

ILLNESS, DISABILITY OR CULTURAL IDENTITY? INTERPRETATION OF DEAFNESS AND ANSWERS FROM THE SPANISH EDUCATIONAL SYSTEM

Deficiência, incapacidade ou identidade cultural?

Interpretação da surdez e respostas no sistema educativo da Espanha

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ABSTRACT

In Spain and in recent years, multiple changes have been experimented in the prevention and care of people with disabilities, particularly in what concerns to deaf people. The interpretation of deafness not only as hearing impairment, but as a communicative difference is causing the provision of educational contexts with bilingual and bicultural characteristics. This new conceptual perspective and the consequent orientation of school practices have positive impact in the fields of health, education and social development, encouraging the development of both deaf as listener students. This article explains the situation of the Spanish context on this field and it has provided the basis for the accomplishment of a European transnational project.

KEYWORDS: Communication; Education; Deafness; Multilingualism

■ DEAFNESS

Deafness is a rather heterogeneous concept, because being deaf can be the result of various and diverse factors. Classifications can be made based on the etiological causes or the level of hearing loss including the possibility to acquire the oral language through audition and/or vision. Furthermore, we have to take into account if the deaf was born deaf or turned deaf at a later stage and if he or she has oral or sign language skills. Identification with the deaf community as a family or as a “place” of belonging is also an important aspect.

In addition, the combination of hearing loss and other impairments like deaf-blindness, the socio-cultural characteristics of the deaf person’s proximal

environment (the presence of other deaf persons in the family and school) and the early detection and intervention and the type of education received/ offered shows that the concept of deafness is a heterogeneous one¹.

As the purpose of our contribution is to give a short overview of important issues regarding deafness in Spain, we will define deafness as a hearing impairment in the way it is described in the survey of the National Institute of Statistics^{2,3}.

In order to understand the significance of deafness we will start presenting some statistical figures about deafness and disability in Spain and we will analyse briefly the opposing views to the use of technology, such as cochlear implants and other devices, as a solution. In this way deaf culture and identity, represented by deaf organizations will be addressed as another perspective on deafness and disability. After a short expose about deaf education in history, we will continue our overview focussing on deaf children in schools, assessment and intervention methods, the development of bilingual and bicultural education in schools and the role of parents.

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In Spain, the percentage of registered disabled people from the age of 6 has decreased 0,5% during the last decennium. According to the provisional results of the Survey of Disabilities, Personal Autonomy and situations of Dependency (EDAD) of 2008³, the percentage decreased from 9% to 8,5%.

However, this decrease is misleading. If we include the growth of the total population, we will get another picture; from 1999 still 2008 the total population in Spain increased from 40.202.160 to 45.828.172 and respectively the number of registered disabled people increased as well, from 3.528.220 to 3.847.900 (Instituto Nacional de Estadística, 2000; 2008). In other words, the growth of the population is a parameter for the decrease of the percentage from 9 to 8,5 % but this doesn't explain the increase in numbers. To understand the growth of the number of registered people we have to take into account the retirement of a big part of the population (14,4%) older than 65 years, which led to more aid requests for disabilities and other limitations during the last decennium.

In addition, the promotion of a better life quality through the improvement of the social and health policy had an impact as well, not only as prevention but also in the provision of aid to those who suffer from diverse disabilities³.

Within these, 3.847.900 registered cases of disability above the age of 6, over 900.000 concern hearing impairments. What has been said about the improvements of the social and health policy goes as well for hearing impairments; the important role played by the prevention of auditory disabilities, especially in the period of maternal gestation and infancy, together with progress in health care have considerably reduced the number of deaf in Spain.

■ CULTURAL IDENTITY. COMMUNICATION OF DEAF PUPILS

This increase of health care for the hearing-impaired can be underlined by the growing number of surgeries, particularly cochlear implants, in the last 10 years. If a person suffers a profound bilateral deafness of neural-sensorial origin and his or her auditory nerve is still intact, a cochlear device can be surgically implanted.

The growing demand for this medical intervention comes especially from hearing parents with deaf children who turned deaf at a young age due to an infection, accident or other cause and thus had already some oral linguistic experiences. However, the deaf community, has doubts about its effectiveness since the operation doesn't solve completely the auditory problem; it requires

additional auditory and speech training with no guarantee of full success.

Moreover, the deaf community is against any medical and surgical intervention aimed at modifying what they consider "a natural distinctive characteristic" of the deaf⁴.

On the other side, the great technological advances in the last years have made the hearing aids (devices used to amplify the sound) smaller and of better quality such as the digital audiphones, used to select the sound frequencies of the human voice to make it more intelligible to persons with hearing impairments. Nevertheless, there are also cases in which this is not recommended. Infections or malformations of the ear, or a profound hearing loss, will make these hearing aids useless. The deaf community is also opposed to these hearing aids as the deaf have their own language and cultural identity.

We will turn now to this issue of cultural identity and the role of the deaf community, particularly the deaf organizations.

Keeping in mind what has been mentioned in the introduction about the multiple factors that condition the situation of each deaf person, it doesn't seem adequate to use the dichotomy deaf versus hearing people. If we consider that deaf persons constitute a homogeneous group as opposed to hearing people we simplify reality.

However, to shed some light on the cultural identity issue, it is common to speak about deaf versus hearing people and deaf culture versus hearing culture. We will follow who distinguish three types of identity.

First, they mention deaf people with a strong deaf identity, who define themselves as belonging to the deaf community, using only or preferably the sign language. Frequently they are deaf-born in deaf families or hearing families and they have established connections with deaf associations or other deaf movements. They consider themselves to be a linguistic minority. While putting great emphasis on the idea of a deaf culture, they refuse to be labeled hearing-impaired with regard to their auditory limitations. Nevertheless, they claim the same rights and support provided for those registered disabled persons with a certificate by the public administration.

Second, some deaf people don't see themselves as culturally different from hearing people. They consider themselves "normal" people with a hearing impairment. Most of them turned deaf due to an infection or accident; or their hearing loss is not very significant. Also some deaf who were born deaf in hearing families and subject to the oral language education, thus having some oral

language competences and lip-reading proficiency through which they are able to communicate with hearing people, consider themselves not culturally different. They prefer to be considered as equals to hearing people and believe that their limitations can be overcome through developing personal strategies (strong motivation and increased effort) and/or through the use of technological aids, such as audiphones, voice amplifiers in the telephone and visual indicators of sound. Some even refuse any support from the public administration and don't like to be registered as disabled with a certificate.

Third, some deaf will find themselves in between these two types of identity. They share elements from both groups; they recognize that their hearing impairment limits their performance of daily tasks and they communicate both in oral language as in sign language. Although their friendships and their leisure activities take place in the context of hearing people, they may participate in deaf associations and the larger deaf community from time to time.

We want to indicate that the subject about the different interpretations of deafness and the kinds of identity, we have indicated, is not an issue that affects only the group of deaf people, is also part of a general process conceptual, scientific, social and political issues that have been occurring in the field of disability. In this field have emerged different interpretive models and practical action: the medical model (deficiency), the social (disability) and a new model emerging: the model of functional diversity⁵⁻⁷. From the last perspectives, people with disabilities or functional diversity beg to be considered as citizens with full rights and greater participation in community life⁸.

Looking back you could say that the first group of deaf people with a strong cultural self-image and deaf identity is the one out of which initiatives are born to set up associations for the deaf representing the deaf community.

In Spain the associations of persons with disabilities have a long tradition, although the part of social and political activism had not the strength as in other countries⁹. Through the initiative of people with disabilities and their respective families organizations have been set up aiming at the improvement of life conditions for their members. Some of them are national organizations, such as the organization for blind people *Organización Nacional de Ciegos Españoles*, National Organization of Spanish Blinds (ONCE). It is a non-profit organization with a mission to improve the quality of life for the blind and visually disabled in Spain and it offers support to people with other disabilities as well. It was founded in 1939, and is regarded as a powerful and successful institution.

However, organizations for deaf people are not set up on the national level, although the different autonomous local, provincial and regional deaf organizations have the possibility to join forces in federations and confederations. But in any case, the identity issue and thus the self-image of deaf persons brands most of the deaf organizations in two different ways: as representatives of the deaf as a linguistic and cultural minority and as an organization of disabled persons.

This bipolarity not only characterizes federations and confederations organizations but also provincial ones. Being a member of one of these associations depends mainly on the deaf predominant identity, his/her personal aspirations and the services provided. The associations are positively valued by the deaf persons, since they give them a place where to meet and share experiences and where to get answers to their needs¹⁰.

The associations facilitate an information service and help to the deaf members in many different ways such as representing them at public offices for disabled persons to get study grants, economical support for hearing aids, adjustments at home, a job, and sign language interpreters.

Older persons with a profound deafness, that communicate in sign language and that consider other deaf persons as their mutual friends and partners, are the ones that usually stay in closer contact with some of the associations. Also parents of deaf young children, who are looking for help and answer, are also very active participants in associations.

Government and other stakeholders, like deaf organizations, consider deaf education very important in the development of deaf children. The discourse on deaf education reflects also the different views that were held during the last centuries. Below, we will give a brief history of deaf education in Spain.

■ PREVENTION AND EARLY INTERVENTION

For years, the prevention and treatment of deafness has been addressed in the policies of different government sectors. In the health sector, prevention, detection and early intervention of all disabilities were considered a priority. In the 70's the different national plans about the prevention and intervention of impairments was implemented, and resulted in an important decrease in the number of persons affected by hearing impairment and a improved intervention in every case¹¹.

With the detection of any anomaly in hearing, newly born will be screened (neonatal screening) and the child will immediately be attended by doctors

and other specialized professionals such as audiologists, speech therapists and otorhinolaryngologists. In this exploration the level of hearing loss and the type of deafness (transmission or perception) is determined to guide further interventions that fit the situation. This early intervention (from 0 to 3 years old) is also offered in the case that someone within the family had similar developmental problems during infancy. When older than 3 years old, intervention will be continued, when necessary, under the responsibility of the education sector.

In addition to the medical exploration, diagnosis and the determination of any required technological aids¹², some psycho-pedagogical and linguistic tests will be part of the procedure. The result of this psycho-pedagogical and linguistic assessment constitutes the basis for a personal development program and educational intervention.

In addition to the health and education sector, also private organizations offer intervention services. It's normal practice that parents and deaf people organizations also conduct an early intervention and give educational support complementing the treatment of deaf children during childhood. In Spain, these services offered by the associations are recognized by the public administration and therefore supported. Educational and family counseling, vocational guidance and labor integration, training and support for youngsters, and leisure activities are financially supported whenever they are planned and developed as projects and are submitted by private organizations in accordance with the yearly official government calls.

Early intervention includes an orientation of the family towards the treatment of their child, and the involvement of professionals.

The frequency of the intervention will be determined in a specific way according to the needs of the child and taking into account the particular circumstances of the situation. It can be offered daily, several times a week, or several times a month.

When the child is integrated in an educational centre, which provides education for 3 to 6 year old children, the child will be attended by, either specialists from the school centre such as, amongst others, the special education teacher, the language teacher and sign language interpreter or by specialists from the school district such as a psychologist, a pedagogue, a speech therapist, a social worker or a medical doctor.

■ EDUCATION

It's important to underline that Spain has its own pioneer in the education of deaf people. In the 16th century Pedro Ponce de León (1509-1584), a

Benedictine friar, took charge of the education of the deaf-born sons of the Condestable of Castilla. In the documents, his method for teaching the oral language to deaf pupils kept being used in the Monastery of Oña in Burgos, (the original documents were lost in a fire at the Ponce de León's monastery in the 17th century). However, the education of the deaf, as the education of the hearing, was the privilege of a few, especially the aristocracy. In due time, the teaching method of Ponce de León, was for different reasons no longer used¹³.

The foundation of the first public special schools for the deaf began at the end of the 18th century. Thereafter more schools were established; all followed the educational models used in other European countries, in particular France.

However, after the congress of Milan in 1880, "oralism", i.e. teaching the oral Spanish language to the deaf, became practice during the rest the 19th and the major part of the 20th century. At the moment Spain introduced a compulsory basic education system, the education of the deaf, although implemented in specific centers for the hearing-impaired until the 80's of the 20th century, became compulsory and free of charge.

During the 70s of the 20th century when social, political, economical changes took place in Europe and beyond, traditional intervention models for pupils with disabilities were discussed and revised. Based on ideas of normalization and integration, new intervention policies were proposed¹⁴.

Although sufficient educational material and professionals were available, the results of segregated special education were not evaluated as positive. The oral linguistic competence of the deaf student was, in general, low. Together with the poor academic results (the majority of the deaf students didn't reach the elementary levels) and the difficulties to integrate into ordinary life when finishing school, doubts rose to continue with segregated special education. A reorganization of the school system, the programs and educational intervention were proposed.

Simultaneously, an important reform of the regular education system was discussed in the 1980's, which culminated in the old General Education Act¹⁵. The Education Act supports the school integration of students with disabilities, who will be taught at regular centers, receiving the support of specialist professionals.

It's a political organizational decision, aimed at concentrating the technical resources, the material means and the necessary professionals to support the educational needs. The former schools for the deaf were closed or reconverted in resource centers

to support the integration, or in regular school centers.

Before we finish the developments leading to the institutionalization of bilingual education in Spain, now we will turn to the implemented policy regarding the assessing deafness at the earliest stage and the range of intervention possibilities offered.

■ BILINGUALISM: DEAF EDUCATION AND EDUCATIONAL SUPPORT

In the recent Education Act¹⁶ rules are formulated for the education of deaf students in the Spanish mainstream or regular education system. Unless deaf students have other impairments that require the intervention in centers or education in specific classes, every deaf student needs to follow the common educational trajectory.

According to Instituto Nacional de Estadística¹ 7.305 students with hearing impairments attended regular school centers while 799 attended classes at the Specific centers for Special Education in 2008.

Concerning the teaching orientation, the predominant “oralism” has given way to the bilingualism, which means parallel teaching of the sign language and oral language. Through bilingualism the development of, especially, the written language was stimulated.

With some adaptations and support from specialists such as language teachers, sign language interpreters and other support teachers, the deaf student follows the mainstream curriculum¹⁷.

According to the legal guidelines, each educational centre needs to set up an organization for the support of individual identified needs with the available resources present. In every school great efforts are made to conjugate schedules, types of curricular materials and the envisaged support needed by each student in order to organize the intervention policy as beneficial as possible for each case.

The provision of language support and adjusted curricular materials mainly take place during normal school hours. However, in some cases, the support is given after regular school hours at the school or outside the school during activities organized by the different associations. Although these activities may be of great value to the educational development of the child, its regulation and control are not part of the educational administration’s policy.

The coordination of the support given by each professional or specialist is very important with respect to the intervention in the development of deaf students and children with special educational needs. Not only it is necessary to plan carefully decisions about the procedures, curricular

adaptations, handed out educational materials and other support, but also to document these decisions and to assess periodically the implementation and its effectiveness.

The way these tasks have to be organized and implemented within the school centers are clearly described in legal guidelines. In addition, the complete procedure has to be justified in the plans that each educational centre in Spain has to submit to the public administration every year (In particular, the Annual Plan of the Centre and the Guidance and Support Plan). At the end of each year an evaluation report is required as well.

On the level of each individual student, regulations prescribe to document the student’s Individualized Curricular Adaptation. It includes the results of the initial psycho-educational assessment, the modification of goals, contents, methods, activities, and materials in each curricular area, the organizational aspects of the support provided and an assessment of the teachers who worked with the individual student. The Individualized Curricular Adaptation contains also an evaluation about the specialized support, revisions made in comparison to the original plan and previsions for the near future.

Reviewing intervention measures and writing plans is a joint responsibility of all professionals who take part in the support given to each student. Based on these reviews and plans parents have to be informed of the educational interventions that their children receive. The director of the school must ensure that this process is adequately conducted and that the parents are informed. Finally, the inspector of the district as legal representative of the public administration controls the implementation of the prescribed regulations and will approve or disapprove accordingly.

The parents are the legal representatives of the students; as such, they have rights and also obligations in the educational intervention. The school is obliged to inform them about any problem detected and any kind of extraordinary intervention. The parents have to be informed if a diagnostic exploration is planned or if the child will receive special attention or is going to attend support classes in a special classroom. Also, when the child will receive an adapted educational program or support from a specialist the school has to contact them immediately.

The school is not allowed to act if the parents are not previously informed and no consent has been given.

If the parents don’t agree with the intervention proposed in the school centre, they can present their complaint to the district educational inspector. The inspector should mediate the dispute and if it

is not possible should look for a solution in another centre.

In addition to these parental rights, parents also have some obligations. First of all, they have to be collaborative and maintain the communication with the teachers. It is also expected that they are present in meetings, interviews and tutorial sessions and when they receive educational guidelines for support at home, they will put them into practice. As mentioned above, the content of the Individualized Curricular Adaptation has to be brought to the attention of parents in order to guarantee the best possible implementation not only at school but also at home.

It is important to state that the lack of agreement between school and parents is something rather exceptional. Generally the parents agree with the educational intervention and actively collaborate with the teachers in the education of their children. Nevertheless, it's important to acknowledge that, frequently, the professional support provided is rather insufficient due to the lack of resources in the school centers.

■ FINAL REMARKS

Although the amount of bilingual and bicultural experiences in education is increasing, you might say that the Spanish road to bilingual education is still a rather new one. In Cordoba it started to

provide bilingual and bicultural facilities in order to enable the learning of deaf culture.

It's very important to have an adequate school context that improves the learning options of the deaf as well as hearing pupils. Active participation is a requirement for each culture, thus also for deaf culture¹⁸. Deaf culture cannot be solely reducible to language; it's a notion that points to the comprehension of deaf people's practices. The pupils in these contexts have the opportunity to experience the connection between language and culture. Although exclusion practices are still visible in the hearing as well as the deaf community, the focus on inclusion is becoming more accepted within society. Cultural diversity in society resulting from religion, language, race, nationality offers the possibility to create a multicultural melting pot in which the identity and expression of each group should be promoted and reinforced. But this is a complex assignment, which demands our flexibility. Only, if education is able to change human beings cultural malleability, an adequate shaping of the present and future society is possible^{8,19,20}.

■ COLLABORATORS

The authors worked together at all stages of production of the manuscript.

RESUMO

Na Espanha, nos últimos anos, têm sido experimentadas múltiplas transformações ao nível da prevenção e no atendimento das pessoas com deficiência, particularmente em relação às pessoas surdas. A interpretação da surdez não só como deficiência auditiva, mas também como forma diferenciada de comunicação está a provocar o aparecimento de contextos educativos com carácter bilíngue e bicultural. Esta nova perspectiva conceptual e a consequente orientação das práticas escolares têm impacto positivo nas áreas da saúde, educação e desenvolvimento social, incentivando o desenvolvimento, quer dos alunos surdos, quer dos alunos ouvintes. O artigo agora apresentado demonstra a situação do contexto espanhol e serviu de base para a realização de um projecto europeu transnacional.

DESCRITORES: Comunicação; Educação; Surdez; Multilinguismo

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