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INCLUSIVE EDUCATION OF CHILDREN WITH RARE DISEASES. THE CREDIBLE PROJECT

Oscar R. Lozano[1], Eirini Tzovla[2]
[1] University of Valencia (Spain)
[2] 4th Primary School of Pefki (Greece)

ABSTRACT

Inclusive education is one of the pillars on which educational policies are based, both in the European Union and in global organizations such as UNESCO. As a result of these guidelines set by these institutions, much progress has been made in general, especially in certain types of disability, gender issues or migration issues, but many sectors of the population still feel "excluded" from the educational system, such as the case of children with rare diseases. Based on these premises, ten organizations from five different countries join forces under the umbrella of the Erasmus+ program in its key action K201, materializing these efforts in the CREDIBLE project (*Children with rare diseases and their inclusion in basic learning environments*). The objectives of the project coincide with those mentioned but, in addition, focusing on teacher training. Providing teachers with tools to carry out an effective educational inclusion of children with rare diseases is essential to achieve successful educational practices and raise awareness among the population. This project offers the creation of three intellectual outputs oriented to this purpose. The first of them is a platform for exchanging cases in which, teachers who have faced this challenge can share their experiences with other teachers who are beginning this path. The second is a self-training course for teachers (MOOC type) in which methodologies and tools are offered for this goal. The third is a pedagogical-health guide of the most prevalent rare diseases and grouped in such a way that the guide can be useful for other diseases with similar pathologies. The project, which began in 2019, and with the difficulties caused by the COVID 19 pandemic, will culminate in August 2022, with a final act in Glasgow in which the final results will be presented.

Keywords: *Inclusive education, rare diseases, Erasmus+, teacher training.*

Introduction. Theoretical framework

The universal right to education has led educational systems towards inclusive practices, adapting the system to the child and not that of the child to the system. This adaptation must take into account all the differences: gender, age, language, ethnicity, health situation, socioeconomic position, disability, etc. when developing the educational process and the appropriate learning environments.

We can find numerous studies and researches about the educational inclusion of ethnic and linguistic minorities, focused on gender bias, or students with unfavorable socioeconomic circumstances. In health aspects, great advances have also been made in the educational inclusion of children with disabilities derived from prevalent diseases. However, given the apparent low impact of “rare diseases”, inclusive educational practices of this community has been little developed. The supposed low social impact due to the low percentage of presence implicit in the definition of “rare diseases”, as well as the multitude of pathologies associated with the term “rare”, has meant that these children have been practically ignored by the “inclusive education”.

In this term, the role of the teachers is important, because they often are called to meet the above needs without having the necessary knowledge. For this reason, the creation of targeted professional development programs is required. These programs are a fundamental element of quality education and are related to the teacher’s role, professional identity, self-confidence, self-efficacy, and can affect the quality of teaching and learning outcomes.

The project CREDIBLE aims to take a step forward from innovation, to serve as a reference for the improvement of inclusive practices and as a starting point for research work as well. Under the umbrella of the Erasmus+ program, several European organizations work together to address this gap, contributing to teachers’ professional development, improving their inclusive skills and increasing the visibility of rare diseases educational issues.

In recent years there has been intense discussion about the right to education and the need for inclusive practices. In this frame, the aim is to create appropriate educational environments, which promote the participation and inclusive education of all students, not only those who have been diagnosed as children with special educational needs but also those who for social, economic, racial, religious, health or other reasons cause, have been marginalized. These environments aim at the inclusion of all the above students and the satisfaction of their needs within the school unit they attend (OFSTED, 2003). It is a continuous and dynamic process, which aims at individual and collective development and progress and has a wider scope. It comes because of the interest in educating people with disabilities, as a response to the principle of exclusion about all groups considered vulnerable, as a philosophy of education for all, and, as an approach to education and society (Ainscow et al., 2006).

Inclusion is a way of thinking, it takes place in a context of genuine interest in fellow human beings and when integrated as a non-negotiable practice in the school environment, it can bring substantial results. It aims at an inclusive society that enables everyone to participate in its activities (Gafoor, 2010) and requires the acceptance of the different, the design of individualized curricula, and the strengthening of school-family relations. The inclusive school offers equal opportunities for learning and participation in the educational process of all students, seeks to sensitize all members of the school community to the individual peculiarities of its members, and utilizes these peculiarities as a wealth of experiences. Inclusion is an issue that has preoccupied most countries in recent years. The trend in the various countries of the European Union is to include children with special needs in general schools by providing teachers with various forms of support in terms of staff, materials, and equipment.

Inclusive education reflects the principle of equality for all students towards opportunities and promotes the reduction of barriers to learning (Booth & Ainscow, 1998). However, little reference is made to inclusive practices for children suffering from rare diseases and these seem to be ignored in inclusive education (Molster et al., 2016). Probably because the word "rare" refers to a small percentage of sufferers. However, a disease, in Europe, is rarely characterized when it occurs in less than 1 in 2,000 people and there are currently an estimated 6,000–8,000 rare diseases affecting around 30 million Europeans and 300 million people worldwide (Nguengang Wakap et al., 2020). Rare diseases are characterized by a wide variety of disorders and symptoms that vary not only from disease to disease but also from patient to patient with the same disease. Relatively common symptoms can hide rare diseases with the result that patients, quite often, receive misdiagnosis, or even remain undiagnosed for years, experiencing a "Diagnostic Odyssey", which can last from 5 to 30 years (Black et al. 2015).

According to EURORDIS (n. d.) rare diseases are chronic, degenerative, and often life-threatening. They cause disabilities, thus affecting the quality of life of patients. 70% of them infect children, with 30% of these children dying by the age of 5 years. 72% are genetic in nature, while the rest are the result of infections, allergies, or environmental causes. For 95% there is no treatment. These patients are reported to have unequal access to treatment, inadequate and poor-quality medical care, and inadequate information, and support (Molster et al., 2016). It is therefore proposed to develop specific health policies, strengthen policies for international scientific and research cooperation, inform and raise public awareness about these diseases, network patients and their families to share experiences and best practices, provide validly, reliable, and comprehensive information and the support of these patients in the school context (Taruscio, 2020) by adequately informed and trained teachers.

Students suffering from rare diseases need support both in the learning context and at the psychological level. In addition to the health problems they face, they often experience rejection by the wider school community and often frustration with any effort they make. In this frame, they need support from both teachers and their classmates, to integrate into the educational process, meet their learning needs, and achieve school performance (Bailey, 1998).

However, the question is whether the educational community is sufficiently prepared, aware, and trained to support these students and their families with inclusive pedagogical practices, methodologies, and strategies and to enhance their self-esteem and self-confidence. In addition, other students need support to accept students with rare diseases as equal members of the educational community (Armstrong & Barton, 2007). Research (Lartec et al., 2015; Majoko, 2019) advocates that the role of the teacher in this issue is crucial. For this reason, the creation of targeted professional development programs is required. These programs are a fundamental element of quality education and are related to the teacher's role, professional identity, self-confidence, and self-efficacy, and can affect the quality of teaching and learning outcomes.

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Some reports on the current situation of children with rare diseases coincide in the weak points of the educational system when it comes to responding to this group (FEDER, 2013, Galende, 2014). Many complaints focus on the scant attention that children are receiving from teachers, who in some cases even refuse to teach their subjects. 73% of the associations express dissatisfaction with the educative inclusion in the pre-compulsory and post-compulsory stages. The problem in the educational environment occurs at different levels, causing a domino effect. Beginning with an ignorance and social incomprehension, which implies indifference from the administrations and is clear taking into account the absence of appropriate resources available to students. Both levels can be harmful to the participation of teachers and families and, in turn, results in discrimination and rejection in the classroom. All this falls on children, affecting their development. The training of teachers and the exchange of information and experiences, together with coordinated intervention with parent associations, are some of the proposed instruments to ensure that the school stage can integrate and empower children with rare diseases to projecting them towards a better social and working future. In these reports, the development and dissemination of educational guides for teaching staff is also proposed, indicating what attention the child and adolescent population will require in certain specific situations.

Methodology. The CREDIBLE project

The Erasmus+ program has inclusive education among its horizontal priorities, encouraging National Agencies to support proposals in this direction. (Erasmus, n. d.). Its key action KA201 supports strategic partnerships for educational innovation. In the 2019 call, ten organizations from five different countries came together to improve the educational inclusion of children with rare diseases. Thus, three schools, *CEIP Félix Rodríguez de la Fuente* (Spain), *4th Primary School of Pefki* (Greece) and *Ashton Secondary School* (United Kingdom), two governmental educational institutions, *Glasgow City Council* and *Valencia Ministry of Education*, two NGOs dedicated on patients with rare diseases, *FEDER* (Spain) and *RONARD* (Romania), an IT company focused on the development of digital platforms, *Softspring* and two universities, the *University of Latvia* and the *University of Valencia* (the latter acting as coordinator of the consortium) have been working in this direction since the beginning of the project.

In accordance with the requirements of the program, various activities and intellectual outputs are developed within the framework of this collaboration. Through collaborative work facilitated by transnational face-to-face meetings and constant virtual communication, three deliverables have been developed. Similarly, three multiplier events support the dissemination of results.

The main intellectual output is a platform for sharing cases. The experience that a teachers accumulate in the face of the challenge of carrying out an effective educational inclusion of some student with a rare disease, in most cases is lost. The fact that these diseases are so rare makes it difficult for these teachers to share their knowledge acquired in teaching practice with other colleagues facing the same challenge. Thus, the platform provides support so that any teacher, no matter how far away they are from another teacher with the same challenge to face, can share the experience uploading it in a standardized format that includes basic data such as illness, age or educational level, the problems faced and the successful responses that worked for them in classroom. In the same way, another teacher who wants to search for information on the platform can create an oriented search of cases that coincide or are similar to the one is facing. It is offered the advice of colleagues and the possibility of contacting them. Data protection is guaranteed at all times and the identity of those involved, both teachers and students, is preserved.

Platform search parameters include:

- Search by disease. The platform supports disease names, preferably in English, but can also recognize other languages. The ideal search method is through the code assigned to the disease in the Orphanet list (n. d.)
- Search by main problem associated. In this case they are grouped into: Nutrition, Mobility, Non discrimination, Bullying, Adapting teaching/Evaluation methods, Accessibility, Using medication – medical equipment during school time, Protocols for emergency situation and Behavior. Once these parameters have been entered, the platform allows a refined search to be carried out by age range (adapted to educational levels) or by country.

Once inside the case, the platform shows a summary and the possibility to expand it and see the implications in the other search elements (behavior, mobility, etc.). By registering, it is possible to send a message to the author of the case (identities remain in the anonymous unless both of them decide otherwise). There are also general tips and all the information that the teacher author wants to offer.

The platform requires the supervision of administrators who verify that the case is real, that it does not contain offensive language, personal data, etc.

The second intellectual product is a MOOC type self-training course for teachers. This course includes the operation of the platform, and a transfer of knowledge gather from the few investigations carried out in the current state of art. This knowledge is adapted in the form of useful tools and techniques to develop their inclusive work in the classroom with this type of student. The teacher training course is based on the research carried out to date as well as input from all partners, patient associations, experts, etc. The basis of the online self-training course is founded on a course developed face to face in which the resource was tested by teachers and the rest of the consortium. Its basic components are information about educational inclusion in general, the characteristics of the group of people with rare diseases, the health aspects that must be taken into account in the inclusion of children with rare diseases, collaboration with health teams, methodologies teaching aimed at promoting the awareness of classmates and families, description of the usual problems that the teacher faces in the inclusion of children with rare diseases, strategies to control the classroom climate, etc. The course will be available in English as a starting point, and will likely be supported by government platforms that facilitate translation of included materials upon request (such as Scientix, nd.)

Finally, a pedagogical-health guide collects useful information for teachers on 50 rare diseases (the most prevalent) structured through the appropriate health-educational duality. The union of these two worlds, apparently unconnected, materializes through the joint contribution of experts in both fields, including in each disease different interesting points of view. The educational-health guide includes the following aspects:

- Description of the disease. Brief description of the most outstanding characteristics of the treated disease.
- Main organs or systems affected.
- Other organs or systems frequently affected.
- Potential issues in the classroom and recommended strategies.
- Pedagogical adaptation. Vital information for the teacher and based on the experience of the institutions in charge of preparing the guide within the project.
- Space adaptation – ergonomic. On many occasions they are essential to achieve effective educational inclusion.
- Environmental Adaptation. These include adaptations, light, sound, etc.
- Accessibility.
- Inclusive strategies. Specific guidelines to achieve effective inclusion beyond the student himself, involving the entire educational community.
- Therapeutic support in the absence of a school nurse. The support of a nurse is not always available and it is the teacher who has to assume small responsibilities in this regard.
- Potential emergencies and actions. In many cases, you have to act quickly in emergency or first aid situations.
- Relevant bibliography.
- Summary table of actions and recommendations.

To disseminate these products, countless actions are carried out. The project's own website (CREDIBLE, n. d.) and three multiplier events held in Romania, Spain and the United Kingdom with the support of authorities with media influence (such as the Spanish Royal House) guarantee that the results of the project are known by the educational community.

Results and conclusion

The results of the project should be understood as a task of transferring research to the educational actual practice. The innovative result is reflected in the interest shown by numerous associations of patients with rare diseases. The incorporation of specific measures, of specific tools placed at the service of teachers is the value of this initiative. Educational policies require concrete actions that facilitate their real application in the classroom, and the CREDIBLE project makes three tools available to teachers to be able to carry out this task. At the time of making this presentation, the project is still alive, and its results are incipient. In all cases, time will confirm the usefulness of the intellectual products developed, although preliminary impressions are very encouraging, since patient associations throughout Europe are taking an interest in them to provide them to teachers. The families of children with rare diseases are the main driver of change in this regard and, in general terms, they are the ones who encourage and collaborate with teachers in the implementation of truly inclusive methodologies. The interest in the project shown by EURORDIS, means that future success is quite guaranteed. However, such success is something that only the future will reveal.

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