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The Inclusion of Students with Chronic Diseases in Regular Schools

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Abstract

This study is guided by the principles of inclusive education; it focuses on students with chronic diseases and considered a vulnerable group within the educational system. The objective of this study is to identify needs relating to these students and facilitate the implementation of proposals to improve schools.

The study methodology is qualitative. In particular, two data collection techniques are employed: discussion groups and interviews with teachers, families, health personnel, and students. The results are presented in accordance with the categorisation of the transcripts for each group.

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1. Introduction

Inclusive education is grounded upon two key principles. The first is respect for group heterogeneity and the consequent lack of categorisation of students. The second principle is avoiding segregation and discrimination against the most vulnerable, by promoting the participation of all students in all activities, including learning activities, thereby combating exclusion in education.

Inclusive education is not simply a trend; instead, it is a necessity for adequately and coherently responding to the diverse realities found in classrooms and 21st-century societies. Inclusive education has the objective of equitably offering quality education for all. Ainscow (2003) notes that inclusion is a key educational element that refers to processes in which particular attention is devoted to groups of students who are at risk of becoming marginalised or excluded and/or achieving suboptimal performances; in other words, inclusion seeks to assist vulnerable student groups.

Our study focuses on a group of students with chronic diseases attending regular schools and classrooms. This group is extremely heterogeneous, in terms of diverse characteristics and needs. The common characteristic shared is their disease, which influences and determines their educational experiences. In accordance with the definition provided by the World Health Organization (WHO), we regard chronic diseases to be “diseases of long duration and generally slow progression”.

In the context of children, chronic diseases are diseases with prolonged durations that seriously disrupt a child’s normal life and require time-intensive treatment by a paediatrician. The current lower limit for a disease to be considered chronic is approximately 12 months, although certain clinicians consider diseases lasting at least 3 months to be chronic diseases. When a prolonged disease appears in a school-aged child, the affected student can fall greatly behind even before 3 months have elapsed if adequate actions are not taken. A child who experiences long and repeated hospitalisations due to a chronic disease exhibits physical, mental, and psychological characteristics during the disease’s appearance, course, and treatment that produce upsetting situations that affect medical, psychological, social, familial, and educational considerations (Fernández Hawrylak, 2002; 71).

Legislative and/or normative bases for educational services for students with chronic diseases do not exist at the international, national, and autonomous levels. Educational services in hospitals are regulated even in cases involving students who cannot attend school due to disease (LISMI - Ley de Integración Social de los Minusválidos [Law for the Social Integration of Disabled Individuals] 13/1982 (April 7), third section, article 29; Royal Decree 696/1995 (April 28); Royal Decree 299/1996 (February 28)). However, to obtain explicit references to students with chronic diseases in schools, we must refer to texts and general regulations that defend the rights of the entire population without specifying the group with which we are concerned (Royal Decree 334/1985 (March 6), first article; LOE: Ley Orgánica de Educación [Organic Law of Education] 2/2006 (May 3), chapter 1, article 1).

The two factors of inclusive education -as a general and fundamental basis for action and a specific interest in vulnerable students in the regular education system- are incorporated into the objective of our study, which is to determine the circumstances and needs that arise in schools with respect to attending to students with chronic diseases in an inclusive manner. The acquisition of this information allows us to develop proposals that favour the presence, participation, and progress of these students.

2. Method

The study utilized a qualitative approach involving focus groups and interviews. This approach allowed for the contextualisation of the results based on not only the experiences of the teachers, families, and health personnel who had been appointed to a school or had a direct relationship with a school but also student input with respect to the educational experiences of students with chronic diseases.

Two data collection techniques were employed throughout 2012-2013, to gather information regarding circumstances specific to mainstream schools and that seek to provide integrated responses to the education of students with chronic diseases:

A. We conducted eight discussion groups with participants from different schools. All discussion group participants have had experiences with educational services for children with chronic diseases. These groups were organised as follows:

1. Educational professionals:

- Primary school teachers: six participants, including three teachers and three teacher assistants.
- Primary school teachers: six participants, including one head master, one head teacher, one teacher, and three teacher assistants.
- High school faculty: five participants, including one school counsellor, one teacher assistant, one speech, language and hearing teacher, and two teachers.
- High school faculty: four participants, including two teachers and two school counsellors.

2. Families:

- Parents of students with diabetes: six participants with children between 3 and 14 years old.
- Parents of students with rare diseases: six participants with children between 3 and 13 years old.

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