

29 - THE ESSENTIAL INTERVENTION OVER CHILDREN WITH SYNDROME OF DOWN, IN THE SEARCH FOR AN INDEPENDENCY BASED ON THE INDIVIDUAL APTITUDES

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INTRODUCING AND PROBLEMATIC

The Syndrome of Down is a genetical alteration that occurs in the baby's development on the beginning of pregnancy, described for the first time by an English doctor in 1866.

Different from what its thought, the Syndrome of Down is not a sickness not even contagious. It is, in fact, a genetical accident that occurs in the cell division, a process out of the parents, doctor or scientists control.

This genetical alteration is characterized by the presence of one extra chromosome in the 21 pairs, causing an error on the distribution, it means, instead of 46, a person with Syndrome of Down has 47 chromosomes in the cells what uses to be called also trissomy of 21. This syndrome happens with no difference in boys and girls.

O'Regan (2007) affirms: "there is not a specific reason for the mutation: its is not a result from what the parents did or didn't do. The extra chromosome can come from the father's sperm or the mother's ovule, or it can happen very after the conception. Women older than 35 seem to be quite susceptible of having babies with Down, but, the father's age seems not to have a similar effect".

There is not "Down degree", but, three Syndrome of Down types: about 95% of babies with Syndrome of Down have trissomy 21 for not-disjunction, already said in this work, and the other 5% are for translocation or mosaicism.

For trissomy of 21 by translocation, there is three copies of the chromosome, however, the extra chromosome is connected to another chromosome, generally the chromosome 14, or other chromosome 21. The estimative is that 3 to 4% of babies with Syndrome of Down have trissomy for unlocation.

The third and last form is known for mosaicism. A round 1% of the people with Syndrome of Down, present this type of trissomy of 21. On the mosaicism occurs an imperfect cell division in one of the first cell divisions after the fertilization; this fact turns into a differential, because, in the two other trissomies, the error in cell division happens before fertilization.

When it is discussed about essential intervention, it shall be understood that this intervention is different from childish stimulation, even the names being similar, the approaches are different, it means, the intervention consists on the interest of developing older babies and children, leading the groups to offer products, ideas and classes methods.

Now, the essential intervention is an union of several types of educational approaches for several types of syndrome, or even to the same syndrome that is characterized mainly for involving the children with the parents and the professionals in the intervention actions, building by this way a special educational program, planned to help on the potencialization of the babies development; therefore, a special baby needs a special intervention.

Many times, the approach is rounded by a team with professional from several areas, demonstrating the objective of making this approach with the patient or the student by the biggest manner it is possible, because, as it had already being said over here, the development does not happen in a pattern, not even in a linear and consistent manner.

According to MCCoonnaughey and Quinn apud Stray-Gundersen (2007); "there is not a substitute for the direct parental development and, with the helping of teachers and other professional, the parents can make a very big difference".

Although this is an area on what a lot of experiences and tries have been made, because according to what is was said here before, each child is unique into its motor and cognitive knowledge development. It is ot possible to think on the approaches in a tight way, once one is connected to the other, being the results very peculiar for a child to another.

"Anyway each child is different. To learn how your child development is affected and how to manage and interact in the best form for helping the kid to grow up and develop, is the main target of the precocious intervention" (Diamond apud Stray-Gundersen, 2007)

OBJECTIVE OF THE STUDY

To analyse the perception of the parents and professionals about the essential intervention act over a child with Syndrome of Down and the search for independency, respecting and stimulating the child individual aptitudes.

METHODOLOGICAL TEORIC MARK

On the building and delimitation act of this research, I defined the limit of the research would be a study of case inside the qualitative paradigma, cause, according to Freire (2000) "it is necessary to move out from the technical view to a vision that takes the afetive cognitive and socio-cultural dimensions of the Phisical Education".

The qualitative paradigma was chosen, because it is studied the universe of each individual its everyday, considering the socio-cultural phenomons what these parameters are submitted to. As said by Godoy (1995) "it is a research that consider the natural environment like a data direct source and the researcher as a fundamental instrument; it is descriptive, uses the written word like a data analyse and obtention form, shall be an essential care of the investigator the meaning that the people are the things of life, on this kind of investigation, the investigators use a lot the deductive focus".

The instrumentation and the data collection on the limit in study of case takes for a start point the observation and the data analysis through the following instruments: analysis of documents, bibliography analysis, recordings (stereo), interviews (semi-structured), transcriptions, questionnaires and the diary. The data were collected for the researcher in person through the semi-structured interviess that gave flexibility to the data collection. The interviewed were several professionals involved in the different approaches of essential stimulation of the girl with Syndrome of Down, beyond the girl's family and their respective acts on the studied process.

The study of case is about a 6 years 10 months girl, student of a primary school from the municipal system of Estância Velha City/RS, With Syndrome of Down, Type trissomy of 21 for not-disjunction.

After the collection and transcription of the interviews, the triangle act or triangulation, happened in a temporal way, what was then primordial for the units of meaning organization, characterizing in it's timeline, where it wal molded in past, present

and future (how it was, how it is, how it shall be...).

CONCLUSION

One thing is right, there is not an approach, but, lots of approaches that reflect in lots of tries of several thought lines, turning evident how diverse we are, and in these approaches building, inside its specific contexts there is the work with the interdisciplinary focus, where each professional works on its area of acting, objectiving the independency through the essential intervention.

"It is the team work that makes us to stand the exhaustion, that help us to pass the obstacles over" (Pacheco, 2004).

Anyway in the beginning of the research, while defining the theme, it was understood that the work of the professionals involved in the intervention process was the primordial point for the process success, but, during the research growing on, firstly of the referentials and on sequency of the interviews, I was noted that the key point of the process was only and exclusively the family and its direct involvement on the process.

"Remember, thought, that your objective is to equilibrate all the competitive exigencies, in a manner that all, in the family, can be an equivalent member and co-worker. This is the challenge that all the genitors face, having them a child with deficiency or not" (Jarret apud Stray-Gundersen, 2007).

The question is not the number of envolved professionals, but, if the family is efetively a part of the process.

The family is, in fact, the approach and not the person who has special necessities, because, these same parents show themselves wide open for new experiencies, being, most of them, actively present in the process, charging, getting informed, investigating, asking, it means, presents and mainly participants, making part of the interdisciplinary team and being detached like the main part of the process.

It is important to elucidate the peculiar involvement of this family that together with the professionals formed a real interdisciplinary team.

Are observations that lead us to a mental changing, that results on the search for a new culture, that calls for the education not of the patient-student, but, of a citizen that knows and is able to exercise this education. Although we are just on the beginning of a walking, if we make a good work, it will bring some relevant results for the envolved parts, but, for all the context around.

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THE ESSENTIAL INTERVENTION OVER CHILDREN WITH SYNDROME OF DOWN, IN THE SEARCH FOR AN INDEPENDENCY BASED ON THE INDIVIDUAL APTITUDES

ABSTRACT

The main target in discussing the essential intervention is to finish with the segregation that exists in the current system, because the construction the citizenship is only reached with the incorporation of diversity. An essential intervention shall not be understood only from the motor aspect, in the motor aspect, in the move acquisition, but, from its several meanings and on what it can result to. The present study intends to analyse the parents and professionals perception about the essential intervention over a child with Syndrome of Down and the search for independency, respecting and stimulating the child individual aptitude. The methodology defined for this research was the study of case inside the qualitative paradigm, once it studies the individual everyday, considering the phenomenons this individual is submitted to, through a temporal analysis. After the datas collection and analysis, the conclusion is that the success of the intervention is only possible with the existence of an interdisciplinary team because the progress onto one area applies a sequency over the development of another, once they are connected. Nevertheless, the primordial point of this interdisciplinary approach is the family, being the intermediary agent of the essential intervention, the beginning, the middle and "the end" of the process.

KEY WORDS: Syndrome of Down, Essential Intervention and Interdisciplinary Approach.

INTERVENTION ESSENTIELLE AVEC DES ENFANTS TRISOMIQUES, À LA RECHERCHE D'INDÉPENDANCE AVEC POUR BASE LES APTITUDES INDIVIDUELLES

RÉSUMÉ

Le principal but discuter l' intervention essentielle est de mettre im terme à la ségrégation qu'il y a dans le système actuel, car la construction de la citoyenneté est seulement atteinte avec l'incorporation de ladiversité. L'intervention essentielle ne peut être comprise uniquement dans L'aspect moteur, dans l'acquisition du mouvement, mais à partir de ses différents sens et ce que cela engendre. Cette étude a pour objectif d'analyser la perception des parents et des professionnels sur le rôle de l'intervention essentielle pour un enfant atteint de trisomie 21 (Syndrome de Down) et la recherche d'indépendance, en prenant en compte et stimulant ses sptitudes individuelles. La méthodologie définie pour cette recherche a été une étude de cas, dans le paradigme qualitatif, puisqu'elle étudie le quotidien de l'individu, en considérant les phénomènes auxquels il est soumis, à travers une analyse temporelle. Après analyse des données recueillies, la conclusion est que le succès de l'intervention est possible seulement si il y a une équipe multidisciplinaire, car le progrès dans une zone a des répercussions sur le développement d'une autre zone. Puisqu'elles sont liées. Toutefois lepoint primordial de cet abordage multidisciplinaire est la famille, qui est l'agent médiateur de l'intervention essentielle du début jusqu'à la fin du processus.

MOTS CLÉS : Trisomie 21 (ou Syndrome de Down), Intervention Essentielle et Abordage Multidisciplinaire.

LA INTERVENCIÓN ESENCIAL EN NIÑOS CON SÍNDROME DE DOWN EN LA BUSCA POR INDEPENDENCIA CON BASE EN LAS APTITUDES INDIVIDUALES

RESUMEN

La principal meta en discutir la intervención esencial es acabar con la segregación que hay en el sistema vigente, pues la construcción de la ciudadanía sólo es alcanzada con la incorporación de la diversidad. La intervención esencial no debe ser comprendida sólo en el aspecto motor, en la adquisición del movimiento, pero a partir de suyos varios significados y en aquello que puede desencadenar. El presente estudio tiene por su objetivo analizarla percepción de los padres y profesionales sobre el papel de la intervención esencial en un niño con Síndrome de Down y la busca de independencia, se respetando y estimulando sus aptitudes individuales. La metodología definida para esta investigación fue el estudio de caso, dentro del paradigma cualitativo, ya que estudia el cotidiano del individuo, considerando los fenómenos la que está sujeto, a través de un análisis temporal. Tras la colecta de análisis de los datos, la conclusión es que el éxito de la intervención sólo es posible se hubiere un equipo interdisciplinario, pues el progreso en un área tiene secuencia en el desarrollo de otra, ya que están interligadas. Sin embargo el punto primordial de ese abordaje interdisciplinario es la familia, siendo el agente mediador de la intervención esencial el inicio, medio y "fin" del proceso.

PALABRAS LLAVES: Síndrome de Down. Intervención Esencial y Abordaje Interdisciplinario.

INTERVENÇÃO ESSENCIAL EM CRIANÇAS COM SÍNDROME DE DOWN, EM BUSCA DE UMA INDEPENDÊNCIA COM BASE NAS APTIDÕES INDIVIDUAIS

RESUMO

A principal meta em discutir a intervenção essencial é acabar com a segregação que há no sistema vigente, pois a construção da cidadania só é atingida com a incorporação da diversidade. A intervenção essencial não deve ser compreendida apenas no aspecto motor, na aquisição do movimento, mas a partir de seus vários significados e naquilo que pode desencadear. O presente estudo tem por seu objetivo analisar a percepção dos pais e profissionais sobre o papel da intervenção essencial em uma criança com Síndrome de Down e a busca de independência, respeitando-se e estimulando as suas aptidões individuais. A metodologia definida para esta pesquisa foi o estudo de Caso, dentro do paradigma qualitativo, já que estuda o cotidiano do indivíduo, considerando os fenômenos a que está sujeito, através de uma análise temporal. Após a coleta e análise dos dados, a conclusão é que o sucesso da intervenção só é possível se houver uma equipe interdisciplinar, pois o progresso em uma área tem seqüência no desenvolvimento de outra, já que estão interligadas. Porém o ponto primordial dessa abordagem interdisciplinar é a família, sendo o agente mediador da intervenção essencial o início, meio e "fim" do processo.

PALAVRAS CHAVES: Síndrome de Down, Intervenção Essencial e Abordagem Interdisciplinar.