152 - THE PARENTS OF CHILDREN WITH DIFICIENCIES: THEIR BELIEFS IN RELATIONSHIP TO THEIR CHILD'S DEFICIENCY: POSSIBILITIES AND LIMITATIONS.

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1. INTRODUCTION

This article was written as a means of investigation of the parents of children with deficiencies: their beliefs in relationship to their child's deficiency , possibilities and limitations. Our anxiety or desire was born out of an experience in the Program of Motor Activities for Deficient persons (PROAMDE) whose reason for existence is to provide opportunities for the practice of motor activities for persons with deficiencies, viewing the possibility of the development of their potentials of motor abilities as well as provide sociability, self esteem, well being and a better quality of life. One of the requirements of the program is the participation of the parents in the activities together with their children. This requirement is not normally found in the majority of the programs for the deficient.

We have seen by experience that the majority of the parents that come to our program do not know much about the capabilities and limitations of their children and this can be a big influence in the expectations of development of their children.

In order to understand the best dynamics of the relationship of parents of persons with deficiencies and the process of development of their potentials, it is necessary above all that they understand their beliefs. Because of this, this article has the objective of unveiling the beliefs of parents of deficient children in relation to the deficiency of their child's possibilities and limitations.

1.1 Some Controversies or Misconceptions about Deficiencies

It is important to recognize the ideas that direct the conception with regard to the deficiency so that we can understand the possible beliefs that the parents of persons with deficiencies have in regards to their child.

According to Omate (1995) Apud Glat (1995) the term deficiency is related to the status acquired by the individual. People with deficiencies generally are looked upon in the stereo-typed way, according to the label that is placed on them. This will determine the standards of conduct of the others as they interact with this person.

It is important to explain the terms deficiency, incapacity and lack of advantage, because regularly they have been used as synonymous.

The deficiency can be characterized in different dimensions and the words mentioned above can be defined, according to the World Organization of Health OMS - as follows:

Deficiency is related to the loss or abnormality of structure or physiological, physiological or anatomic functions, being temporary or permanent. We can site as an example of an abnormality the loss of or defect of a member, organ or any body structure.

Incapacity is in regards to a restriction to perform an activity considered normal for the human being.

Disadvantage represents a loss to the person, as the result of a deficiency or incapability that limits or impairs the realization and the expectation of the individual or of the group, and are linked to conditions and social values. (OMS, 1995)

In our society, even though the ONU and the OMS have tried to eliminate the incoherencies of the "concepts", the word "deficient" has a very strong meaning or force. In a way it is opposed to the word "efficient". To be "deficient" among other things means to not be able to function up to capacity. (RIBAS,1985)

In every place in society there exists different cultural values that are based on the way society is organized. These are values that are reflected immediately in the minds and images of man, and direct their actions. These are values that end up reflecting in the words that man utters. Thus being in all societies the word "deficient" acquirers a cultural value according to their pattern or value, rules, normality's that have been established in the center of their social relationships.

1.2 Theoretical considerations in regards to beliefs.

According to Soares (2001) Beliefs reveal themselves in a network of dimensions and of aspects where there are found various problems in play. The belief is named in a way that it reveals our sensitive impressions and our perception of the world, of the pitied observations - here is manifest its dimension cognitive and rational, of our attitudes, of our decisions - manifesting our undeniable dimension and custom.

The expressions of the beliefs reveal many times modality or logic that come out of considerations of a possibility to submission.

Beliefs, desires, impulses, intentions, make up reasons to act in this way or that: They are motives in the cause of action.

Another definition of belief is given by Ajzen e Fishbein (1980) apud Freitas (2004) for these authors beliefs are basic cognitive structures on which the attitudes are founded.

In this context so we can understand the beliefs it is necessary that we understand the meaning of attitudes.

According to Wanderey (1981) apud Freitas the word attitude indicates a predisposition learned by about an object or a representative symbol. For Ajzen e Fishbein (1980) cited in Freitas (2004 attitude is made up of affections, beliefs, behavior, intentions and behavior itself.

In this way beliefs represent the information that the person has about the object of attitude. A belief is joined to an object and an attribute. The object of the belief may be a person, an institution, a behavior, a political view or an event, for example.The attribute associated to the object can be another object, a trace, a property of, a quality, a characteristic, a result or an event.

By this means the beliefs serve as a basis to determine what will be the attitude of a person in regards to a determined object.

According to Freitas (2004) the attitude of a person in light of an object is based on their strongest beliefs about the object, or should we say, the beliefs that an individual has, expresses most commonly and with the most intensity, what he feels. Therefore if the beliefs are associated to the object are formed by favorable attributes, the attitude will tend to be positive. In the same way the reverse may occur.

1.3 The Relationship: Parents and the deficient child.

The parents have a primary role in the development of their children, being that they are the first contact with social and emotional relationships with the child, and they are the ones that help in their growth and development. The image of a perfect child ends up being predominate while one waits for his arrival. To birth a child with a deficiency may have a great impact, and may even cause a disaster in the stability of the family until the child is accepted.

There are various phases that the parents will have to go through and reactions that present themselves during this process of comprehension/adaptation/ and acceptance of this child with a deficiency. It is important to reiterate that these phases do not happen in a sequence and status, and that not all parents necessarily have to pass through all. We can find families with children of an adult age and still living with the predominate sentiments of the time of birth.

Bonadiman (1995, apud Souza,2003) confirmed the idea that these parents tend to over protect the deficient one, suggesting that this behavior occurs as a means of protecting the child of all their related social problems, related to or not of the question of their deficiency.

But, these attitudes can be justified by the nature of their culture, or their social economical system. According to Aranha (1991,1995 apud Silva, 2001) in the capitalistic system the deficiency is treated as being a synonym of in productivity and deviation. For this author the deficiency is multiply determined by factors that aligned with values of the operative system in society, leading to segregation and stigma of the deficient individual. On the other hand they are considered incapable and weak, because they do not fall into the mold op productivity of the capitalistic system. Therefore the deficiency gains a declined aspect in the social context.

In a study done by Silva (2001) it was verified that social pressures generate degrading sentiments, causing the begetter to limit the cultural activities or their deficient child, as well as contact with friends, relatives, and neighbors. Some studies cited by this author demonstrate various internal and external factors that cause an increase in stress that the parents live with and execute direct or indirect, influences in the completion of the family relationship.

Principally the mothers are affected strongly when they realize that their new born child has a deficiency. Many mothers and fathers avoid reading good books about deficiencies or to consult with doctors or specialists in rehabilitation so as to not suffer or (what they believe) not to see the child suffer. The derogatory image of the deficient in the Heads of the family reflects the education that the parents give their children. (RIBAS, 1985)

Each family is the only ones, and singularly the ones to confront the deficiency in different ways, but to be aware of the beliefs of the parents in relation to the deficient child, will make possible ideas and concepts better, on the part of the parents, in relation to the child with a deficiency, thereby offering different attitudes to the child, making possible in this way the development of his potentials.

2. METHODOLOGY:

In this study we had 50 participants of students that were cared for in the PROAMDE and that remained active in the program in 2005 and including the parents of some that were matriculated in 2006. In this group there were 7 males, and 43 females whose ages varied from 17-64 years. In relation to the level of education we had parents with only elementary studies, some with High school and college. The children demonstrated motor deficiencies, mental and physical with a varied range, of a stages.

For the collection of the facts we point out an inventory that was more or less structured. It was elaborate with a set routine for the interviews, with the subject matters directed towards the objective of our research, containing questions from anyone and some demographic information for a better characterization of the participants.

The interviews were taped, and transcribed, therby captivating the expressions of language used by those interviewed.

We followed the following steps: First the written part of the interview was read, and then we began the analysis of the extensive material collected during the interviews. Then we had the recordings, assigning a person to take notes, and write down the analysis**.**

In order to treat the information gained we used the analysis of the content. This provides multiple technical factors and it has as its final results, the inference of knowledge relative to diversified content. With the aid of this technique of analysis of content we were able to obtain the indication of possible beliefs of the parents of the persons with deficiencies. The care information of the interview were put in order and piled up in units, searching out what each one had in common. This is a process of codification which will permit the exact description of the peculiar relationship of the content. This all is in function of the type of analysis proposed, all of the categories in refernce to a certain subject are presented not being reoccupied in quantity.

3. DISCUSSION OF THE ANALYSIS

When analyzing the interviews with the parents of deficient persons, we found 10 indicators:

Knowledge about the deficiency, searching of knowledge, impact on life, discovery of deficiencies, possibilities and limitations, dependence, possibility of learning, protection, relationship of parents with child, sentiments (affectionate), expectancies

The information obtained from the parents during the interview permits us to understand the knowledge that these posses about the deficiency of their child. We recognized that they all have a lack of information about the situation, but even then there are very few that try to obtain more knowledge. The impact of the deficient child was manifested from the information of the parents, in 3 ways: the first being the need of change of routine especially of the mother. Some had to quit work or studying in order to dedicate more time to the child, other modifications were necessary in the realm of thinking. Another big impact in the life of the parents was the prejudices, and how to handle the prejudices in society. Many parents related the difficulty of obtaining a vacancy in the schools, because the child was seen as ill, this bringing on sadness to the parents.

The discovery of the child's deficiencies in some cases only showed up later, months or years after birth. We can say that this delay in discovering could possibly be to a denial in not wanting to admit that the child is deficient. In reality the possibility of their child's limitations, the parents believed that the child would be able to do activities that did not involve the affected part of the body of the deficient. The possibilities of learning are interrelated with the level of dependency of the deficient child, therefore the parents that characterized the child as having a great or total deficiency showed unfavorable attitudes in relation to the possibility of learning. The same thing happened with the factor of protection. The parents who are over protective of their child, were exactly those in which the child showed the greatest degree of dependency.

In the relationship of parents and a child that is deficient what we were able to notice was that the relationship was made more difficult when the deficiency was mainly in the cognitive area. We also detected from the conversation of the parents various sentiments, and even though there were many negative sentiments, the sentiment of satisfaction of the child's conquering something was also manifest. We found two types of expectations coming from the parents to the deficient child. Expectation of a cure and or betterment, being that the expectation of a cure comes in two forms: The first the intense aspiration for the cure is so great that it almost becomes an obsession, and secondly is when this waiting is a desire that may or may not come to pass.

4. FINAL CONSIDERATIONS

By looking at this information we can conclude that the parents have very little in relationship to the deficiency of their children. Maybe this is the explanation for expectancies, beliefs and irrational attitudes. Even though the idea that the parents hold in regards to deficiency is that stereotyped idea full of prejudices. The word deficiency is directly connected to cultural values of a society full of rules and regulations. Society selects and discriminates in the majority of times, the individuals that are out of line (rule) and of the pre-established patterns those called "abnormal" or "different". Thus from the vary start these children are subjected to an inferior plane or level, because of these prejudices elaborated and carried out on the social sphere.

The positive and negative expectations as to the development and future of their child can be influenced by the understanding of the information offered. Some misinformation may hinder in some cases the offering of specialized recourses necessary for the well development of the child.

Because of this it is necessary that there be more comprehension on the part of the parents in regards to the causes of the deficiency of their child and especially the consequences forthcoming from these causes. It is necessary that the family receives the greatest possible information, starting with the information given by the doctor, and up to the accompaniment realized by schools and institutions specialized, that all their doubts or questions be made clear, so that in this way they can be secure in their fundamental decisions of the best development of their child.

Because of this the follow up of the parents with the psychologist is essential, hoping for a redirection of their lives so that the deficiency of the child is not considered the only accidental factor , that the family, is not able to realize their dreams or plans.

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THE PARENTS OF CHILDREN WITH DIFICIENCIES : THEIR BELIEFS IN RELATIONSHIP TO THEIR CHILD'S DEFICIENCY: POSSIBILITIES AND LIMITATIONS.

ABSTRACT

The parents have an important participation in the development of the children. They are the ones who will search ways so that their child can grow up to become independent.. The deficiency is considered as a frustrating experience for the family. Its diagnosis generates in the begetters an emotional misalignment, mobilizing them in the direction of the need to adapt to a new situation. The attitudes that they have in relation the deficient child results in their beliefs. The beliefs, in turn, are based on the cognitive structures on which the attitudes are based. With the objective of unveiling the beliefs of parents of deficient children, with regards to the deficiency of their child's, possibilities and limitations and the importance of their participation in the accomplishment of the education process of learning, we carried out through 50 interviews with parents of pupils registered in PROAMDE - Program of Motor Activities for Deficient of the Federal University of Amazon. For the accomplishment of the interviews a half-structuralized script was used, previously tested. The data obtained was analyzed qualitatively through the analysis of contents. Through the analysis we acquired ten pointers: knowledge of the deficiency; searching of knowledge; impact on life; discovery of the deficiency; possibilities and limitations; dependence; learning possibilities; protection, and relationship of parents with their child, sentiments (Affectionate) feelings ;expectations and beliefs. We perceive that the parents had shown negative feelings in relation to their child and good part of them still possess the belief of the cure for the son. Such behaviors are related mainly to the lack of information since all the parents had shown a lack of knowledge about the deficiency of their child. For this reason it is necessary not only the accompaniment of the doctor, for the children, but much more information on the part of these professionals, for the parents as well as psychological support, aiming to help them in the emotional reorganization themselves in way that the deficiency of the child is not seen as something terrible, making the genitors look for the potentialities of the child, and not at their limitations, thus facilitating the process of learning of the child.

Key-words: Beliefs, deficiency, parents.

LES PARENTS DES GENS AVEC DÉFAUT : SES CROYANCES EN RELATION A DÉFAUT DE SON FILS - POSSIBILITÉS ET LIMITATION

RÉSUMÉ

Les parents ont une importante participation dans developpement du fils. Sont lui que chercheront millieurs pour qui le fils puissa grandir, dévellopper et devenir indépendance. La défaut est considerée comme une expérience frustrée par la famille. Son diagnostique cause dans les parents un pertubation emocionnelle, les mobilisant au sens de se adapptarient a nouvelle situation. Les atitudes de leurs dans les liens avec son fils déficients en resultant des ses croyancess. Les croyances, sont scructures cogntives basilaire sur lesquells les atitudes se fundent. Avec l'objective de reveler les croyances de parents de déficients avec relations à la défaut de son fils, possibilités et limitations, a été realisée 50 (cinquante) enterview avec parents des élèves inscrit au PROAMDE - Programme des activités moteurs pour déficients de l'Université Federal d'Amazonas. Pour la réalisation de les enterviews a été utilisé un recit demi-structurée, avant testée. Les colletes d'informations obtenue a été analysée qualitativement à travers de l'analyse de contennus. À travers de l'analyses obtenons 11 (onze) indicateurs : connaissance sur la défaut recherche du connaissance, impacte dans la vie decouverte de la défaut, possibilité et limitations ; dépendance, possibilité de l'apprentissage, protetion, lien père et fils, sentiments (afectivité), expectatives ; nous apercevons que les parents demonstrent sentiments negatives dans relation au fils et une part posséde a espoir de la guérison de son fils. Telles conduite ont relationées principalement à faute d'information dejà que leurs demontreraient ne pas connaître la défaut de son fils. Ainsi, il faut que ne seulement l'accompagnement du médecin par les enfants, mais meilleurs information de la part de cettes profissionelles para les parents aussi comme un support physicologique. En visant les aider, dans reestructuration emocionel de manière que lá défaut du fils ne soit pas regarde, comme une chose terrible, en faisant les parents regarder par les potencialités de les enfants et ne pas pour ses limitations, en facilitant ainsi au processus de enseignement - apprentissage du fils.

Mots - Clefs: Croyances, défaut, parents

LOS PADRES DE PERSONAS CON DEFICIENCIA: SUS CREENCIAS EN RELACIÓN A LA DEFICIENCIA DE SUS HIJOS - POSIBILIDADES Y LIMITACIONES

RESUMEN

Los padres tienen una importante participación en el desarrollo de los hijos. Son ellos que buscan medios para que el hijo pueda crecer, desarrollarse y tornarse independiente. La deficiencia es considerada como una experiencia frustrante para la familia. Su diagnóstico genera en los genitores un desajuste emocional, movilizándolos en el sentido de adaptación a la nueva situación. Las actitudes que ellos tienen en relación al hijo deficiente resultan de sus creencias. Esas, por su vez, son estructuras cognitivas básicas sobre las cuales las actitudes se fundamentan. Con el objetivo de dar una luz a las creencias de los padres de deficientes con relación a la deficiencia de sus hijos, posibilidades y limitaciones, fueron realizadas 50 entrevistas con padres de alumnos matriculados en el PROAMDE - Programa de Actividades Motoras para Deficientes de la Universidad Federal del Amazonas. Para la realización de las entrevistas, fue utilizado un rol parcialmente estructurado y previamente probado. Los datos obtenidos fueron analizados cualitativamente a través de la análisis de contenidos. Por medio de ellas, se retiró once indicadores: conocimiento sobre la deficiencia; busca del conocimiento; impacto en la vida; descubierta de la deficiencia; posibilidades y limitaciones; dependencia; posibilidades de aprendizaje; protección; relación padre e hijo, sentimientos (afectividad); expectativas. Se notó que los padres mostraron sentimientos negativos en relación al hijo y buena parte todavía posee la creencia de la cura para el hijo. Tales conductas están relacionadas principalmente a la falta de información, ya que todos los padres mostraron no conocer la deficiencia del hijo. De ese modo, se hace necesario algo a más que el acompañamiento médico para los hijos, como mayores informaciones para los padres por parte de eses profesionales, así como un apoyo psicológico que vise ayudarlos en la reestructuración emocional para que la deficiencia del hijo no sea vista como algo terrible. Con eso, los genitores logran visualizar las potencialidades del hijo y no sus limitaciones, destacándose, así, en su proceso de enseñanza y aprendizaje.

Palabras-Claves: Creencia, deficiencia, padres.

OS PAIS DE PESSOAS COM DEFICIÊNCIA: SUAS CRENÇAS EM RELAÇÃO A DEFICIÊNCIA DE SEUS FILHOS - POSSIBILIDADES E LIMITAÇÕES

RESUMO

Os pais têm uma importante participação no desenvolvimento dos filhos. São eles que buscarão meios para que o filho possa crescer se desenvolver e tornar-se independente. A deficiência é considerada como uma experiência frustrante para a família. Seu diagnóstico gera nos genitores um desajuste emocional, mobilizando-os no sentido de se adaptarem a nova situação. As atitudes que eles têm em relação ao filho deficiente resultam das suas crenças. As crenças, por sua vez, são estruturas cognitivas básicas sobre os quais as atitudes se fundamentam. Com o objetivo de desvelar as crenças de pais de deficientes com relação à deficiência de seus filhos, possibilidades e limitações, foram realizadas 50 entrevistas com pais de alunos matriculados no PROAMDE - Programa de Atividades Motoras para Deficientes da Universidade Federal do Amazonas. Para a realização das entrevistas foi utilizado um roteiro semi-estruturado, previamente testado. Os dados obtidos foram analisados qualitativamente através da análise de conteúdos. Através das analise retiramos onze indicadores: conhecimento sobre a deficiência; busca do conhecimento; impacto na vida; descoberta da deficiência; possibilidades e limitações; dependência; possibilidades de aprendizado; proteção; relação pai e filho, sentimentos (afetividade); expectativas; Percebemos que os pais mostraram sentimentos negativos em relação ao filho e boa parte ainda possui a crença da cura para o filho. Tais condutas estão relacionadas principalmente à falta de informação já que todos os pais mostraram não conhecer a deficiência do filho. Desse modo faz-se necessário não só o acompanhamento médico para os filhos, mas maiores informações por parte desses profissionais para os pais assim como um apoio psicológico, visando ajudá-los na reestruturação emocional de modo que a deficiência do filho não seja vista como algo terrível, fazendo os genitores olhar para as potencialidades do filho e não para suas limitações, facilitando assim no processo de ensino aprendizagem do filho.

Palavras-chaves: Crenças, deficiência, pais.