activities for projects and writing texts, it is important that teachers be aware of their potential uses.

5.3. Facilitators of Digital Transformation in Schools

The process of digital education is a complex system involving several interrelated dimensions (European Agency, 2022). At the base is the individual dimension, consisting of students and teachers who may use similar or different digital technology in teaching and learning, independently or together. Educational institutions are another critical dimension in digital transformation, connecting the individual level with support measures, innovation policies, and community relations. Finally, the regional/national dimension is at the macro level, where the legislative aspects necessary for change emerge, including governance, funding and quality control.

The importance of teachers and educators for successful digital transformation is highlighted. Price and Carstens (2020) cited a 2018 study by the Organization for Economic Cooperation and Development (OECD) which found that, on average, less than 40% of educators in the European Union felt comfortable applying digital technologies in teaching. Digital opportunities, applications, and environments are of little use if they are not properly framed and embedded in school activities by teachers (Kalimullina et al., 2021). The success of digitalization and the change process towards higher quality education implies that teachers are motivated and prepared for this new conception of learning (Fleischer, 2012; Kalimullina et al., 2021). Obviously, this effort involves preparing future teachers but also updating current teachers' skills so they can get the best out of digital technologies in teaching and learning environments. According to this line of analysis, digitalization and associated technology are pedagogical tools that should be integrated into initial and continuing teacher training programs. The focus of this training should be on the technical mastery of new equipment and, above all, on technologies and the acquisition of broader digital skills that enable them to use these tools in a critical, reflective, and situated way to facilitate student learning (Kalimullina et al., 2021).

In fact, the digitalization of schools will only have a relevant impact if it is not limited to the importation and implementation of digital technologies but is accompanied by the transformation of pedagogical practices, leadership, and organizational structures. Without these changes, digital technologies tend to perpetuate previous practices and do not translate into benefits for

the student or teacher (Pettersson, 2021; Schmidt & Tang, 2020).

5.4. Technology-based Teaching and Learning Methods

The digital transformation process of schools is inevitable and has been accelerated recently with the COVID-19 pandemic. It is estimated that at the pandemic's peak, about 90% of students worldwide had changes in their educational process (Reuge et al., 2021). As a result, new forms and contexts of education based on digital technology have intensified and become popular due to the need for education systems to ensure the continuity of school activities.

The primary compensatory measure during the COVID-19 pandemic was the use of online teaching-learning environments (e-learning) to replace or complement traditional face-to-face learning. In online learning, the student is physically distant from the teacher and uses some form of technology (usually a computer) to access the learning media and interact with the teacher and other students. In some phases of the pandemic, hybrid learning

(blended learning) has been implemented, combining face-to-face teaching with online learning. Online learning allows the student to be in a different physical space and create synchronous solutions, occurring at the same time or asynchronous at different times (Schmidt & Tang, 2020). The availability of various methods and technologies in face-to-face and distance formats allows learning environments not to be limited by space and time.

During the pandemic, some faculty adopted flipped learning models. This model contains an inversion of how teaching-learning activities are organized, as students use digital tools and resources (e.g., videos and/or instructional texts) to acquire knowledge about specific subjects before class. Then, during the class, the teacher can spend more time developing interactive learning activities, including discussion groups and collaborative problem-solving learning (Lo & Hew, 2022). It is possible to implement this model exclusively online, where distance sessions replace face-to-face sessions via video conferencing platforms (e.g., zoom).

5.5. European Commission's Action Plan for Digital Education 2021-2027

Recognizing the relevance of schools in the global process of society digitalization, the green transition, and their potential to develop inclusive and high-quality education, the European Commission has recently defined the action plan for digital education 2021-2027 (European Commission, 2020).

The European Commission (2020) highlights several benefits of digital transformation in education, as represented in figure 15.

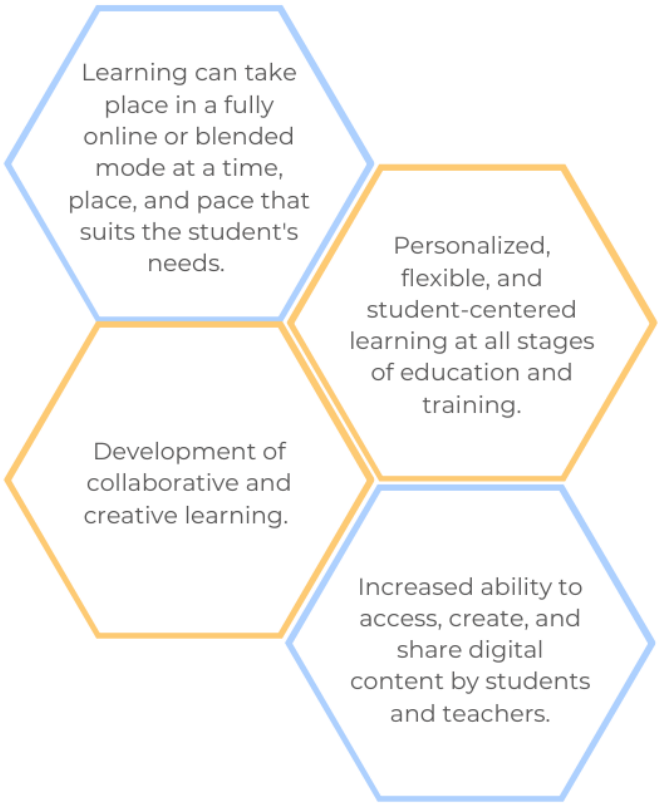

Figure 15. Some of the main benefits of digital transformation in education (European Commission, 2020)

The action plan for digital education 2021-2027 presents two priority areas.

1) Promoting the development of a highly effective digital education ecosystem. This involves improving digital infrastructure, connectivity, and equipment; improving the digital training (and confidence in its use) of teachers and education and training staff; developing high-quality learning content; developing co-collaborative tools and secure platforms.

2) Strengthening digital skills and competencies for digital transformation. This involves equipping all students with digital skills and competencies that enable them to live, work and learn in a world characterized by the relevance of digital technologies.

It is highlighted by the European Commission (2020) that the characteristics of technological tools and platforms, as well as the digital pedagogy used, directly impact the inclusion or exclusion of individuals from learning. An open public consultation was held to inform the plan for digital transformation. People with disabilities reported difficulties in accessibility to digital educational technology and material; availability of assistive technology; technical support provided to students with disabilities, and teachers' capacity to promote digital inclusion for students with disabilities (European Commission, 2020).

5.6. Towards an Inclusive Digital Transformation

Inclusion and equity are the pillars of education transformation. They are developed through actions and good practices that value diversity and a sense of belonging and help people express their full potential (European Agency, 2022). The closure of schools during the COVID-19 pandemic and the adoption of distance learning have highlighted that there are vulnerable groups of the population who are disadvantaged in the field of digital literacy, including access to technological resources associated with digitalization (European Agency, 2022; Reuge et al., 2021).

Not only should digitalization in education ensure that all learners benefit from new learning possibilities, but it should also be a way to address the specific needs of vulnerable groups, including children and young people with disabilities (Vlies, 2020). To this end, inclusion in digital education

should be understood as a multidimensional phenomenon, influenced by a wide range of factors, including society, technical equipment, educational institutions, learning situations, and the individual (European Agency, 2022). This cross-sectoral view is crucial to avoid a digital divide phenomenon characterized by society's inability to ensure that all citizens benefit from the digital transformation.

The European Agency for Special Needs and Inclusive Education (European Agency, 2022) considers that the implementation of inclusive digital education depends on several elements, in particular technology, learners, teachers, educational institutions, and regional/national level constraints. Technology-based approaches should be pedagogical in nature, and technological products should preferably be of a universal design that enables them to be used by the broadest range of learners without the need for specific adaptations. If necessary, assistive technologies should be used to meet the needs of students with disabilities. These technologies should be functional and eliminate or reduce motor, sensory, or intellectual limitations.

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.

Figure 16. Recommendations for the integration of digital devices in the classroom (Bock & Probst, 2018, cited by Schimdt & Hang, 2020)

Virtual reality and augmented reality allow students to immerse themselves in virtual scenarios or enrich the real world by adding information, respectively. The evolution of smartphones and tablets has made virtual/augmented reality more accessible, allowing students to enjoy more realistic experiences on specific topics. A recently published systematic literature review concluded that using augmented reality effectively improves functionality and learning for students with specific learning needs (e.g., intellectual development, autism, sensory impairment) (Baragash et al., 2020).

MODULE 6. ACTIVITY 3

CASE STUDY: TABLET FOR STUDENTS

The technologies offer a valuable and undisputed help in teaching aimed at students with disabilities or special educational needs. In the first place, they allow individualized teaching, based on experiences and objectives within a classroom context that does not marginalize the student. The so-called "digital" class forms a cooperative and collaborative work environment.

Mobile learning is learning that occurs with the mediation of a mobile device. The use of these devices (e.g., smartphones, tablets, smartwatches) has had promising results in learning for students with functional limitations and can act as an alternative to the use of assistive technology, which is often more expensive and difficult to access (European Agency, 2022). Many schools have invested in tablet computers and/or laptops for students (Blackwell et al., 2014). Eventually, these devices can be taken home, increasing their potential use. There are also examples of schools where students bring their own devices from home - the "bring your own device - BYOD" concept (Schmidt & Tang, 2020; Vlies, 2020). Whatever solution is found, it is crucial to ensure that all students can access and use technology regardless of their socioeconomic status (Karakose et al., 2021).

Some digital technologies are still under development but have great potential for inclusive education, among them home robotics, mobile telepresence systems, chatbots, or virtual assistants. There are already successful examples of using artificial intelligence techniques within inclusion for children with autism, visual impairment, hearing

impairment, or learning disabilities (European Agency, 2022). Gamification is also a good strategy to make educational activities more motivating for students.

Digitalization can be an excellent opportunity to promote the inclusion of students from vulnerable groups, but it can also increase inequalities if proper strategies are not defined (Vlies, 2020). Digital inclusion requires holistic and systematic consideration of the individual (e.g., students' digital skills) and environmental (e.g., social inequalities) conditions that influence the degree to which students are included (European Agency, 2022). There is evidence that schools have the ability to compensate for socioeconomic inequalities associated with the digital domain if they implement appropriate measures (González-Betancor et al., 2021). In this regard, investment in technological devices and infrastructure (e.g., Internet connectivity and digital device provision) is not enough, but the development of digitalization skills and competencies of students and teachers is crucial (González-Betancor et al., 2021).

The leadership of educational institutions at administrative, pedagogical, and scientific levels also

plays a significant role in the institution's orientation towards digital inclusion. Creating an institutional culture of innovation impacts faculty professional development, networking, infrastructure to support digital transformation, and implementation of good pedagogical and administrative practices (Karakose et al., 2021). Finally, government organizations (e.g., ministries) and the scientific sector (e.g., universities and research centers) are key in defining inclusive digital strategies in education and creating the conditions for their success (Vlies, 2020).

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6

INCLUSIVE METHODOLOGIES IN THE DIGITAL ENVIRONMENT

6.1. Contextualization

The school that wants to be inclusive, in the sense of responding to the diversity of students who attend its spaces, has an obligation to promote the use of pedagogical approaches and active and differentiated methodologies in its classrooms, so that students become involved in their learning itself. This way of thinking about school assumes that students learn better when they take an active role in their own learning (Bruner, 1996). That is, the participation of each student in the various learning activities of the curriculum, carried out in the context of the class, is a necessary condition for inclusion to take place. In this perspective, learning is understood as a socially contextualized process (Lave & Wenger, 1991; Wenger, 1998), carried out in interaction with peers and the teacher.

For this to happen, it is necessary that pedagogical practices become increasingly motivating for learning and more inclusive. It is important to make the transition from simultaneous teaching, centred on expository practices, to differentiated teaching, centred not only on the

curricular contents to be learned, but also on the means that allow students to learn, considering their potentialities and interests. Many of the classrooms we know are organized in rows of tables and chairs, with students sitting with their backs to each other, and the teacher facing the students. Underlying this organizational proposal is the idea that the teacher speaks, and the students listen, and that learning happens through transmission. At the school of the century XXI, we cannot perpetuate the transmissive pedagogy, and it is urgent to assume a participatory and interactive pedagogy, transforming the role of students and teachers, for

learning to happen in dialogue and interaction. In this transition process, digital technology is a pedagogical tool to support learning, with the potential to help transform educational contexts, making them more motivating and inclusive for students (UNESCO 2004; de la Garza, Zarate & Zermeño, 2019). But, as digital technology alone does not transform, the teacher will play a very important and fundamental role, as a member of the class with responsibility for organizing the classroom and pedagogical differentiation (Imbeau & Tomilson, 2011; Tomlinson, 2014).

In Table 1 we can identify two perspectives on learning, identifying the role of the teacher and the students and some conceptions associated with them.

	Learning Teacher Centered	Learning Student Centered
Class activity	Teacher centred	Student and class centred Interactive
Teacher's role	Knowledge transmitter Main source of information Holds the knowledge	Learning mediator Inclusive environments organizer Don't know everything
Student's role	Passive attitude Knowledge receiver	Interventional attitude Active participant
Learning conception	Individual activity Accumulation of contents Encyclopaedic knowledge	Activity carried out in interaction with peers Knowledge transformation
Use of digital technologies	Repetition and practice	Encourage cooperation. They are used to communicate and access information. Promote the game It is controlled by students
The planning	It is performed by the teacher Follow the manual	It is carried out by the teacher with the students
The evaluation	Testing is summative	Process documentation Multiple forms of assessment It is formative

Table 1. Teacher-centred learning and student-centred learning (adapted from UNESCO, 2004)

These two perspectives help us to identify types of teacher's pedagogical action and some of the activities associated with it. This does not mean that there cannot be exposure times, or that students must always be in interaction, or in group work. There is also a need for individual work supported by the teacher, as well as autonomous work by students and cooperative work in small groups (Niza, 1998). The important thing is to have pedagogical differentiation that breaks with masterful teaching. In an inclusive classroom, the organization of work can welcome all students, in their uniqueness.

Some pedagogical and methodological proposals are presented below to support the process of educational inclusion at school. They are action proposals for the organization of all students' learning, to be experimented and enhanced in the classroom context, by the teachers.

6.2. Learning through projects

Originating in the Progressive Education movement, in the USA, in the 1st and 2nd decade of the 20th century, project work is inscribed in the thinking of John Dewey, who defended an education based on experimentation, linked to life, having as a starting point the students' interest. This thought was later theorized by William Kilpatrick, a student of Dewey in his book "The Project Method" (Vasconcelos, 2011)

Vasconcelos (2011) recalls that project work is a pedagogical proposal of age transversality, which can be developed with children of various educational levels and is therefore suitable for "primary" education. Learning through projects is a dynamic and interactive process based on a basic structure that follows four key stages (Niza, 2005; Vasconcelos, 2011) (fig 17).

As can be seen in fig 17, it starts with identifying a problem, an interest, or a need, and then planning the project, usually in a table, organizing the known information, as well as the one you want to know. Then follows the development of the project, its execution, according to plan, with intermediate moments of balance. In the final phase, the project is socialized and evaluated. We now proceed to describe each of the phases in more detail.

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

Figure 17. Stages of Learning through projects (Niza, 2005; Vasconcelos, 2011)

Problem definition

It constitutes the starting point based on a student's interest in a curriculum content, or a teacher's proposal and begins with the formulation of a question, which will guide the following steps. In this step, several questions are produced about the problem that will help to better define what you want to know, do, or change. In this initial phase, students can be heard and participate in defining the problem. The prior knowledge of each student is considered and serves as a basis for raising hypotheses that will or will not be confirmed at the end of the project. It is a time to share ideas, to discuss possible ways to learn what matters. It is at this stage that the working groups are defined. There may be a question from a student that may be of interest to others. It should be noted that the teacher, as a member of the group, can also make suggestions for an investigation, an intervention or for the realization of a product. The teacher supports the explanation of ideas and gives opportunity for students to communicate their thoughts. Students' communication can be through speech and/or be supported by digital means of communication. There can be more than one study question at the same time, so there will be different projects running at the same time.

Project planning

It is a phase in which the project plan is registered, with negotiation and decision-making on what needs to be done to answer the question initially formulated (What are we going to do?) initial survey of students' knowledge on the subject to be learned (What do we already know?). It is also a temple for dividing tasks among the students in a group (who does what?), for choosing the means and resources to respond to the subject under study (How are we going to do it?) and for anticipating the proposal for socializing the learning accomplished (To whom are we going to communicate?), as well as the moment when this communication will occur (When). See Table 2.

What do we want to know?	What do we already know?	Who participates?	What do we do?	How are we going to do?
Teacher's feedback:		Submission date: ___ / ___ / ____	Content covered:	Products to build:

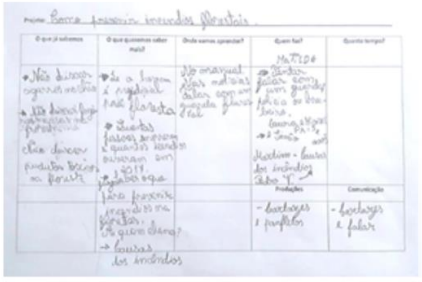
Table 2. Questions to be considered in project planning.

Development of the project

It takes place over a period to be defined in the class, depending on what needs to be done in relation to the scheduling of classes. This step involves research in various digital media and may involve the participation of families. Family participation can happen through research support or through sharing knowledge about the subject under study. During this period, it is very important that resources for research and production are appropriate for all students. The time to work on the project can be defined in the weekly agenda of the class. For example, you can define that the days to work on a project are Tuesday and Thursday in the morning. To accompany the development of the projects, the professor supports the groups of students in rotation, in order to give feedback, whether in the form of comments, or in the form of suggestions. The teacher assumes the role of guide, who supports and values learning, who lets students take risks without letting them fail, and supports the resolution of possible conflicts. A key aspect throughout the process is process documentation. This documentation can be done through written records, photographs, videos, audios.

Dissemination of the project

After finding the answers, multiple means of representation and communication are used to present the final product of the study or production. The project results are confronted with the prior knowledge registered in the first phase. To socialize the project, compilations of the process can be presented through digital resources. Learning can be shared in the form of games; film, posters, building a mural in Padlet, PowerPoint and others. The evaluation is carried out according to the criteria previously defined and explained in the class and participated by the children.



Example: from planification to socialization of the project

Project Work is thus a way of learning that invites and promotes the participation of students according to their abilities and calls for cooperative work. The teacher's role is to monitor and support the various stages of the process, with particular attention to the formation of groups. The advantages of project learning work are the following:

- Establishes links with students' prior knowledge, valuing them as a starting point for learning.
- Promotes peer interaction and cooperation.
- Promotes the participation of each student according to their abilities.
- Promotes questioning and critical thinking.
- Develop skills needed for life.
- It's a tool to learn how to learn.

Throughout the various phases of the projects, the use of digital tools is a means of research, but also of production and communication that can support written communication and access to content. It means that the teacher must guarantee the necessary adaptations to the students according to their singularities.

MODULE 5. ACTIVITY 3
PROJECT IN COOPERATION

Project work is an excellent approach to promote student engagement and participation. It involves co-operation and allows the use of various digital resources for learning, in an integrated way.

Cooperative learning implies group work, but not all group work is cooperative work. One of the basic conditions for group work to be cooperative is the establishment of positive interdependence among its members.

6.2.1. Types of projects

Projects can be typified according to the starting question about the problem (Folque, 2012), although in each type of project there is always research and production. In Table 3 we identified the 3 types of projects with identification of the starting questions:

Types of projects

"This project culture takes the act of educating to another paradigm: no longer the transmission of information without connection with what is experienced, but learning as a means of understanding and acting on everyday life, oriented towards solving problems and difficulties, provoking new and more intense questions to make us all (educators and students, animators and animators) more cultured and better citizens"

(Peças, 1999, p.58).

Table 3. Summary of three types of projects.

6.3. The Universal Design for Learning

The Universal Design for Learning (UDL) is an approach to curriculum, which considers the diversity of students in a class and seeks to support the pedagogical practice of teachers (Pereira et al, 2018). In this sense, the UDL is considered a proposal for the development of the inclusion process (Fuentes, Villoria & Almaraz, 2015; Pastor, 2019) that promotes the elimination of barriers to learning and student participation (Dolores, Campos, Canabal & Pastor, 2018). For this to happen, it is important that strategy planning is well designed according to the students' needs (Capp, 2017).

From the research produced in the field of neuroscience, technology, and learning theories, UDL has been gaining visibility in the field of education, since it offers proposals for educational action (Nunes & Madureira, 2015; Pastor, 2019) that can be used by teachers.

According to Pastor (2019), UDL derives from the initial proposal of Universal Design, a concept in the field of architecture, which proposes the design of products, equipment, and structures capable of serving all people, without the need for adaptations, and accessible to all people. It was in this perspective that, according to Pastor (2019), the UDL was extended to the educational area, and, at first, its orientation was more directed towards technology, in supporting children with special needs (Madureira & Nunes, 2015). Currently, A is assumed as a theoretical and practical proposal (Pastor, 2019) for all children considering their diverse abilities.

MODULE 1. ACTIVITY 5
USING THE 3 PRINCIPLES OF UDL

Not everyone learns in the same way, so if pupils are taught in the same way, then we are not being inclusive, and teaching will not be effective. In a class situation where the teacher uses only rote learning, repeating teaching content repeatedly, the teaching approach will probably only accommodate a small group of learners (those who prefer verbal learning). Other children might have more difficulties in following the lessons. When implementing UDL, the content of what you are teaching remains the same. Instead, there is a transformation in how you present the information facilitating learners' understanding. UDL can be use into any subject or integrated into pre-existing instructional plans through minor adjustments in approach.

This can be especially helpful for children with rare diseases and muscular dystrophies, but it is also helpful for all the children in the class. The advantage of using UDL in the classroom is that it will motivate learners to learn and take benefit of their different strengths.

The UDL is defined by a set of three principles (Cast, 2018)[1], represented in fig. 18:

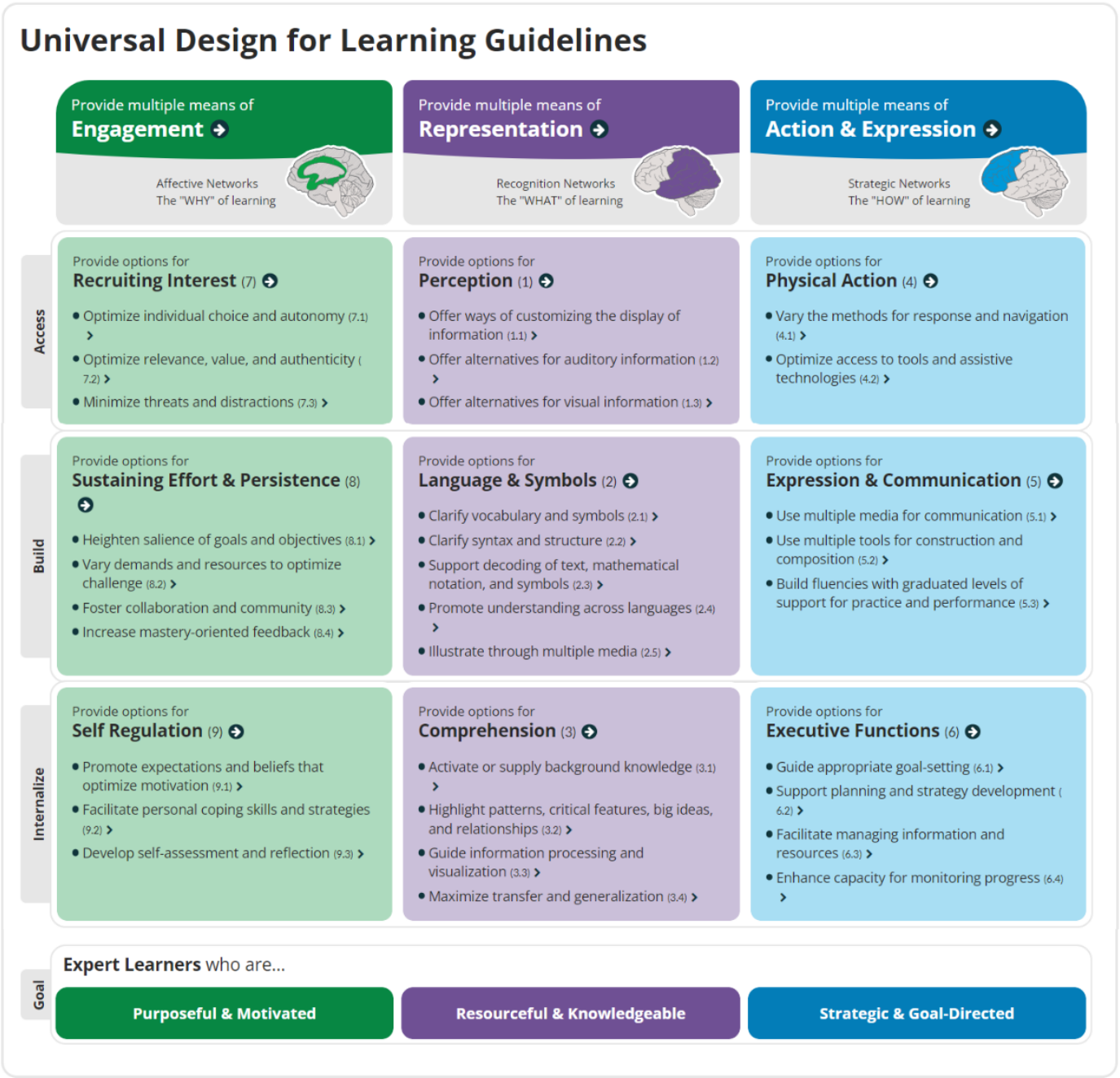


Figure 18. The Universal Design for Learning Guidelines (CAST, 2018)

[1] https://udlguidelines.cast.org/

PRINCIPLE OF INVOLVEMENT

The **principle of involvement** considers that students are not all interested in the same thing at the same time, that the same student's interests fluctuate according to the context, according to the knowledge he or she acquires. So, to promote the involvement of each student, the teacher needs to develop varied strategies that allow establishing connections with the students' interests. This principle is related to the motive of learning, in the sense of capturing the interest of each student. At the same time, it points out the need for support throughout the activities, until students are able to self-regulate (CAST, 2018).

PRINCIPLE OF REPRESENTATION

The **principle of representation** points out that there are differences in the way students perceive information, and that information is not always presented in different formats or media according to the needs of the students, which can be a barrier to learning. For the same information to be understood by everyone, it must have multiple forms of representation that meet different perceptions. CAST (2018) exemplifies with text that may need to be enlarged for the student with low vision to read, or with care in the use of symbolic language, such as mathematical signs and representations. Above all, it is about creating forms of representation that make it easier for students to understand.

PRINCIPLE OF ACTION AND EXPRESSION

The **principle of action and expression** considers that not all children express themselves in the same way, for a variety of reasons, and that therefore different ways of acting and expressing must be considered. To this end, it is important that learning support materials are appropriate and adapted to the various needs, and that assistive technologies can be used. It is also important to scaffold students at different levels of complexity during activities (CAST, 2018).

To carry out planning based on UDL principals, teachers can use a set of questions:

- What do I want students to learn?
- How can I present the activity in different ways and use previous knowledge to help the students make connections?
- What are my options for promote understanding?
- How can I promote guided participation?
- What activities will students do that create challenge, autonomy, and relevance?
- In what ways students can express information and what help do they need?
- What activities do student that allow them to practice and grow in real world situations?
- How will students do their self-assessment?
- How will I do the assessment and give feedback?
- Do the students know the goal means?
- Are my learners able to visualize and / or describe the desired outcome in their own words or in their own ways?
- How have I offered flexibility in how learners can demonstrate mastery of the intended goal?
- What barriers are removed by offering some flexibility in the means?
- Am I providing flexibility in other areas such as topic choice or choice of assistive tools?
- Does my assessment align with what I want students to know?
- Have I given opportunities for students to reflect on their learning experiences?
- Did I notice any barriers to attending the goals in my assessment materials, or methods?
- What will I change for the next time lesson?

6.4. Gamification in education

One of the great challenges in education is the ability to create motivating environments that encourage students' participation, dedication, and success in school. Unfortunately, students often consider traditional education methods boring and monotonous (Darina et al., 2015), negatively impacting learning. On the contrary, video/computer games are known to have characteristics (e.g., fun, challenge, graphics) that make them very popular among children and young people. Gamification, or game-based learning, seeks to import elements of games (e.g., mechanical, aesthetic, and thinking strategies) that make teaching activities more exciting and rewarding with the ultimate goal of facilitating students' acquisition of knowledge and skills (Darina et al., 2015; Ofosu-Ampong, 2020).

Klock and colleagues (2015) systematized the elements that characterize computer games and that can be considered in the process of gamification in education: narrative (storyline), rules, challenges, integration (of new users), reinforcement and feedback, achievements, points, performance levels, leaderboards (rankings), badges/distinctions, customization, and virtual goods (e.g., more powers for the game character). Points, rankings, and badges seem to be the most widely used elements of gamification in education, which does not necessarily mean that they are the most effective in supporting student learning (Ofosu-Ampong, 2020). For example, there is some discussion among education experts regarding the impact of using rankings in the educational context (Toda et al., 2018). For gamification to be successful, the construction and use of applications need to result from the collaboration of researchers, educators, designers, and software and programming experts (Lämsä et al., 2018; van Roy & Zaman, 2017). This dialogue is crucial so that technical, pedagogical, and curricular

aspects are considered simultaneously in gamification in education.

Overreliance on educational games on extrinsic motivation, through obtaining points, badges, or other virtual rewards, can compromise their long-term impact (Manzano-León et al., 2022). In line with self-determination theory, it has been pointed out that gamification achieves the best results when it supports the achievement of three basic human psychological needs, namely, autonomy, competence, and relatedness/connectedness (Deci & Ryan, 2000). In this sense, 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.

MODULE 5. ACTIVITY 1
PLAY ... WHAT IF I...?

Playing is a way of learning, and it can be carried out through make-believe. This is an activity to do with children to let them experience different ways of feeling the world. By being aware of the situation of another person we can adapt how we speak, move, what we say and how we act for a better communication and interaction.

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.

6.4.1 Gamification and inclusion

Gamification-based approaches have become increasingly popular in the field of special education. For example, a recent meta-analysis confirmed the benefits of game-based approaches on students with intellectual developmental disorder's motivation and academic skills (language and arithmetic) (Koh, 2022). In addition, for students with learning disabilities, it has been shown that gamification can aid in the development of reading and math skills (Lämsä et al., 2018).

Stone and colleagues (2019) demonstrated that gamification could help children with autism spectrum disorder improve their social skills. In this study, the authors used an ethnographic approach, concluding that multiplayer gaming (in this case, they used the game Minecraft®) promotes the online and offline social interactions (gestures, speech, and writing) of children with an autism spectrum disorder. Recently, another study reported the benefits of using games in language acquisition for children with hearing impairment (Chan et al., 2022). The authors pointed out that games appear most effective when coordinated with teacher instruction.

Gallud and colleagues (2021) conducted a systematic literature review on improving learning for children with special educational needs through technology and gamification, highlighting the following Intellectual Disability, Autism Spectrum Disorder, and Down Syndrome are the most studied developmental disorders; Microsoft Kinect® is the most used hardware platform; a significant diversity of software was found in the reviewed studies; cognitive and social skills have been the most studied; mathematics (e.g., numbers, geometric shapes, money management) and civic education are the most researched academic areas.

Several authors report that relatively little information is still available on the best design of games and the mechanisms responsible for their positive effect on student learning (Koh, 2022; Lämsä et al., 2018). In line with this, a recent literature review concluded that it is still unclear which technological tools and games are best for children with specific needs and which academic subjects are best suited for their use (Gallud et al., 2021).

MODULE 5. ACTIVITY 2
USING GAMING

Gamification offers numerous benefits for improving learning outcomes. By incorporating game elements into educational activities, gamification taps into children's natural inclination for play and engagement. It enhances motivation, making learning more enjoyable and encouraging active participation. Gamification also promotes critical thinking, problem-solving skills, and creativity...
This can be especially helpful for children with rare diseases and muscular dystrophies, but it is also helpful for all the children in the class.
The advantage of using UDL in the classroom is that it will motivate learners to learn and take benefit of their different strengths.

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7

COLLABORATIVE WORKING METHODS: PARENTS, TEACHERS, AND EXPERTS

7. Collaborative working methods: Parents, teachers, and experts

7.1. What collaboration means?

Collaboration refers to diverse people working together around common goals and values (Baragash et al., 2020). In educational inclusion, a collaborative team is characterized by sharing experiences, resources, knowledge, and responsibilities, facilitating the creation of effective and meaningful educational services for students with and without specific educational needs (Baragash et al., 2020).

In inclusive schools, teams are multidisciplinary and vary according to the characteristics of the students and the educational and social context. Depending on the composition of the teams, it may be necessary to coordinate the work/contribution of students, mainstream teachers, special education teachers, families, school principals, heads of scientific-pedagogical school bodies, psychologists, doctors, therapists, and others (e.g., physical and speech therapist) (Belzer et al., 2022). It is important to note that collaborating does not assume that all participants always agree. Instead, collaboration is a vehicle for sharing and discussion, where the confrontation of ideas and perspectives on issues allows for constructing new strategies and educational responses (Solone et al., 2020).

Several authors have sought to understand the key qualities needed to build healthy and effective collaborative environments. In their work on support and intervention services for people with disabilities (e.g., health, education, and social services), Gomes and McVilly (2019) identify prioritizing the well-being and development of recipients, establishing good communication among team members, effective leadership, professional commitment, and valuing collaborative activities as critical elements.

Figure 19. Important collaborative characteristics in educational inclusion. (Solone et al., 2020)

Solone et al. (2020) highlights some important collaborative characteristics in educational inclusion (see fig. 19)

7.2. Collaboration between regular education teachers and special education teachers

Collaboration between regular and special education teachers is one of the most studied pedagogical dimensions in inclusion contexts. Paulsrud and Nilholm (2020) conducted a literature review of qualitative research published between 2005 and 2019 on interprofessional cooperation between mainstream and special education teachers. The authors highlight two forms of collaboration, namely co-teaching and special education consultations. In co-teaching a special education teacher and a regular education teacher collaborate and teach children with and without special educational needs together in the same physical space (Paulsrud & Nilholm, 2020; van Hover et al., 2012). In turn, advising by special education teachers occurs when the special education teacher advises their mainstream colleagues about working with students with special education needs and/or helps them reflect on their practices to facilitate inclusive education.

Several models of co-teaching are identified in the literature (Paulsrud & Nilholm, 2020; van Hover et al., 2012) (see fig. 20)

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). However, co-teaching is also fraught with challenges, and the literature shows that its full potential is not always mobilized. For co-teaching to be effective, shared planning time, specific professional training, and personal compatibility are important, among other factors (European Agency, 2022; Scruggs et al., 2007).

The one-teacher, one-assist co-teaching model appears to be the most common in schools (Paulsrud & Nilholm, 2020; Scruggs et al., 2007; Strogilos et al., 2023). However, the effectiveness of this model has been the subject of discussion because of

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.

Figure 20. Models of co-teaching identified in the literature (Paulsrud & Nilholm, 2020; van Hover et al., 2012)

the risk of unequal responsibilities and authority distribution among teachers, causing feelings of undervaluation among special education teachers (Conderman & Liberty, 2018; van Hover et al., 2012). Also, for Paulsrud and Nilholm (2020), the one teacher, one assist model can relegate the special education teachers to the background in which they develop the activity peripherally with students with individual educational programs. Therefore, it is necessary to ensure that both teachers are viewed as equals by their peers and students. This can only be achieved when teachers collaborate in parity at multiple levels (including co-planning and co-teaching) and learn from each other (Conderman & Liberty, 2018).

Despite the above, it is essential to point out that studies are not unanimous as to the best model of co-teaching. A recent literature review found no robust evidence in favour of the effectiveness of either model (Iacono et al., 2021). In this review, the one-teacher, one-assist model and the team-teaching model were the most prevalent in schools. Another literature review found that co-teaching has been progressing from a very focused approach supporting students with special educational needs to one that targets all students, thereby facilitating whole-class learning (Strogilos et al., 2023).

7.3. Collaboration between school and parents/families

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). 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 (Haines, McCart, & Turnbull, 2013, cited by Francis et al., 2016).

MODULE 10. ACTIVITY 1
COMMUNICATION STRATEGIES

In recent decades, communication between educators and parents has largely shifted to digital systems. This allows us to save time and to establish new channels to share information However, it is necessary to implement some methods to ensure a successful and effective communication for both parties. Given the context of the child/student, communication must be constant and fluid.

Francis et al. (2016) conducted qualitative research in the context of inclusion on the factors that parents consider to underlie trust between families and educational professionals. Five themes were identified:

1. A strong school culture of inclusion.
2. Positive leadership (especially from school principals).
3. Positive relationships among stakeholders (highlighting attributes such as communication, respect, commitment, and professional competence).
4. Opportunities for family involvement.
5. Focus on achieving positive outcomes for all children.

Francis et al. (2016) choose inclusive school culture as the most salient and influential aspect in building positive partnerships between families and professionals. The inclusive school culture is leveraged by the actions of school principals through the adoption of a strong and effective leadership style, through their active involvement in the inclusive dimension of the school, and through the creation of high expectations of the positive impact of inclusion (European Agency, 2022; Francis et al., 2016).

Several studies point out difficulties that need to be addressed regarding collaboration between parents and schools. For example, parents often report disagreements in the design and implementation of their children's individual educational programs and a lack of consideration for their opinions (Tucker & Schwartz, 2013). In turn, in some studies, teachers report a lack of time and training to communicate with parents and the perception that parents are sometimes too involved in their children's education or, on the contrary, show too little interest (Bezdek et al., 2010). It is also noted that the language used in special education uses concepts, terminology, and acronyms that are not always easily understood by most parents (Solone et al., 2020).

MODULE 10. ACTIVITY 2
EMERGENCY PLAN

Given the context surrounding the young person affected by a rare disease, it is necessary to develop an action protocol that allows us to face any situation that may arise. Both parties must know all the details and be prepared to react to unforeseen events that may affect the child well-being.

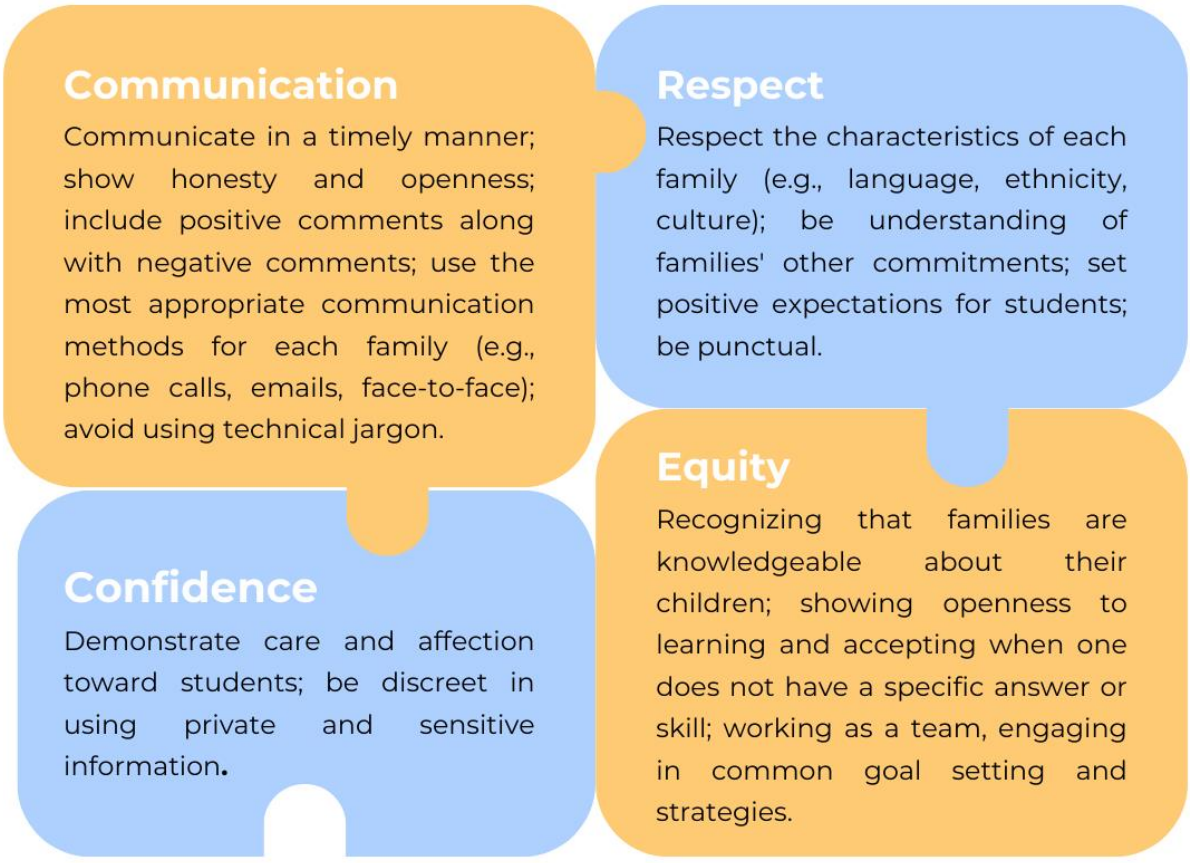

Figure 21. Good practices for teachers to adopt when interacting with parents or guardians, according to Solone (2020).

Solone et al. (2020) propose good practices to be adopted by teachers in their interaction with parents in four dimensions; communication, respect, trust, and equity (figure 21).

The importance of parent participation should have the right to participate and cooperate actively in the education of their child, particularly about measures to support learning and inclusion. Among others, parents or guardians should have the right to participate in the preparation and evaluation of the individual educational program, accede adequate and precise information concerning their children, and participate in multidisciplinary team meetings.

7.4. Digitalization and collaborative working

Digitalization and information and communication technologies can facilitate collaboration between professionals and between professionals and parents (Verger et al., 2021). Students with special educational needs, especially those

with more severe limitations, encounter many education and health professionals and services. Building specific mobile platforms (apps) can support communication and coordination between parents, school staff, and health professionals, including monitoring the measures and goals recommended in the Individualized Education Program. Syam and Abdallah (2022) used an app (IEP-Connect) to facilitate the coordination of activities related to learning and therapy for students with special educational needs, reporting good usability and satisfaction with the app. In turn, Mazon et al. (2022) describe the development process of an app, "ToGather", to facilitate communication and collaboration between education professionals, health professionals, and parents of children with an autism spectrum disorder. The app included various information about students' profiles (e.g., needs and talents), work meetings, students' progress in multiple domains (e.g., communication, autonomy, arithmetic, literacy), and effective educational strategies and activities. Several sections of the app were editable by team members, and a dedicated channel was created for message transmission between participants.

Another recent study (Newton & Williams, 2022) suggests that the use of the Instagram social platform – teacher community Teachergram, can stimulate collaboration and reflection among special education teachers and thereby promote their professional development. Despite these advantages, the authors also mention some specific precautions in the use of social platforms such as Instagram.

León-Nabal et al. (2021) examined the impact of a smartphone app on school-family interactions during the COVID-19 pandemic. The authors reported that most conversations conducted via the app were initiated by the school and pertained to classroom activities. The

advantages listed included the fact that the app allows direct and immediate communication, the stimulation of a closer relationship with parents, and the possibility of sharing various types of information - photos, videos, text, etc. The main disadvantages reported were the low usage of the app by some families and the difficulty in maintaining personalized interactions (León-Nabal et al., 2021).

7.5. Collaborative work in the educational response to rare diseases

A recent study conducted in Spain (Verger et al., 2021) investigated the impact of coordination between education professionals, health professionals, and parents on the inclusion of children and young people with rare diseases. The authors conducted several focus groups with the various professionals involved and with parents. The results confirmed that poor collaboration has a negative impact on the inclusion of students. Among other measures, the authors mention the need for improved cooperation between education and health services and the importance of teachers having access to cross-disciplinary training that gives them greater knowledge about specific aspects of rare diseases (Verger et al., 2021). Probably due to the fact that the available information on rare diseases is often scarce, the role of parents in providing teachers with information about their children's specific health conditions is highlighted. The difficulty in managing health care associated with rare diseases was also emphasized by Muntaner et al. (2014), who stress the importance of good communication and collaboration between schools and health centres on this type of disease.

MODULE 7. ACTIVITY 1
EXCLUSION, INTEGRATION AND INCLUSION

Among people there may be differences for which an individual or a group are "excluded" from society. There can be many reasons, such as race, gender, culture, religion and disability. Hence the need to promote inclusion. Inclusion, in the social sphere, means belonging to something and feeling welcome; eliminating any form of discrimination, but always with respect for diversity.

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8

INDIVIDUAL CURRICULAR ADAPTATIONS AND PEDAGOGICAL DIFFERENTIATION

8. Individual curricular adaptations and pedagogical differentiation

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.

MODULE 4. ACTIVITY 3
INCLUSIVE SCHOOL ENVIRONMENT

Usually the school context is oriented towards the community. For this reason it is essential to bring out and recognize the needs and specificities of the individual in order to promote and encourage integration. If the individual has needs that are specific of their condition, the challenge is even greater. With this activity we want to outline all the key elements to break down school architectural barriers and to encourage the inclusion of children with neuromuscular pathologies with reduced mobility.

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.

Figure 22. Some examples of common learning support measures.

Adaptations can be based on UDL considering different learning styles, but also based on pedagogical differentiation. The specific measures implemented may vary depending on the educational context, the student's needs, and available resources. The goal is to provide students with the support they require to thrive academically and reach their full potential.

8.1. Pedagogical differentiation

According to Roy, Guay, and Valois (2013) Pedagogical differentiation is an approach whereby the teacher introduces variations in the way learning is organised, adapting it to match learners' competences, through systematic procedures for monitoring learning. Pedagogical differentiation or differentiated instruction involves adapting teaching methods, materials, and assessments, including whole class, small group and individual arrangements, and where teachers use time, space, materials, and instructional strategies in flexible ways to address varied learner needs' (Tomlinson, 2005). It comprises modifying the process, content, product, (Tomlinson and Allan, 2002) and educational environment (Tomlinson, 2014) to ensure that all students can access and engage with the curriculum effectively (figure 23).

Teachers may differentiate according to pupils' needs or characteristics, as pupils differ with regard to their interest in activities or topics, their learning profiles, which may be influenced by learning style and group and context preferences.

MODULE 7. ACTIVITY 3
ASKING FOR HELP

In this activity we want to deal with and address the issue of help which involves different variables, such as having to ask for help, receive help and help someone else with relevant and significant emotional implications. There is no specific time to ask for help, however it is defined by each of us's specific limitations and resources.

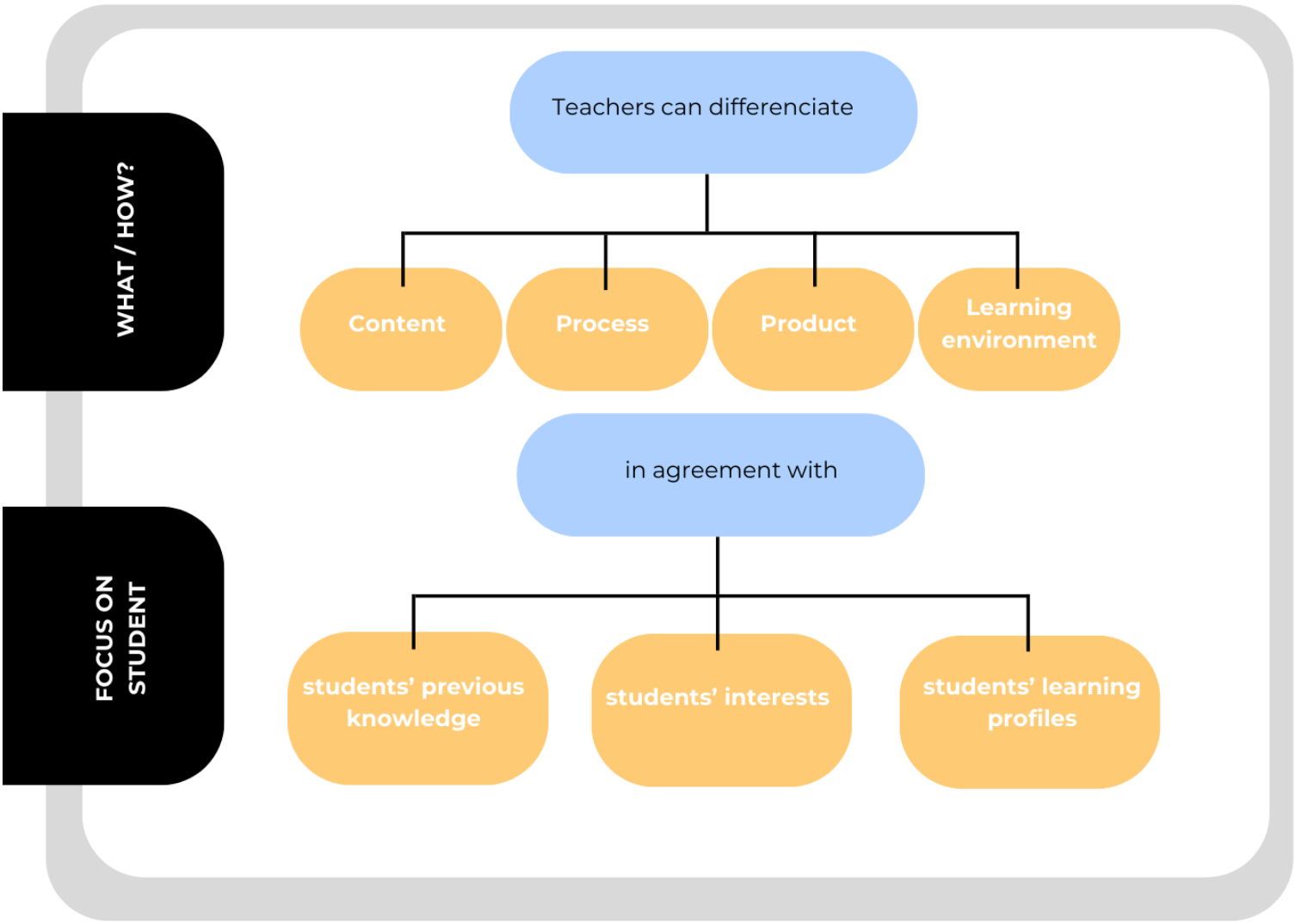

Figure 23. Pedagogical differentiation scheme.

CONTENT

It refers to the concepts, principles, and skills that teachers want pupils to learn. For Tomlinson and Allan (2002), all pupils should have access to the same core content and pupils with difficulties should be taught the same big ideas as their peers, not alternative content. Content also refers to the tools that teachers use to support learners' skills and knowledge, such as texts, demonstrations and field trips. By differentiating the content, teachers accommodate students with different readiness levels, enabling them to deepen their understanding and engage in meaningful learning experiences.

- What does the teacher want pupils to learn according to the curriculum?
- How do pupils access the knowledge, understanding and skills required?

PROCESS

Process refers to the activities that help learners understand and take ownership of the ideas and skills being learned. Teachers can modify these activities, differentiating them to present them in more or less complex ways, depending on the learners.Like the content, the process can be varied according to learners' interests and learning preferences (Tomlinson and Allan, 2002). By differentiating the process, teachers provide students with various ways to learn and demonstrate understanding, allowing them to progress at their own pace and in ways that align with their learning styles.

- Which type of organisation is most conducive to a particular pupil's learning?Working in pairs? Individual work?

PRODUCT

The product is about how learners demonstrate what they know, understand and are able to do after a long period of continuous learning. A product is not something that learners produce in a single lesson or as a result. It implies that learners can communicate their learning in various ways and transfer that learning to the social context in which they participate (Tomlinson and Allan, 2002). Formative assessment through portfolios can be an example. A good product allows students to: apply what they can do; extended their understanding and skill; became involved in critical and creative thinking; reflect about they have learned.

LEARNING ENVIRONMENT

Learning environment:Is the 'atmosphere' of a classroom. It includes the physical layout of the classroom, as well as the interactions between the students and the teacher, class rules, routines, furniture, procedures and processes that support learning. The differentiated learning environment is characterised by flexibility (space, materials and time) and is carefully constructed to support the need of each learner (Santangelo & Tomlinson,2012). When pupils are aware of the classroom rules and their roles in the class, as well as knowing the routine to be able to anticipate what will happen next, their learning is facilitated.

When a teacher differentiates, there are 3 factors to consider individually or together (Tomlinson & Allan, 2002):

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.

In this perspective, the student is considered as the agent of their learning process and the teacher assumes the role of mediator, making available to the students a set of differentiated proposals at the service of learning. This proposal differs from traditional teaching in several aspects identified in the table 4.

Subject and actor	changing from	to
Teacher's role	Knowledge transmitter; main source of information; content expert; source of all answers	Learning facilitator Collaborator; tutor, participating guide in the learning process
	The teacher controls and directs all aspects of learning	The teacher enables the learner to be more responsible for their own learning and offers them a variety of oprtions for studying
Role of the student	Passive receiver of information	Active participant in the learning process
	Knowledge recipient	The learner generates and shares knowledge, sometimes participating as an expert
	Learning is seen as an individual activity	Learning is seen as an individual activity

Table 4. Changing roles of teachers and learners in learner-centred learning environments (Adapted from Newby et al. 2000 in UNESCO 2004, p.28)

In this sense:

Teacher acts as a guide in pupils' learning and learners are active participants in the teaching-learning process and the relationship between the teacher and the learner is more horizontal.

Assessment is done by using the knowledge acquired and internalised by learners through their use and experimentation in a formative assessment process.

The knowledge is understood as plural and capable of being complemented and extended.

The type of reasoning most used with this methodological tool is induction.

Practice and theory are interrelated in a praxeological perspective, and both are considered as bases of knowledge, in dialogue.

Knowledge should be acquired considering the learners' context and their prior knowledge. It allows for dynamism, creativity and interaction of the resources used as well as the intrinsic motivation of the pupils.

Digital resources are used in view of the current social reality and learners are not only exposed to the content, but they can create it, thus extending the real educational world.

Learning opportunities are extended and there is an adaptation to the difficulties presented by the pupils, and co-operative working structures prevail.

The development of social competences such as collaboration, interpersonal relationships and negotiation play a key role, contributing to the acquisition of lasting learning.

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facing SCHOOL

9

RECOMMENDATIONS TO BUILD INCLUSIVE SCHOOLS

9. Recommendations to build inclusive schools

Creating inclusive environments in schools is crucial to ensure educational success and well-being for all students, especially those with rare diseases and muscular dystrophies. Leaders at all levels, including administrators, teachers, healthcare professionals, and parents, have an extraordinarily relevant role in promoting inclusion in educational settings. Effective leadership is essential to foster inclusive practices. School leaders

should develop a vision of inclusion, create policies and structures that support diverse students, and promote a positive school culture that values inclusion (Ainscow & Miles, 2008; Carter & Abawi, 2018). Similarly, middle leaders, such as coordinators/department heads, also play a relevant role in creating a culture of inclusion by actively collaborating with teachers and advocating for inclusive policies and practices within their departments or areas of responsibility. Other healthcare professionals, such as school nurses or therapists, also have a significant role in promoting the health and well-being of students. They should provide appropriate support and intervention in collaboration with teachers, parents, and other stakeholders to meet the

MODULE 7. ACTIVITY 5
CONCEPT OF IDENTITY

The concept of personal identity is fundamental for students. By the term identity we mean the complex of characteristics that distinguish one person from another, that make us unique and unmistakable and, at the same time, different from others. The important thing is that self-recognition, and hetero-recognition can coincide totally, or at least partially. For children, the concern about being recognized is immediate; the younger they are, the more unstructured and still forming their identity, and therefore they constantly need confirmation, a process that contributes to the formation of their own identity.

unique needs of students with rare diseases and muscular dystrophies.

Educational resource centres also play a significant role in promoting inclusive education for these students (Šiška, Bekele, Beadle-Brown, & Záhořík, 2019). They should provide specialized resources, training, and expertise for educators, enabling them to create inclusive learning environments and implement effective strategies for students with diverse needs. Lastly, the importance of effective collaboration between parents and schools should be emphasized. Parents should actively engage with teachers and school leaders, communicate the needs and abilities of their children, and participate in decision-making processes to ensure an inclusive and supportive educational environment. Clear communication between home and school is vital for children with muscular dystrophy (Muscular Dystrophy UK, 2016, p.9). School personnel, especially those working closely with the student, should work collaboratively with parents (Sandberg & Ottosson, 2010) to ensure that the messages they wish to convey to the students are clear.

MODULE 7. ACTIVITY 2
INDIVIDUAL DIVERSITY

In this activity we want to deal with and address the theme of equality and diversity, which should never be confused with difference. The assumption from which to start talking about diversity and equality is that people are all equal, that is, they all have the same rights that cannot be questioned. Once this basic principle has been defined, it must also be said that the uniqueness of the individual must be respected. Being the same does not mean looking alike, thinking, speaking, dressing and behaving all in the same way. It is important to dedicate an adequate treatment for the conditions of each one, taking into account the real differences between people, in this way the tangible factors of diversity are understood, and equality is pursued as a right. Equality is inclusive and includes within itself the various diversities and respect for the person.

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.

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.

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.

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.

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.

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10

THE IMPORTANCE OF BEING ADVISED BY EXPERTS

10. The importance of beign advised by experts

To ensure that students with muscular dystrophy and rare diseases are well accommodated and can fully participate in school life, it is essential for principals (Pivik, McComas, & Laflamme, 2002), teachers, and parents to receive guidance from experts, such as external healthcare professionals and special education teachers (Muscular Dystrophy UK, 2016).

It is important for schools to be familiar with the variety of healthcare services and external organizations in the region where they operate and to have procedures/protocols in place to communicate with them to optimize the quality of interventions for these students, whether at an individual, small group, or whole-school level. This is particularly relevant for students with more significant and permanent needs, who benefit from a multidisciplinary approach to identifying their needs and developing interventions.

There are several arguments justifying the counseling of educational stakeholders by specialists, including a better understanding of students' specific needs, the development of effective inclusion strategies, the promotion of accessibility and equal opportunities, and proper management of health and well-being challenges.

MODULE 8. ACTIVITY 5
MENTAL HEALTH ROUTINE

Living with a degenerative long-term medical condition is associated with heightened risk for mental health and psychosocial difficulties. In these cases, the most advisable thing to do is to contact a specialist who will study the case of the young person and apply a personalized treatment. In the following activity we propose a series of exercises and activities that will benefit the mental health of the young person.

Specialists in muscular dystrophy and rare diseases possess in-depth knowledge about these conditions, their characteristics, and the challenges that can impact students' lives. By receiving guidance from these specialists, principals, teachers, and parents can better understand the students' specific needs, such as environmental adaptations and appropriate emotional and pedagogical support.

Experts can also provide valuable insights into effective educational strategies and practices for these students. They can guide education professionals in adapting the curriculum, providing individualized support, utilizing assistive technologies, and promoting active student participation, ensuring equal access to education. In this regard, expert guidance enables principals, teachers, and parents to identify barriers to inclusion and work towards removing them.

Specialists can also provide guidance on making the physical and digital school environment more accessible, as well as on available resources and supports to ensure all students have equal learning opportunities.

Specifically, the actions of specialists can be relevant in the following ways:

MODULE 9. ACTIVITY 3
SHARED DECISION MAKING

Stress, uncertainty or lack of sleep can generate tensions in the family environment. There are some methodologies that allow us to manage such situations. In this activity we propose a series of these methodologies that can help you when making complex decisions for the benefit of your child.

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.

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11

CONCLUSIONS AND RECOMMENDATIONS FOR THE FUTURE

11. Conclusions and recommendations for the future

Inclusion and accessibility are still a challenge for people affected by rare diseases, which society must address, especially after the impact of the Covid-19 pandemic and the digital transformation of the educational environment. Suffering from a rare disease, in addition to the specific circumstances of each pathology, entails numerous problems as highlighted throughout the text. Therefore, the partnership aimed to facilitate the schooling process through tools that promote inclusion and accessibility. In line with the Universal Declaration of Human Rights by the United Nations, the consortium of the Erasmus+ project "THE VALUE OF FACING SCHOOL" understands that all individuals, regardless of their health status, should enjoy equitable and quality education. Firstly, because education is necessary for intellectual and personal development. And secondly, because through education, individuals acquire knowledge, skills, and competencies that prepare them to overcome challenges and benefit from opportunities that may arise in their lives.

With the aim of contributing to ending this problem, in this guide, we have provided rigorous information on the origin and consequences of these pathologies. Furthermore, we have identified the main needs of affected individuals and their families. Regarding the school environment, we have been able to provide methodological guidelines, curricular adaptations, and evaluation mechanisms adapted to the reality of the students, which we understand will act in favour of a more inclusive education. We believe that by implementing the necessary tools, adaptations, and support mechanisms, we will ensure that these students receive comprehensive education that meets their specific needs and promotes their academic and personal growth.

However, we are aware that the implementation of such practices sometimes requires additional resources and services, the absence of which may hinder the full inclusion of students with specific needs.-Likewise, we understand that the lack of training and awareness among teachers and professionals in the educational environment can hinder the implementation of quality inclusive education responses. For this reason, various social and political actors must promote new tools that support accessibility and inclusion in the educational context. Likewise, effective

models of teacher preparation and ongoing professional development programs that equip educators with the necessary knowledge, skills, and attitudes to support and respond to the diversity of diverse students in classrooms should be encouraged.

Simultaneously, society must make an effort for real change to occur. Inclusive education is not solely the responsibility of schools but also requires collaboration with families, communities, and relevant stakeholders. Schools must explore new strategies to enhance the involvement of parents, families, and community members in supporting inclusive education initiatives. For this purpose, it is necessary to research, implement, and evaluate effective collaboration models between schools and communities.

Regarding digital transformation, it is essential to create a learning environment that guarantees complete accessibility to educational materials and platforms. We must understand technology as a tool that allows us to promote accessibility and inclusion in schools, through the use of assistive technologies and personalized educational materials adapted to the needs of students.

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.

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Co-funded by
the European Union