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PSYCHOLOGICAL SUPPORT TO FAMILIES OF STUDENTS WITH DOWN SYNDROME AT MUNICIPAL OFFICE IN LOBITO

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Abstract: It is our interest to study the psychological support of familiesof students with Down Syndrome.Internationally, social and scientific development to improve the system of actions aimed at raising the quality of life and education of children and their families is a priority. And Angola is no exception to the rule, seeking, in universities and beyond, to develop studies on people with disabilities, the educational role of the family, social incorporation and support networks, promote lectures, counseling sessions for families. Hence we raise the following problem: how to support the families of students with Down Syndrome? It is, therefore, our general objective: To create strategies of support and psychological orientation to the families of students with Down Syndrome. In light of the general objective, we aim to:Search for theoretical references on psychological support for families with children with Down Syndrome; to characterize the current state of psychological support and guidance for families of students with Down Syndrome treated at the GAP (Psychopedagogical Support Office) of the Lobito Municipal Education Department; to evaluate the results that are obtained with the application of the proposed psychological orientation strategy for the preparation of families of children with Down Syndrome assisted in the GAP. For the present investigation work, we defined as Population the totality of the families of students with Down Syndrome assisted in the GAP. The application of the qualitative research method, the participatory action, allowed us to operationalize the studied variable, provided us with practical elements for the systematization of information and for the characterization of the object of study, whose results allow us to affirm that the research developed is applicable the preparation of the family and the community in terms of psychological and educational support for the stimulation and integral development of children with Down Syndrome.

Keywords: Psychological Support, Family, Down Syndrome.

INTRODUCTION

The social development and scientific progress that contribute to improve the quality of life and the level of schooling of children, as well as families, is presented as a global priority. In parallel with this aim, the need to invest in a society and in school systems that promote inclusion by facilitating access and, above all, success for people who are different, has increased (UNESCO, 2004). Studies on children with Down Syndrome have made it possible to reinforce psychological support for their families, maintaining investment in the search for everything that can contribute to the improvement of these services (Madrigal, 2007).

In Angola there is little work experience in caring for people with disabilities and, in particular, those with Down syndrome. It is true that in the Municipality of Lobito we have the Psychopedagogical Support Office of the Municipal Department of Education, Science and Technology. However, this does not meet the needs of the entire population and the care model in use responds to a narrow view of this medical condition (disability), which does not include the family, psychopedagogical care in the management of other institutions to meet the educational demand of students with Down Syndrome.

Authors such as Carther, Bueno and Ingalls (2010, p.67) see Down Syndrome as “one of the most frequent congenital syndromes in the etiology of mental retardation, that is, the most prevalent chromosomal abnormality and, in turn, the cause recognized as the most frequent of mental retardation. One of the variants of Down Syndrome is trisomy 21. Trisomy 21 and most trisomies are usually caused by a lack of separation of the chromosomes in the first division of miosis (deductional miosis), a phenomenon that is known as non-disjunction. This lack of disjunction can also occur, although less frequently, in the second division of miosis or in the first divisions of a normal zygote. This last situation determines the appearance of Mosaicism, that is, the appearance of two or more cell lines with different numbers of chromosomes or with different chromosomal morphology. *(*Mustacchi & Peres, 2000, p.54).

With advancing age, according to Coelho (2018 pp. 5 and 6), "there is a food intake, which justifies monitoring the diet and the practice of physical exercise. As for the genitalia, in men, the penises are small and there is cryptorchidism; in women, the lips and clitoris are poorly developed. Boys are sterile, but girls ovulate, although periods are irregular."

From what has been said, Down syndrome requires a multi and interdisciplinary intervention, because:

Clinically, individuals with Down Syndrome may have multiple associated medical conditions, in which vision and hearing problems, obstructive sleep apnea and congenital heart disease prevail. The prognosis of Down Syndrome varies depending on possible complications such as heart problems, susceptibility to infections and eventual development of leukemia.

If, in the view of Coelho (2016, pp.5 and 6), "obstructive sleep apnea affects between 50% and 75% of cases of Down Syndrome, and can lead to aspects such as snoring, pauses in breathing, abnormal postures during sleep", sleep, daytime drowsiness, irritability and fatigue", in La Peña's (2002, p.93), "cardiac malformations associated with Down Syndrome are predominantly caused by defects in the endocardial cushion". These structures are formed in the embryonic period and give rise to the interatrial partition, the part of the interventricular partition and the valves that communicate the atria and ventricles.

On a psychological level, Down Syndrome is the most common cause of mental retardation, the intellectual quotient (IQ), which can be determined through the administration of a standardized intelligence test, which can vary between *mild* degrees (IQ between 50 and 70,) moderate (IQ between 35 and 50) and *severe* (IQ between 20 and 35), placing most cases in the *mild and moderate degrees.* Individuals with Down Syndrome have a delay in neuropsychological development, with a predominance of motor deficits in early childhood and cognitive deficits in school age. (Coelho, 2016).

Most of the limitations in the development of the brain appear during the first months and years of postnatal life, causing a reduction in the population of cortical neurons and in the capacity of synaptic connection. According to Florez (1993, p. 37), "deficiencies in synaptic transmission, in the integration of evoked potentials and in the functional correlation between different cortical lobes are often observed. These alterations preferentially affect the primary and association areas, the frontal cortex, the hippocampus and the cerebellum".

Other literatures indicate the presence of difficulties in the transmission process of some neuronal circuits, promoting the cognitive level, attention problem, higher reaction times, problems in auditory-vocal processing and in short and medium term memory, difficulties in of correlation, analysis, calculations and abstract thinking, limitations in perceptual discrimination, in the ability to generalize and in symbolization, she may also have difficulties with fixing eyes due to slowness and muscular hypotonia. Hearing difficulties can lead the child not to hear and to prefer visual and concrete means of communication. (Coelho, 2016, pp.6,7).

The reality of family life changes with the birth of a child. But when a child with Down Syndrome is born, their dynamics become even more complex, giving rise to feelings of rejection, pity, guilt and other negative attitudes. As a matter of fact, feelings of insecurity, isolation, anxiety and low self-esteem are generated among the closest family members, which make it difficult for the family to work in the formation of the personality of these students and, on occasions, and demotivate them in the effort to face the treatment that such students students require. It is in this particular that psychologists can intervene to help in the curriculum planning to be carried out by teachers, as well as support students in the interaction with colleagues in the classroom and teams of a multidisciplinary nature can create strategies that integrate adequate motor tasks, cognitive promotion and social interaction, in order to promote higher levels of quality of life in children (MOISÉS & Rebeca, 2011).

THE ROLE OF THE PSYCHOLOGIST INSTUDENT FAMILIES WITH DOWN SYNDROME

The psychologist assumes a decisive role in the development, social, affective and physical well-being of people with disabilities, mainly in childhood and adolescence, intervening, through guidelines, in the family with the aim of providing a preventive modality of mental and physical health and help in family relationships permeated by a network of fantasies, anxieties, defenses and conflicts that are externalized in the relationships between parents and children. It is justified because parental attitudes, conscious or unconscious, can affect the emotional state of children. Therefore, the psychologist's role consists of empowering the group in its real capacities and helping them to find the solution through the search for emotional resources (Vizzotto & Gomes, 2009, p.72).

Within the family, the psychologist, when helping the child and the family, showing the potential and strength that it brings, despite the difficulties that the child presents, will make the family invest in the person and not in the disease, showing them that despite the disease, she is a being with feelings and who needs to form her personality and, in order to be well formed, she needs the support of her family.

Given that psychology has the function of evaluating, directing and monitoring the person's motor, psychic and social development, and that Down syndrome conditions such as lifestyle, the level of learning, the psychologist helps family members to respect, listen, value and accept children as they are and believe in their dreams. The psychologist's action will ensure that the family members have a socio-emotional development capable of overcoming the fear, shame and prejudice of having such a child.

Within the scope of curriculum planning, the psychologist assists teachers in the task of helping students with Down syndrome to interact with colleagues in the classroom and ensures a multidisciplinary intervention with the aim of creating a strategy of motor and cognitive tasks that stimulates them. children to have a better quality of life.

METHODOLOGY

The present study, of a descriptive nature, using a qualitative methodology, through a semi-structured interview with 15 families (parents of children with Downa Syndrome), assisted at the GAP (Psychopedagogical

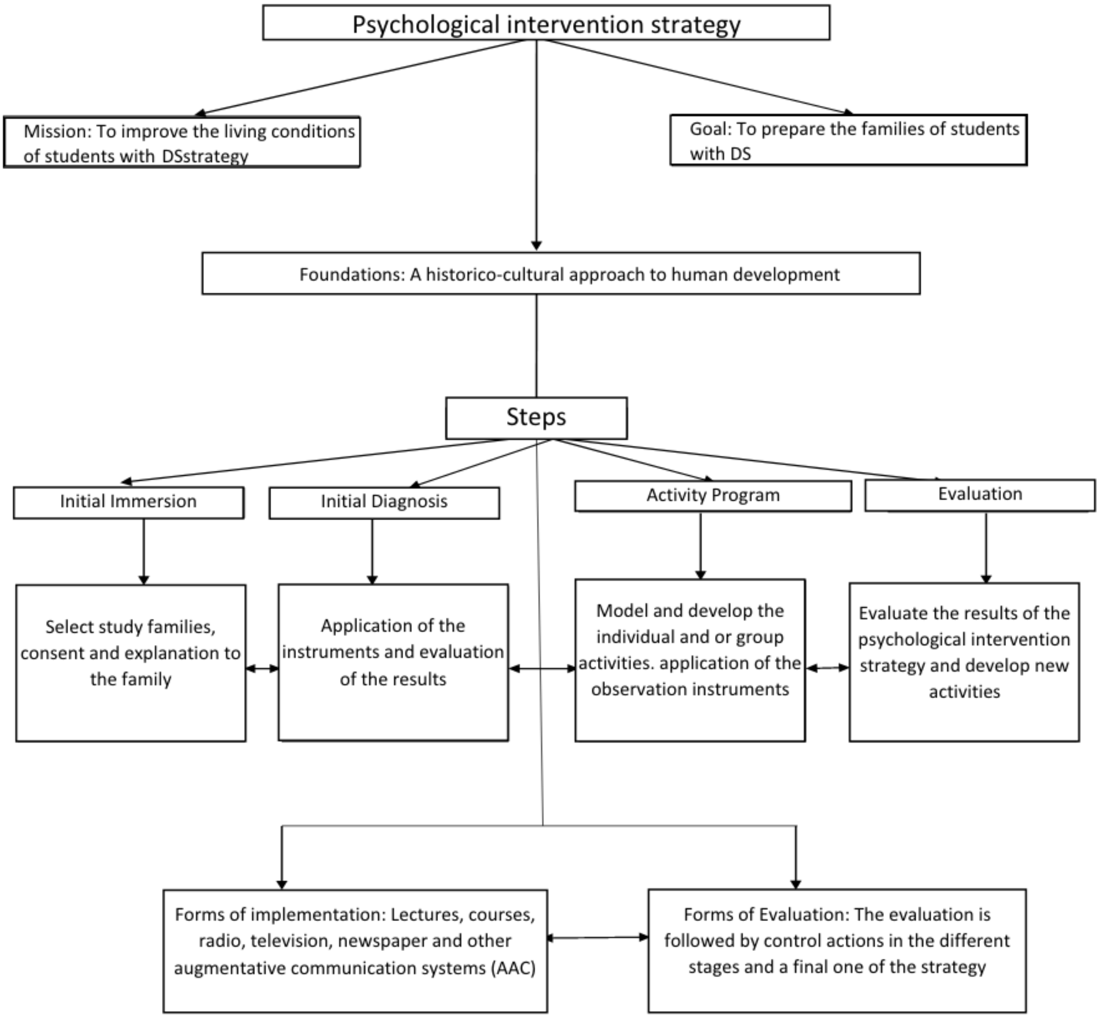
Support Office of the Municipal Department of Education), located in the Benguela Province, in the Municipality of Lobito.

The GAP opened its doors for the first time on October 22, 2015. There are 3 employees at the GAP, including a Director, a Coordinator (psychologist), and a vice-coordinator (pedagogue).Currently, the GAP monitors 20 children and their families, 20 with Down Syndrome, 4 with cerebral palsy and 4 with mental retardation, out of a total of 190 children enrolled with different special educational needs for their assessment, diagnosis and follow-up.

For the operationalization of the study, we elaborated tasks and actions, distributed in dimensions, as follows.

Dimension definitions: Support for families of students with Down Syndrome is conceived in the view of Sateleia (2016.p.48), "as a professional help that prepares parents to enhance the personal and social development of their children, as part of the preparation for life, of a preventive and/or corrective nature, the creation of basic conditions, supports and resources in lines of greater well-being of these children".

The first dimension is the educational function of the family, conceived as an active process of dynamic interaction with the child, where the roles, actions and responsibilities in the education and potentiation of the development of their children are manifested, which conditioned to a large extent by



the family of origin., family dynamics and the communication systems employed.Its indicators are:Survey: in this investigation, the strategy of guidance to Down Syndrome families to be applied in the Psychopedagogical Support Office was used at the discretion of the specialists. It is presented to them in the form of a closed questionnaire where they must evaluate aspects such as the foundation, structure, content, feasibility and evaluation for its subsequent implementation.

Preparation for the educational role of parents, which refers to the willingness and preparation before birth or once the diagnosis of the child with DS is known, to assume the attention that the child needs, which can be: High - when the family shows willingness to learn about the education of the child who expects and seeks information, support and advice; Medium – when the family is willing to learn about the characteristics of the child they are expecting, but in a passive way, without seeking actions in this sense; and Low – when the family shows little or no interest in finding out about the disability of the child they are expecting.

Attitude towards disability: refers to beliefs, opinions about the child's disability, acceptance of it and channeling the disturbing feelings, articulating in: High - when the family shows acceptance of the disability, properly channeling the initial disturbing feelings to be in conditions to offer the child the necessary treatment, being able to create a harmonious environment of trust and security that promotes the child's development and protects or preserves family functioning; Medium – when the family shows moderate or instability in accepting the disability, with difficulties in elaborating the negative experiences that it generates and does not achieve the necessary family dynamics in favor of the child's attention or good family functioning; and Low – when the family shows rejection or little acceptance of the child's incapacity, persisting the negative feelings that hinder the relationship and affect the family dynamics.

The second dimension concerns the educational methods used: they include actions that parents carry out on a daily basis and means on which they rely to educate their children and carry out their schooling, considering also to be: High - when the family carries out potentiating actions for the child's development. Corrective and/or compensatory activities, aimed at achieving autonomy, validation, communication, sociability or other areas according to the child's needs and possibilities, that is, taking advantage of their area of potential development, as well as the assessment of aids and support that other family members and the community can offer : Medium – when the family carries out corrective and/or compensatory activities, but not systematically, nor does it take into account all the real needs or possibilities of the child and does not always consider the support of other family members; and Low – when the family is not interested in carrying out activities aimed at the integral development of their child and does not seek the support of other family members or specialists.

The third dimension is social incorporation and support networks: it deals with the integration of parents in activities and/or social groups, as well as the existence of social support networks that support the family in the care of the child with physical limitations. motoras.Its indicators are: Social participation: the family's participation in charities, religious groups, political parties, community groups is explored, all for the purpose of helping. It is operationalized as follows: High – when the family systematically participates in social groups of different types that offer support in beneficial relationships for the parents and/or help for the children;

Medium – when the family participates but not systematically in social groups; and Low - when the family does not incorporate into social groups.

Social support: social resources accessible and/or available to a person, found in the context of interpersonal and social relationships and that can positively influence the well-being of the individuals involved in the process. Support from families of origin, friends, co-workers or other parents in the same situation, health institutions, education, social reintegration and NGOs is considered. It operates as follows: High -when the family demands the presence and/or participation of others to share experiences or evaluate solutions to face certain situations, considering the interpersonal relationship as a fruitful space for building well-being; Medium – when the family shows moderate interest in personal exchange as a source of social support; and Low – when the family does not seek or consider the benefits of the interpersonal relationship as social support.

The educational role of the family studied in the GAP is illustrated in the following graphs:

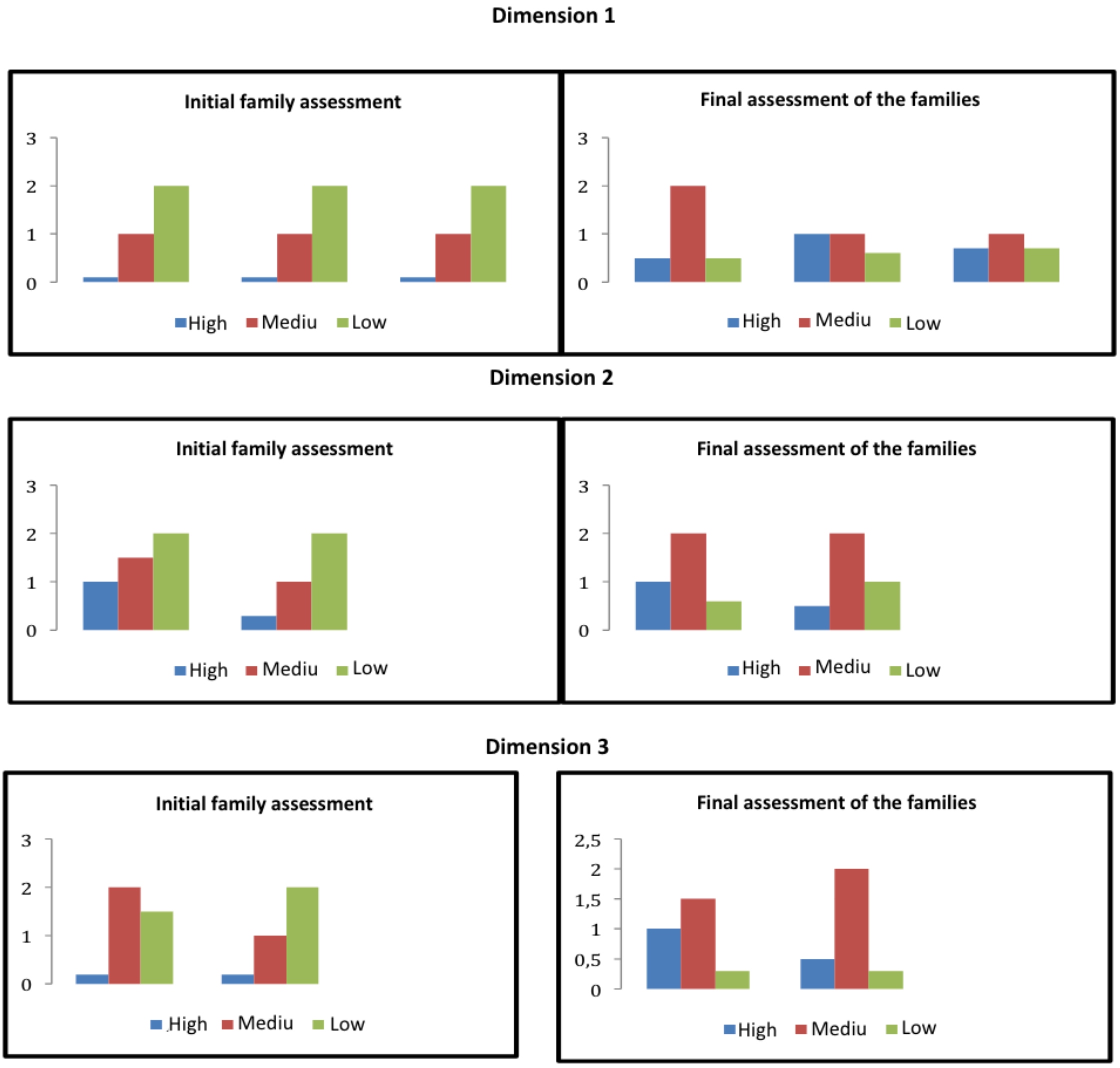


Figure 3: Initial and final assessment of indicators in the 3 dimensions.

RESULTS OF THE DIAGNOSTIC STEP

Distribution of families according to the dimensions and indicators of the variable: The result of the analysis of the data obtained through the different methods applied during the diagnosis, such as the interviews with families and observation, are detailed below:

In the 1st Dimension the educational function of the family, the variable was studied according to the Educational Guidance, which results in the following way:

The preparation of these families to play the educational role with their child diagnosed with DS is insufficient, despite their willingness to learn about disability (6 families) not all of them carry out active search actions in this direction and 4 show little interest in this aspect. This way, the existence of family dynamics that do not develop the potential of their children with DS in 8 of the families stands out.

In the indicator, attitude towards disability, families declare that they accept it, 9 out of 10, however the safety environment that promotes the child's development in 6 is not put into practice. It is an interesting result that most families, 7 out of 15, were able to adequately elaborate the negative experiences that their children's incapacity generates. The remaining 8 families openly express feelings of rejection or negative emotions such as sadness, anger and fear.

The educational methods used are inadequate in 10 of the 15 families, which is the indicator of the worst results in this dimension. These families are characterized by not putting into practice adequate resources for the formation of habits and skills in their children and by the difficulties in communicating with this child in all of them.

Mutual help family relationships in 10 of the 15 families showed low results. In addition, an inequitable distribution of roles was appreciated, with an overload of housework and care of the child with a disability for the mother and other female figures in the families.

Some causes that cause difficulties in the distribution of roles are the absence of a father figure, the existence of non-functional family dynamics, little diligence in seeking support from social networks and, to a lesser extent, the mothers' tendency to negative emotional states.

Dimension 2: Due diligence for environmental conditions and satisfaction of basic needs. The results in this second dimension, referring to the diligence carried out by the families, point to: The existence of economic difficulties in these families to guarantee the best environmental and material conditions for their children with DS. The economic income, not enough to satisfy the basic needs of 6 of these families, has an impact on the standard of living that they can achieve and on the possibility of offering a better quality of life to their children with DS. The low economic income of these families is associated, in 6 of them, with the impossibility of finding work for the adults responsible for the minor, because they are their primary caregivers. In the families there is no external help that improves their savings, only one of these families receives health insurance from the father's work center. Despite the willingness to provide recreation, rest and social well-being with alternatives that employ resource savings, these families were evaluated with low results. Efforts to improve the constructive state of the residences in favor of greater comfort for the child, nor the lighting and ventilation conditions in them, are not considered sufficient. It is also recognized the existence of difficulties in the disposition to eliminate architectural barriers where they reside. These problems were found in 8 of the 15 families in the study.

Dimension 3. Social incorporation and support networks.

In the third dimension, which includes incorporation and social support as an indicator, the results reveal that: Families direct efforts in the search for relationships external to family systems and participate socially, most of them, in religious groups. The greatest difficulties lie in social support networks, with 9 of the 15 families being disadvantaged in this important aspect. They do not have support from state or government organizations, nor from the center where their children receive rehabilitation treatment.

CONCLUSIONS

The training of families is recognized by the families themselves as being insufficient, despite their willingness to learn and train. They recognize not putting into practice and not using adequate resources and feel particular difficulty in communicating with children. The greatest difficulties also appear associated with the few social support networks, without state support and without differentiated framework in the rehabilitation center; the absence of the father figure, the existence of dysfunctional family dynamics and negative emotional states of the mothers. Psychological support for families of students with Down Syndrome struggles with the insufficient preparation of families and lack of actions that optimize the child's development. The contribution of the GAP of the Lobito Municipal Education Department is recognized in supporting families, overcoming difficulties and creating well-being. It is important to systematize psychological guidance actions for families of students with Down Syndrome and promote social training and legitimize the value of the family in the development of their children. Train health technicians to identify and inform families, from birth, and promote early follow-up.

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