

## SCHOOL CARE FOR THE SICK HOSPITALIZED CHILD: STATE OF THE QUESTION

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With this Final Degree Project, we wanted to investigate a work that is unknown to many and not always sufficiently valued: the educational care provided to hospitalized children. We have teacher/s, students, classroom, and to this cocktail we add a particular touch consisting of white coats, stethoscopes, drip feet, operating rooms, beds... and a very particular environment: A Health Center. We have left the walls of the schools and we have entered the health centers, discovering a work developed by professionals who have arrived there guided by the teaching vocation and love for children, developing an unknown care and that is strongly conditioned by the state of health that many of them are going through, often quite delicate. These children have the right to education, and that is the reason for their existence. Throughout the research, we have collected its origins, the objectives it pursues, the methodology used, and the legislation that contemplates it. To make the study more truthful, we have sneaked into these classrooms and we have met children who deserve to be cared for, to be comforted, to be encouraged not to put aside their learning.

**Key words:** Hospital classrooms, home educational support service, hospital pedagogy, children with special educational needs, sick children.

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## **HOSPITAL CLASSROOMS.**

Origin. The hospital classroom programs are aimed at hospitalized children between 6 and 16 years of age, which is the compulsory school age. However, the educator's work extends to all those children who, although they are outside this school period, can benefit from the resources offered by the classroom. It was in the second half of the 20th century when pedagogical care began to take place in many European and American hospital institutions, as well as in Spain. Today, many hospital centers have school classrooms, but achieving this has not been an easy challenge. In Spain, the first classrooms appeared in the 1950s in centers dependent on the San Juan de Dios order. Later, in 1965, there was an epidemic of poliomyelitis in Spain and the idea of helping these children not only with medical treatment, but also with school and educational treatment was born. It was then when the first classrooms began to be created in hospitals in different Spanish provinces, such as in the hospital of Oviedo, in the hospital of La Fe in Valencia, in Manresa and in Madrid in the hospitals: Clínico, Niño Jesús, Hospital del Rey and Gregorio Marañón, all these classrooms are dependent on Insalud. In 1966, 10 special education classrooms were created in the Niño Jesús hospital, in response to the demand existing at that time. Later, in 1997, only 4 remained. Today there are a total of 10 classrooms. At the beginning they were dedicated to "entertain", with the passage of time this was becoming a more didactic function. From 1982 onwards, an important legislative work began, directly involving the Ministry of Education and Culture, the Ministries of Education and Health, and in 1986, the European Parliament approved the European Charter of the Rights of Hospitalized Children, which stated that "all children have the right to education, including sick and hospitalized children". Finally, in 1998, an agreement was signed between the Ministry of Health and Consumer Affairs, the National Institute of Health and the Ministry of Education and Culture, where the bases and compensatory policy were established in order to solve the problem of schooling for children admitted to hospitals.

## **Hospital Classroom Teachers.**

The role of the teacher in these classrooms is fundamental and without him the educational actions would not be possible. The hospitalized child continues to attend school in the center of origin, and it will be the teacher who will contact the center to request the necessary information so that he/she can be properly attended to in the curricular subjects he/she has to study. His role in the hospital center is related to the following functions: Educational. Giving continuity to the educational process of the children who are hospitalized. Compensatory. Developing compensatory actions related to the child's school life situation. Preventive. Trying to avoid

a possible school delay due to the interruption of the curriculum. Therapeutic. Palliating the hospital syndrome and avoiding the preoccupation for the disease, by means of school activities that provoke their motivation. Normalizing. Trying to make their situation in the hospital as similar as possible to that of the child in their daily life through school activities. Integrative. Establishing a good coexistence in the hospital center, taking into account the child's age, illness, origin, etc. Coordination. Coordination exists at 2 levels: internal coordination with the other teachers working in the classroom, with the health personnel and the child's parents; external coordination with the teachers of other hospital classrooms, with the tutors of the child's school of origin, with the collaborating entities, etc. Access to these positions is done in two ways: through a transfer competition (as it is in the Community of Madrid) or through a service commission, renewable every year.

### **Psycho-pedagogical attention.**

The purpose of hospital psychopedagogy is the same as that of education: to seek the integral development of the person, trying to achieve the maximum evolution of their capabilities, even in a different situation such as being sick and hospitalized. This is achieved through a main objective: to prevent and avoid the marginalization of school-age children admitted to hospital from the educational process (Lizasoáin, 2003). The forms of intervention are classified into 4 sections (Lizasoáin, 2003): School teaching. The aim is to prevent, through educational activities, the loss of the child's study habits and motivation. It helps the child to reinforce his learning, avoids delays in his studies and favors the incorporation of the child in his school of origin (Lizasoáin, 2000). Playful activities. If the child suffers constant boredom, he/she becomes sad and takes a passive attitude towards things. To avoid this, games and stories are important activities that provide the child with well-being and self-confidence. At the same time, they have educational, therapeutic and entertainment functions (Palomo, 1995). Personal guidance. It is the help to the sick child, through talking and company (Lizasoáin, 2000). Psychopedagogical strategies. These include special programs to prepare for hospitalization and specific educational and therapeutic initiatives (Ortiz, Serradas and Alves, 2004).

### **Pedagogical objectives.**

The general objective is to provide educational, formative, recreational and human attention to children who, because of their illness, have to be admitted to a hospital. This care also includes helping the child to continue, within his possibilities, with a social life as close as possible to the one he had before being hospitalized. The objectives included in the program of hospital classrooms under the guidelines of the Ministry of Education and Culture are the following: Pedagogical. It is intended to continue with the educational process and that the incorporation of the child to his school life is as little affected as possible. To achieve this: Individualized and flexible programs will be carried out taking into account the interests, expectations and curricular competence of each child. To try that the child loses as little as possible the contact with his/her classmates and the tutor of his/her regular school. To maintain the child's motivation to

learn and to achieve a work habit. Encourage a constructive occupation of free time, through activities that help the child's overall development. Continuously motivate them to create positive relationships with the environment in which they find themselves. To organize therapeutic and specific activities in specific cases. Psychological. To achieve a good adaptation of the children to their new environment, as well as to help them understand what is happening and why. To reduce the anxiety and anguish that the child has during hospitalization. Respond to the child's concerns in simple language and help him/her to clarify any doubts he/she may have about his/her pathology. Encourage the child to attend the hospital classroom and to participate in it. Social. Create an environment as close as possible to their daily life, facilitating the relationship with the rest of their classmates: To favor a humanizing environment based on trust and security relationships. Encourage situations for children to interact with other hospitalized children both in the classroom and on the ward where they are hospitalized.

## **Methodological principles.**

Play is the first form of relationship within the hospital center. It is the first contact with the hospitalized child. In this way we try to avoid the rejection of the adult person with whom he/she meets and a climate of trust is created. The game as a methodological guideline is followed by the educational actions we want to carry out. The basis of the methodology within the hospital classrooms program are: Operationality. Before carrying out a pedagogical activity, prior information is very important and several factors must be taken into account, such as: the child's abilities, the environment where the activity will be carried out, the acceptance of the parents and the support of the professionals working with the child. Normalization. Educational and social activities and actions are carried out taking into account the child's age and the context where they will be performed. It is necessary to act as if it were a "normal" school, taking into account the variations that may be necessary for health reasons or the child's current situation. Individualized and personalized teaching. It is essential to take into account the characteristics of each child. All educational actions must be adapted to their school level, to the child's interests and to their affective and health situation, even making curricular adaptations if necessary. Global training. It is necessary to integrate the health environment in the classroom programming, always from a positive point of view and seeing the hospital as a source of educational resources that motivate the child. Socialization. Relationships with the peer group should be encouraged. That is why it is very important, if possible, that children go to the classroom and interact with other children who are in a similar situation to theirs. Participatory action. Programming should be carried out with the participation of: Health personnel. To inform them of the aspects related to their disease and so they can advise on the possibilities of activity that the child has. The teachers or tutors of the school of origin. To give initial information to take into account at the time of programming and tell us how are the activities that the child is used to do in class. Parents. They are a very important axis in the process of recovery of the child and must participate in their educational process. All these methodological principles are closely related and all of them must have a common objective, which is the motivational component that arises from the child's own activities, concerns and experiences. In hospital classrooms there are a series of conditioning factors that can have a great influence on the implementation of the methodological principles mentioned above.

They can be classified as follows: Physical conditioning factors: isolation situations, infectious pathologies, immobilizations, etc. Psychic or social conditioning factors: related to terminal illnesses, oncological diseases, difficulty in relating to their usual environment, etc.

## **Development of activities.**

The development of activities with children is always different and varied, always taking into account the special situation of each of them and are also conditioned by a number of variables such as: The time they are hospitalized. It is important to have an estimate of the time the child will be hospitalized in order to be able to count on this variable in the development of the activities. When a child is hospitalized for a long period of time, the activities range from curricular activities to psychological and social activities, which are so important in this type of cases. Specific health conditions. With children who cannot follow a normalized teaching, it is necessary to opt for other types of recreational activities, games, relaxation activities that require little effort and little concentration on the part of the child. The story is a good resource in this type of circumstance, it is very important that the child is entertained. With children who can have a normal treatment of the activities, activities are carried out taking into account the child's age, the information given to us by the tutor of the school of origin, etc. Everything that can help us in their teaching-learning process. Making everything as similar as possible to their school but adapted to the new context where we are. Individualized Attention. In this type of context, the hospital centers, this type of attention has a greater importance than in the school context. Teachers working in these classrooms, not only have to take into account the curricular level and competence of the child, but also other elements that influence the psychological and social level. The different ages of the children. In hospital classrooms we work as in "unitary schools", since the children are of different educational levels. So the teachers have to have a great variety of activities suitable for the different levels. In this way, the relationship with other hospital classrooms is very important in order to exchange experiences and help each other. Attention in the classroom or in the room. Being able to carry out the activities in the classroom or in the room will condition the development of the activities. The ideal place to develop the educational work is the classroom for the following reasons: - In the classroom the materials with which the activities are carried out are more accessible. - The child can choose the material he/she is most interested in to carry out the activity; in the room he/she is limited to what the teacher brings. - There are computers with Internet connection that cannot be brought to the room. This type of resource is considered a very important motivating element in the child's learning. - They experience situations of personal relationships by being in contact with other children. - Group tasks are performed, discussions are held, etc. - By going to the classroom, the child disconnects for a few hours from the hospitalization itself, "goes to school" as he/she would do in his/her daily routine.



## **HOME-BASED CARE**

The children who receive home care are those who, once they have been discharged from the hospital, remain convalescent at home for a more or less long period of time. This program is developed in coordination between the Ministry of Education and Culture and the Ministry of Labor and Social Affairs, which have approved agreements with volunteer organizations, composed of educational experts such as teachers, pedagogues and graduates, without any economic interest. Currently, this competence has been transferred to the Ministry of Education and Culture of the different Autonomous Communities.

### **Origins of home care.**

Home care does not have a marked date of origin, but it is in the 90's when it begins to develop its activity in most of the Autonomous Communities. From 1997 is when this attention to convalescent children at home who can not go to their school is carried out by the Red Cross Youth (volunteers) in coordination with the Hospital Classrooms, School Center and External Support Educational Services.

### **General objectives of SAED.**

To ensure the continuation of the educational process of the sick child and to prevent children who remain at home for a prolonged period of time from falling behind in school. To avoid the stages of anxiety that arise during the illness. To improve the child's quality of life. To facilitate that their return to school is as normal as possible. For the good development of this process it is essential the coordination of all the implied elements, which will have to follow the following steps: - The child's school has to communicate to the Provincial Delegation of Education and Culture the cases that appear. - The Educational Guidance Team assesses which children will be assisted at home. - The Provincial Delegation of Education and Culture is in charge of having the appropriate personnel for this type of care. - Finally, the tutor of the child's school coordinates with the person who will assist the child at home, so that he/she can continue with his/her school activities and be able to fulfill the curriculum.

### **Specific objectives of home care.**

Maintain the child's motivation to learn and train the study habit. To optimize the child's productivity. Encourage family collaboration. Inform parents to request medical appointments outside school hours so that the child does not miss school, whenever possible. Discover possible gaps in learning so that they can be filled as soon as possible. To have a continuous communication with the reference centers and the teachers of the Hospital Classrooms. To ensure that the child can communicate with his/her teachers and classmates through the Internet. To continue to use the school material from their center of origin. To develop the welcome plan in their center of origin.

## **Organizations in charge of home care.**

The home care service is provided by different non-profit organizations, the most important of which are the Red Cross and Save the Children. In Madrid, the Servicio de Apoyo Educativo Domiciliario (SAED) has been created in order to remedy the deficiencies found in voluntary organizations. The Madrid Regional Ministry has assumed the provision of this service with its own resources in order to ensure the right to education in the best possible way.

## **LEGISLATIVE FRAMEWORK**

As we mentioned in the previous section, at the end of the First World War, the first hospital classrooms began to appear outside Spain, to attend to children who were unable to attend classes due to health problems. In this way, the first teaching spaces were created in health centers. As far as our country is concerned, they began to operate much later, as far as the legislative framework is concerned. It was not until April 7, 1982, with Law 13/1982, when the first legislative reference was published in Spain, which was none other than the INTEGRATION LAW FOR THE DISABLED: this was intended to meet a demand of Spanish society ... the educational needs, not only of children, but of adults admitted. In this Law, the basis of what should be the educational performance in health centers was established. Article 29 of the aforementioned law states that all public hospitals with beds occupied by children, rehabilitation and/or permanent pediatric services should have pedagogical units or sections. This is aimed at prevention and marginalization of students between 3 and 16-18 years of age. Complementarily, the Organic Law 1/1990 of October 3, 1990, on the General Organization of the Educational System (LOGSE), in Chapter V, Article 63.1, also attempts to regulate the activities that take place in hospital classrooms and thus support children who, due to hospitalization circumstances, are disadvantaged. From then on, and once the Autonomous Communities had assumed the competences in education and health, numerous laws were passed in our country aimed at meeting the right that all Spaniards have to education and that our Spanish Constitution of 1978 includes in article 27. In 1986, the European Parliament approved the European Charter of the rights of hospitalized children, which was intended to address the problems that arose in hospitals with hospitalized children. The Ministry of Education was responsible for organizing and implementing these school units within the hospital centers. The role adopted by the National Institute of Health (INSALUD) was to provide sufficient material and human resources for their proper functioning (including the provision of sufficient credit). Today, the Autonomous Communities are responsible for its proper functioning. The Organic Law of Education 2/2006, of May 3rd, states that the development of compensatory actions in unfavorable situations will be determined by the Public Administrations. In addition to the aforementioned Laws, we have a series of Royal Decrees developed throughout these years, which we mention below:

Royal Decree 334/1985, of March 6, 1985, on the Organization of Special Education, where it is established that the Educational Administrations will be the ones who will be able to arrange with the public health institutions the establishment of pedagogical provisions. Royal Decree 696/1995 of April 28, 1995, on the organization of the education of students with special educational needs. Article 3.6 states that the Ministry of Education and Culture will establish school services in hospitals and rehabilitation centers for the proper development of the educational process of children admitted to the hospital and belonging to the Infant, Primary and Compulsory Secondary Education. Royal Decree 299/1996, of February 28, 1996, on the organization of actions aimed at compensating inequalities in education, in Chapter III, in its 2nd section, there is an extensive section on the actions to be carried out with hospitalized children. In the articles that go from 18 to 20, it is specified that: Children will maintain their schooling in their center while they are hospitalized (article 18.1). They will have the possibility of distance education, provided that their physical condition and by medical prescription, they are obliged to remain at home and not attend their educational center (article 18.2). The Ministry of Education and Culture will be in charge of creating school support units in public hospital centers that have enough students of school age. Likewise, private hospital centers that obtain public aid will be given the opportunity to enter into agreements in order to have these school support units (article 19.1). Finally, Article 20 details the possibility for the Ministry of Education to formalize agreements to develop programs for educational care at home for children who remain at home for a prolonged period of time due to health problems. The Organic Law for the Quality of Education 10/2002 (LOCE), devotes chapter VII to the care of children with special educational needs, but does not mention hospital classrooms. If we talk exclusively about the COMMUNITY OF MADRID, since it assumed, like other Autonomous Communities, the competences, it has been legislating extensively on the subject: There is an Agreement for the Improvement of the Quality of the Educational System of 1999, in which the main objective is in point 2, the equality of opportunities for all children regarding their education...to those who suffer from psychiatric disorders and deals with the reinforcement of the actions within the hospital classrooms and the adequacy of the home care according to their needs. We also have an Order of October 15, 2316/1999 of the Regional Ministry of Education, which establishes the framework and organization of the school support units in Hospital Centers for educational compensation. In 2002, there is Order 992/2002, dated December 11, in which the Regional Ministries of Education and Health establish the collaboration between them to attend to the hospitalized children of compulsory school age. This Order devotes a large part of its articles to a review of the existing regulations on classrooms prior to that date. With regard to evaluation, the Resolution of June 11, 2001, which issues Instructions on the monitoring and evaluation of students with prolonged hospitalization or convalescence at home, is very interesting. It is worth mentioning some recent instructions (2004-2005 school year) from the General Directorate of Educational Promotion on the functioning of the support school units in our Community, which includes the objectives of these classrooms, the students to whom they are addressed, how they should be organized and function, the characteristics of their teaching staff and the functions to be developed, as well as how the coordination of the classrooms with the Hospital Center should be. To conclude, a comparison has been made of the Organic Law for the Improvement of Educational Quality (LOMCE), of 8/2013, of December 9, 2013 with the Organic Law of Education (LOE) 2/2006, of May 3, regarding the issue at hand, and except for error, we have been able to verify have added a new article 122 bis, which refers to the actions

aimed at promoting quality in schools and that should involve a promotion and specialization of the educational projects of the centers, regarding measures to be taken among others....for the attention of students with specific educational support needs. This could include hospitalized students.

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