FAMILY AND DISABILITY
FAMÍLIA E DEFICIÊNCIA

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ABSTRACT: The inclusion of students policy with special educational needs in the regular school system, not merely the physical remains of these students together with other students, but is the need to review concepts and paradigms, as well as develop the potential of these people, respecting their differences and meeting their needs. Currently, we have faced with new paradigms that are changing the social representations around people without disabilities and showing that they can ok participatory and able, provided they are propitiated conditions, respect and appreciation of their differences and they are offered opportunities. For both the proposed including society contains, implicitly, the idea of mobilizing the various social groups in the pursuit of well-being. However, it is necessary intrinsic transformations, breaking up crystallized and excluded barriers, becoming subjects of their own history. From this perspective should ok the idea of appreciation and respect for human diversity, where inequality and all forms of exclusion are repudiated guaranteeing, everyone access to goods and services of social life. The role of education is of fundamental importance, as they are highlighted and hired the school's commitment to all and for all.

Keywords: Affectivity. Builds. Learning.

RESUMO: A inclusão da política de alunos com necessidades educacionais especiais na rede regular de ensino, não se limita apenas aos restos físicos desses alunos juntamente com os demais alunos, mas é a necessidade de rever conceitos e paradigmas, bem como desenvolver o potencial dessas pessoas, respeitando suas diferenças e atendendo suas necessidades. Atualmente, nos deparamos com novos paradigmas que estão mudando as representações sociais em torno das pessoas sem deficiência e mostrando que elas podem ser participativas e capacitadas, desde que sejam propiciadas condições, respeito e valorização de suas diferenças e sejam oferecidas oportunidades. Para ambos a proposta de inclusão da sociedade contém, implicitamente, a ideia de mobilizar os diversos grupos sociais na busca do bem-estar. No entanto, são necessárias transformações intrínsecas, rompendo barreiras cristalizadas e excluídas, tornando-se sujeitos de sua própria história. Nesta perspectiva deve-se aceitar a ideia de valorização e respeito pela diversidade humana, onde a desigualdade e todas as formas de exclusão sejam repudiadas garantindo a todos o acesso aos bens e serviços da vida social. O papel da educação é de fundamental importância, pois são destacados e contratados o compromisso da escola com todos e para todos.


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INTRODUCTION

The advances and changes that have taken place in recent years are marked by the process of economic and cultural globalization and are demanding new dynamics of family and social interaction that lead to critical reflections about current paradigms and current social practices that still show growing inequality between people and families, in all social segments.

Particularly in the case of families that have a child with a disability, these inequalities are still reflected and present themselves more intensely when the children receive the most different labels, because they are perceived as different and incapable.

For these differences to be respected, it is necessary to change centuries of history, of deeply rooted prejudices, and this does not happen overnight. First, it is desirable and necessary that parents see him as a living being, a human being with heart, soul and feeling. Hence, the importance of the role of the family in being attentive to the needs of their children, understanding them, valuing them, knowing how to deal positively with individual differences and fighting for a more just and egalitarian society, where there is a policy that respects in all aspects the human diversity.

Thus, the primary objective of this work to conclude a specialization course in special education has its origins in a personal process of searching and reflecting on our life trajectory as a mother and as a professional working in the area of special education, dedicating work and affection to those with special needs. Special people, who as much as anyone else are important members of our society, our families and our lives. Realizing the need to search in various sources of information as well as analyzing and reflecting on lived situations and concrete everyday issues in relation to the Family Faced with Disability.

THEORETICAL DEVELOPMENT

When we make a retrospective of the history of the man, as a social subject, we verified that his ways of thinking and acting are directly linked to the forms of economic production that have determined the model of man considered ideal for each time, as well as have inspired the social practices of acceptance and exclusion of those considered unproductive.

Fontes (1997, p.31), states that:

exclusion has a direct link with the social dynamics as a whole, especially with the unfolding of the capitalist mode of production. Thus, all those who for one reason or another cannot produce quickly and efficiently are excluded from the production process. The author also adds that what is considered today as social exclusion actually encompasses different conceptions throughout history. People who present within the
social context a dysfunction or individual inadaptation end up generating governmental actions or by part of organized civil society, which translate into a corrective technique of repair, characterized by a social intervention, of the philanthropic or social assistance type.

For Martins (1996, p. 27):

Disabled people have always been considered outsiders, on the margins of participation in the economic, political and social system — a minority — even though they represent 10% of the world’s population. of disabled people and that attitudes towards them have changed according to developments in different cultures, such as scientific and technological progress and the characteristics of each historical period.


The different social attitudes regarding this segment of the population, these were considered as subhuman beings, degeneration of the race, as objects of ridicule, deserving of pity, recipients of public charity, eternal children, deficient or incomplete beings. Finally, as people and citizens.

However, these attitudes, although they characterize basically determined, coexisted in several periods and can still be found coexisting nowadays.

In fact, the conquest of individuals with special needs for a space in society was slow and gradual, mainly due to the existence of stereotyped prejudices in relation to them. The fact is that social relations in agreement on emotional bases, impregnated with pieguism and not in the fact that they are subjects of social rights.

In the past, society was first faced with the stage of extermination, in which the disabled person had no right to life. These individuals were seen as punishments and should be banished from society with death.

According to a UNESCO survey (1977, p.44), the history of humanity can be divided into five phases:

1 — Philanthropic phase — in which people with disabilities are considered eternal children, sick, invalids and incapable.

Still at this stage, assuming that people with disabilities were segregated from social life and treated with feelings of pity and pity, actions for treatment and health care prevailed.

2 — Public assistance phase — in which the same status of sick and disabled implies the institutionalization of aid and social assistance, that is, purely paternalistic actions, offered in specialized and specific institutions for certain groups of people with disabilities.

3 — Fundamental rights stage — in which rights are equal for all people, whatever their limitations or disabilities. It is the time of individual and universal rights and freedoms that no one can be deprived of, as is the case with the right to education.
4 — Equality of opportunities phase-time in which economic and cultural development leads to the massification of schools and, at the same time, gives rise to a large contingent of children and young people who, not having a school performance adequate to the objectives of the school institution, to join the group of mentally handicapped children and young people or those with learning difficulties.

5 — Phase of the right to integration — in the previous phase, the increase in deficiencies was promoted, since ignorance of differences, non-respect for individual differences masked as defense of rights and equality aggravated these differences, now it is the concept of normality or of standardization, which is now called into question.

When analyzing the terms normality/normalization, we found in the dictionary (Aurélio, 1986, p. 355), some concepts related to them:

Normality — act or effect of normalizing; make normal; regularize, submit to the norm; standardize; Normalization — act or of returning to normality or normalizing.

Therefore, normalizing does not mean making the person with a disability normal. She has the right to be different, to have her special needs recognized and met by societies. In other words, it is the right of people with disabilities to be accepted as they are, respected as any citizen with rights and duties, even though they are different, but not always, at different times, this was the understanding given to the disabled.


Just as in Europe, in Brazil the disabled person was considered for several centuries within the broader category of the miserable, perhaps the poorest of the poor... The most fortunate who had been born in a cradle of gold or at least well off certainly spent the rest of their days behind the gates and hedges of their grand mansions, or else in hiding, voluntarily or individually, in the country houses or on the farms of their families. These less poor disabled people ended up meaning nothing in terms of social or political life in Brazil, remaining a burden to their respective families.

Soon after the effective arrival of the Portuguese in Brazil, it was observed that the Indians had practically no cripples and when there were deformations, they were admittedly of traumatic origin.

After years of colonization, as with other peoples, and at the same level of incidence, Brazilians exhibited cases of congenital or acquired deformities. The lame, blind, zambros were common.


Many of the Africans who were brought to Brazil as slaves, and here suffered many physical punishments, even having their bodies marked by the mistreatment inflicted
on them. They were often victims of rickets, beriberi, scurvy, that is, of the most serious syndromes detaining food shortages.

Formal attention to people with disabilities began with the creation of boarding schools, still in the 17th century, an idea imported from Europe during the imperial period.

According to JANUZZI (1985), “the first was the Imperial Instituto dos Meninos Cegos, current Benjamin Constant Institute — IBC, this was created in Rio de Janeiro, by Emperor D. Pedro II, through Imperial Decree nº 1428, of 12/12. 09/1 854.

The second was the Instituto dos Surdos Mudos, currently the National Institute for the Education of the Deaf — INES, also created in Rio de Janeiro and officially installed on 09/26/1857. Both were created through the intercession of friends or people institutionally close to the Emperor who responded to the requests, given the friendship he maintained with him.

This practice of favor, of charity, so common in the country at that time, established the welfare character that permeated the attention to people with disabilities, in the country, and to special education, in particular, since its beginning.

The institutions gradually took on the nature of asylums, intended for the reception of disabled people and for a long time the assistance to the disabled was unsystematic, almost non-existent from the point of view of official initiatives in the educational field.

In 1906, public schools began to serve students with mental disabilities in Rio de Janeiro. Soon after, in 1911, a medical-school inspection was created in the Public Health Service of the State of São Paulo, which would work together with the Education Service, in the defense of Public Health.

In 1912 (according to JANUZZI, 1985) or 1913 (according to PESSOTTI, 1984) the Experimental Pedagogy Laboratory or Experimental Psychology Office was created at Escola Normal de São Paulo, currently Escola Caetano de Campos.

In 1917, the first attempts to establish the norms for the selection of abnormal appear, since at the time the concern with the eugenics of the race prevailed, being the fear of degeneracy and defects a determining issue in the area of Public Health.

In the 20th century, especially in the 20s, the expansion of special education institutions began, characterized mainly by the proliferation of entities of a private nature, with an assistance personality.

With regard to the public education network, it initially only served people with mental disabilities, having been systematized and organized for this, with the creation of norms and the centralization of care.
It was then determined that children with mental disabilities should be referred to a health educator, who would ensure that the school would only accept them if they did not interfere with the smooth running of the class (JANUZZI, 1985).

In the 1960s, Brazil was the stage for the emergence of rehabilitation centers for all types of disabilities, in the Paradigm and Services, aimed at the goals of integrating people with disabilities into society and its various instances.

In the 1970s, more specifically in 1973, the National Center for Special Education (CENESP) was created through Decree No. 72,425 of 07/03/73.

For the first time, we can talk about the installation of guidelines for the care of people with special needs in the public education system.

In this context, the Declaration of the Rights of Disabled Persons appeared in 1975, and in the 1980s, currents flourished that value every human being, whether or not they belong to minorities. And the disabled are fighting to achieve two important achievements: Integration and Equal Rights. In 1981, the international year of the Disabled Person, it motivated a society that clamored for significant transformations in this area, to debate, organize and establish goals and objectives that led to important new developments.

In the 1990s there were great advances in the area, with the creation of the National Policy on Special Education and the Inclusive Education Movement based on the political acceptance of the Education for All proposal, produced in Jomtien, Thailand, at the UNESCO World Conference.

Upon assuming such a commitment, the Country determined to profoundly transform the Brazilian educational system, in order to be able to welcome everyone, indiscriminately, with quality and equality of conditions.

Continuing this process, Brazil adopted the proposal of the Salamanca Declaration in 1994, committing itself to the construction of an inclusive education system specifically with regard to the population of students with special needs.

The National Curricular Parameters - PCN and the Curricular Adaptations published by the Ministry of Education and Culture MEC, came to guide and guide Education professionals.

As stated by SASSAKI (1997, p. 71):
Schools for all need to change their perspective and be based on a philosophy that accepts diversity as a human differential axis, which implies their own positioning on the concept of education.

Based on these premises, thinking about the inclusion of any student in the school space, without being the target of discrimination, implies knowing the reality of the school and how relationships are established within it to collectively build the supports and establish a plural space that can respond positively to the needs of learners.

In this view, the school has the duty to seek educational answers considering the basic needs of each student, involving School, Family and Community in the search for the re-signification of individual differences, re-examining the pedagogical practice in order to guarantee the democratic ideal of a school that guarantees the learning and the exercise of citizenship by disabled and non-disabled students.

Affectivity is the activity of affections. Affects are passive states of the I and are the contents of affectivity. Affects are the only mental events that are exclusively subjective, that is, they are never objectified, not even through their effects.

BALLONE (2000, p. 4), defines affectivity as follows:

Affectivity is the psychic attribute that gives value and represents reality. This affection is also capable of representing an environment full of people as if it were threatening, it is capable of making us imagine that there may be a snake inside the room or even, it is capable of producing panic by making us imagine that we can die suddenly. Affectivity values everything in our life, everything that is outside of us, such as facts and events, as well as what is inside us (subjective causes), such as our fears, our conflicts or our desires. Affectivity also values the facts and events of our past and our future perspectives.

According to this author, the characteristic of absolute subjectivity makes the study of affects extremely problematic. Indeed, building knowledge about them implies the use of language, which is a system of objectified signs, it is linear and discontinuous, while affects are holistic states and without any objective correspondence. The only transposition we have from affects to language is their naming.

When we talk about happiness or sadness, we know what we are talking about, and everyone is talking about the same things and everyone knows it.

However, it is not possible to say what is joy or what is sadness. How to overcome such difficulty? It is necessary to make use of an artifice. It is known that each affection corresponds to an experience and about the experiences one can speak perfectly. Thus, instead of talking about an affection, we talk about the experience that it integrates, of which it is a part. Thus,
joy is the affection corresponding to the experience of satisfaction of pleasure, contentment and sadness.

The family is the first group to which an individual belongs and where he has the opportunity to learn through positive experiences, such as: affection, stimulation, support, respect, feeling useful. And negative ones: frustrations, limits, sadness, losses, all of them factors of great importance for the formation of your personality.

For ACKERMAN (in Regen), “the family is the basic unit of development and experience, achievement and failure, health and illness”.

The role of the stable family is to provide a safe training ground where children can learn to be human, to love, to form their unique personality, to develop their self-image, and to relate to the wider and changing society, from which and for which they are born.

According to Fleming (1998, p. 30), “when we refer to the family nucleus, we think of fathers, mother and children. Extended families may include grandparents, uncles and cousins.”

The family is the first integrating social unit in which the individual participates and the love, understanding, trust, stimulation and communication that permeate this relationship are forms of motivation that it uses to facilitate the process of integration and participation of the individual in the different community/society social groups.

For Miranda (1978, p.53), “the family represents the fundamental institution of society. It is the basic and nuclear social group and at the same time the oldest and most primitive”.

According to Fagundes (1991, p. 8),

The family is an active structure, in which each member modifies the behavior of the other through constant exchange, establishing a dynamic between giving and receiving.

For AMIRALÍAN (1986, p.45):

The family is not a simple natural phenomenon. It is a social institution that varies throughout history or that presents different forms and purposes at the same time and in the same place, depending on the social group that is being observed. She is the basic social unit and the origin of the first social and physical contacts for the baby. Therefore, it is up to him the important task of leading the child in the performance of various social roles during the development process.

These concepts reflect the great importance that the family has acquired in this century, as the first social cell of which we are part and which will be responsible for our individual and social formation.

We can consider the family, as explained by Maria do Carmo B. Carvalho, as a very complex system, since:
• Each family is unique, differing in size, elements that compose it, values, etc.

• It is a highly interactive system, as what happens to one of its elements affects the entire system.

• It goes through several stages of development, with major changes, such as the entry of each child into the relationship, the stage of old age of the parents, etc.

• High expectation of performance in activities, and, on the other hand, feelings that he is incapable of producing.

• It is inserted in a larger social unit, suffering the impact of sociopathologies, such as wars, economic recession, etc.

The family performs its functions in seven basic areas, namely:

1. Economic — it is up to the parents to maintain their offspring.

2. Home and health care — providing shelter, food, hygiene and health care.

3. Recreation — provide children with leisure time.

4. Socialization — developing in children the ability to relate to other groups.

5. Self-identity — offering children a sense of reality and awareness of limits: Who am I? What is my worth?

6. Affection — offering affection, enabling children to develop the ability to love themselves and others, to express emotions.

7. Educational / Vocational — preparing your offspring to be in the world.

Parents are the most important elements in this trajectory. In general, every couple wants to have a child. The expectation of being a parent generates many fantasies that are created in childhood and adolescence.

In an article by Lara (1999, p49), Every couple, or almost every couple, dreams of children. But perfect children who come to fulfill their childhood fantasies and who can prolong all the realizations of the ideal and of being human. Parents anywhere in the world the same dreams and hopes for their children. But this does not always happen and when a disabled child is born, expectations generate real conflicts. In general, no family is prepared to have children with disabilities, much less society has enough structure to overcome the barriers of prejudice.

Kogan & Tyler apud Telford & Sawerey (1984, p.177), comment that,
The presence of a disabled child in the family constitutes an additional strain, and defensive reactions are likely to occur more frequently and to a greater degree in these families than in families in which all members are reasonably normal.

The influence of the family group on the development process of the person with a disability is as significant as its interference in the family dynamics.

Although parents have a more important role, we cannot forget the influence exerted by siblings and collaterals. Many provide support and understanding, others discredit and destroy any kind of help that parents want to give this child.

This is a reflection of the general panorama of the many reactions and emotions that overwhelm the hearts and minds of parents who have a disabled child, which in turn is also nothing more than a reflection of the lack of definition of a policy in all government sectors. support with disabilities, or even the lack of practical compliance with existing laws in favor of these people.

Léo Buscaglia (2002, p. 35) emphasizes that “giving birth to a disabled child is a sudden event. There is no advance notice, there is no time to prepare.”

When the child presents some kind of problem at birth, each of the family members will react differently, with, in most cases, a change in the performance of roles; this is because in addition to learning, for example, to be a father / mother, you will have to learn to be a father / mother of a different child. From one moment to the next, they will have to live with a child they didn't expect, establish a relationship they didn't want and that seems to be very difficult for them.

**FINAL CONSIDERATIONS**

The individuals who are more socially integrated, that is, those who lead a more normalized life, are those who are treated in a more natural, more normal way by their family members who are more integrated into the family constitution.

The family must believe in the potential of the child, considering it capable of being independent, capable of developing as many things as other normal children do.

The influence of the family in the process of social integration of the disabled is an issue that must be analyzed taking into account two angles: the facilitation or impediment that the family brings to the integration of the disabled person in the community and the integration of the disabled person. in the family itself.
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