

The student's families with disabilities in school, their needs and demands. Ecuador case

Las familias de estudiantes con discapacidad en la escuela, sus necesidades y demandas. Caso Ecuador

Investigación

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Abstract

This paper identifies the needs of families with children with disabilities, strengths to support educational processes and analyzes how family requirements affect the continuity of parents' life projects. This research aimed to know the emotional status of parents, commitment to the education of their children, the dreams of the family to ensure their inclusion in life.

In the analysis of the information gathered, from the implementation of the survey and focal groups, to the families of students who attend different special education schools was obtained as a finding that a high percentage of parents leave and/or delay their personal life projects because of the birth of a child with disabilities, just as a list of needs that educational institutions do not take into account or do not believe that must be satisfied. When the school has a role in providing the relevant supports to the student and his family with the aim of providing quality education to develop the highest levels of autonomy of their students.

Keywords: family, disability, inclusion, rights, education, life project, needs.

Resumen

El presente trabajo identifica las necesidades de las familias con hijos con discapacidad y analiza cómo los requerimientos de la familia influyen en la continuidad de los proyectos de vida de los padres, así como las fortalezas de la familia para apoyar el proceso de inclusión social y educativa de sus hijos e hijas con discapacidad.

En el análisis de la información recabada a partir de la aplicación de la encuesta y grupos focales a las familias de los estudiantes que asisten a diversas escuelas de educación especial, se encuentra que un alto porcentaje de padres de familia abandonan y/o postergan sus proyectos de vida personal a causa del nacimiento de un hijo con discapacidad, de igual manera se identificó un listado de necesidades que las instituciones educativas no toman en cuenta o no consideran se debe satisfacer; cuando es la escuela quien tiene la función de brindar los apoyos pertinentes al estudiante y su familia con el objetivo de brindar una educación de calidad que desarrolle los máximos niveles de autonomía de sus estudiantes.

Descriptor: familia, discapacidad, inclusión, derechos, educación, proyecto de vida, necesidades.

Introduction¹

In the framework of the continuous Curricular Design training course from the Functional Ecological perspective, developed by the *Universidad Politécnica Salesiana* in 2015-2016, an event attended by thirty special education teachers from thirteen institutions from all over Ecuador, the research project entitled "Study of the applicability of the functional ecological approach in institutions of Special Education of Ecuador" was formed, study led by the research group of Inclusive Education (GIE). As part of the topic addressed in the course, it was referred to the situation of the family of the person with a disability since their participation is relevant to achieve the learning objectives of students attending special education institutions.

The current paradigms that define disability also allow redefining the role of the family in the life of a person with a disability, the Convention on the Rights of Persons with Disabilities in its 1 article states: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments that, by interacting with various barriers, may impede their full and effective participation in society, on an equal basis with others."

This concept forces the family to banish ideas that regard disability as divine punishment or illness that prevents those people from fending for themselves. The historical evolution of the notion of disability emphasizes that the limitations are in the environment where the person develops. According to this concept, a family that does not appropriate this new conception of disability can become the first barrier to the growth of their son or daughter, and in this way also limit their own personal growth (Díaz, 2011, p. 125).

Knowing the needs, parenting styles, limitations and potentialities of the families of students with disabilities is an important step so that they

become the main support of the personal growth of their children and achieve a life project of their own, as well as a life project together with the family.

The support provided by specialized education services to families should be focused on accepting their child's disability status and complying with school regulations. The institutions do not analyze the situation of the parents from their personal sphere, how they feel, what dreams they have, how their presence affects a child with a disability, what their personal life plans are; no processes are observed where parents are supported to find themselves again, to resume their lives and their projects.

Teachers in special education institutions manifest almost no collaboration from parents in school activities, we wonder if parents do not find in school enough motivation and confidence about the educational proposal for their children. It may be that the educational design is decontextualized or does not meet the real demands of families. Very few teachers visit the homes of students with disabilities, the school-family relationship focuses on alleviating the difficulties of the student, but not on the family, however, in the literature consulted it is stated that, although the family which has a disabled member has greater challenges than other families, this should not mark or be an obstacle for those families to give up their own lives.

Given the importance of family participation in education, the following questions arise: What situations do they face and what are the support needs of the families of students with disabilities in school? What is the index of cancellation or postponement of the life projects of the members of the families with people with disability?

The present research's general objective was for teachers to identify the demands and potential of the families of students who attend special education institutions so that they can provide the support that the family and student require.

Theoretical basis

Currently in our society coexist different forms of families, a situation that makes it difficult

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to establish a general definition of family, however, for the purposes of this research, the family is defined as “the union of people who share a vital project of existence in common that is to be endured, in which strong feelings of belonging to these groups are generated, there is a personal commitment among its members” ... “(Palacios and Rodrigo, 1998, p.53). This definition allows us to go deeper into the fact that the family is the space where the needs of its members are met and at the same time are generated through a family life project and the attainment of the present and future dreams of each one of the members and its social projection (Palacios, 2008, p. 97).

For this reason the family is a space to be protected by society as stated in the Universal Declaration of Human Rights in article 16, numeral 3 and the Political Constitution of the Republic of Ecuador in 2008: “The family is the natural and fundamental element of society and has the right to the protection of society and the State” in line with the charter the Code of Children and Adolescents Articles 22 and 33 states that:

Children and adolescents have the right to live and develop in their biological family. As a matter of priority, the State, society and the family should take appropriate measures to enable them to remain in the family. In all cases, the family must provide a climate of affection and understanding that allows the respect of their rights and their integral development (Código de La Niñez y Adolescencia, 2003).

Families with one or more members with disabilities perform the same functions as a family without this condition. However, the birth of a disabled child constitutes an unexpected event for the family, and no family is prepared for that eventuality. Acceptance of a family member’s disability status requires a process in which the family member successfully addresses the unforeseen situation.

It is also known that many families fail to accept this process of acceptance and live immersed in a feeling of guilt and nonconformity. “Some are blocked and do not know how to react, others enter into a state of shock and trigger emotions that will

accompany them the rest of their lives” (Buscaglia, 1983, p. 27). Regardless of the time parents take to accept their child’s disability status.

Most of the needs of families with persons with disabilities are the same as those of all families; however, the presence of a disabled member may generate different requirements in the various stages of family life, needs mediated by Social, economic and cultural factors.

Many authors consider that the life process of a family with a disabled member:

It should be as close as possible to the processes of any other family. And we believe that it must also be prepared for the possible independence of the disabled person. Many times more than accepting and integrating the disabled person is difficult for the families to let them fly to the best of their ability and, in their case, to enable their independence (Fantova, 2000, p. 40).

Since time does not stop for the disabled person, at each stage of their life cycle demands different types of support from the family, therefore, it is imperative to meet the needs of families from an early age.

It is hoped that the family will not only accept the condition of disability of their child, but will become a space that empowers the person’s abilities to achieve the highest levels of autonomy.

For the family to be a positive environment for the disabled person, nothing is needed that goes against the spontaneity of the relationship, although sometimes the advice of other parents or specialists will do well to do things better (Fantova, 2000, p. 42).

Families should know that their children with disabilities have the same rights as others “to fall, to fail, to suffer, to censor, to curse, to despair. If we protect them from these experiences, we prevent them from living their own lives “(Buscaglia 1983, 95). It is important to reflect that “all families are currently experiencing tensions of this time in history” (FEAPS, 2000), That is, all families face tensions due to several



causes, the most common, and that have a direct impact on the learning process in the school are: tensions due to the limited time that the parents dedicate to the family and influence of the media; According to Minuchin (1998, p. 125), the family is made up of three subsystems, the parental, the conjugal and the filial, this means that:

The appearance of the disabled person can unbalance or exacerbate the imbalance in the relationship between the subsystems... For example, there are risks that the siblings may be left out, in the face of the greater attention required of the disabled person; or that the conjugal system can be resented ... (Minuchin, 1998, p. 126).

According to (Núñez, 2007) in the stage of adolescence and youth, families increase their concerns about the future of their children with disabilities: "What will become of him when we are no longer here? Can he handle it by himself Questions that can increase in parents the feeling of overprotection limiting the possibilities of self-realization and self-determination of the person with disability, it is here that the support for parents is indispensable for their children to assume and define their life project with their new projections and personal dreams, such as working, living alone among others (Valdés and Ángel, 2010).? Can he have an independent life? "(P.24)

At this stage young people with disabilities want a relationship of camaraderie with parents that takes into account the needs of the age and the challenges that this stage represents in their lives and guide them in the important issues of life. If parents assume an attitude of overprotection, they can influence the consolidation of a project of personal life disconnected from the interests of their child and on the other hand consider that the person with disabilities cannot have a project of their own.

These tensions that appear in families with people with disabilities can influence family plans and lifestyles, may encourage parents to change or postpone their personal projects planned before the birth of their disabled son or daughter. This

can also happen with the siblings, so families need additional support both to improve their own quality of life and to resume or support their personal and family projects (FEAPS, 2000) and thus become effective support for their child. From the educational point of view, the family is considered as the first and most vigorous natural resource and support for the children, therefore, working collaboratively with the family is a guarantee to enhance the life project of each person with disabilities; otherwise the family may become an obstacle to their development. According to Durán (2014), there are many overprotective parents who do not believe in the possibilities of their children, who look at their children as eternal children, prevent their living during activities of daily living, leisure, recreation and use of free time, consequently, any contribution to meet the needs of the family, will define the lifestyle of the disabled person and his family.

Consequently, the styles adopted by parents in the education of their children have a direct influence on their socialization; these models or educational styles are not fixed or stable models; they are referents that vary according to different factors such as age, sex, place that occupies among the siblings. . As a result of Baumrind's (1967) research on styles of parental educational practices, he refers to global behavioral trends, and this author identifies the following styles that parents adopt in education and parenting, the democratic, authoritarian, permissive and indifferent.

It is important to analyze that each family has its own lifestyle and circumstances that condition it, regardless of the presence of a member with disability, hence it is necessary to establish a way of life in the home where there are rules or regulations that make attractive the coexistence of all its members. It is important to emphasize that the lifestyle contributes to the formation of family identity; hence the way of life of the people is determined by the lifestyle of their family. "From a holistic perspective, it is necessary to consider lifestyles as part of a collective and social dimension,



which comprises three interrelated aspects: material, social and ideological” (Bibeau, Pedersen and Fuentes 1985: 23). From this integral perspective, lifestyles can not be isolated from the social, economic, political and cultural context to which they belong and must be in line with the objectives of the development process, aimed at enhancing the person in society through better situations of life and of biological, social and spiritual well-being, in harmony with the personal and familiar project, that is, life projects must be projects that allow the full realization of the individual.

When we refer to, self-fulfillment, life projects, we are placing the individual in the context of their everyday social relations as transformative and therefore critical, reflective, problematizing and proactive entities capable of giving new form and new meaning to situations Interactions of their environment, professional activity and personal life (D’Angelo, 2003, p.14).

This concept of life project is given through the lens of a holistic view of the human being, which takes into account the complex articulations of the person and their social environment. In agreement with D’Angelo, Maslow in his pyramid of needs places at the top, self-realization as the goal of the life of the person.

Self-realization is the full utilization and development of our talents and abilities, which is why self-actualization occupies the highest part of the hierarchy of needs (Chapman, 2007, p.8).

Human needs are usually developed in a sequence, firstly, the satisfaction of the physiological needs, followed by those of safety and then come the social ones that involve the self-esteem and the obtaining of achievements and abilities that are recognized by their surroundings and allow the acceptance in society and the achievement of the life project.

Life projects are not only limited to the individual plane, family life projects, also play a decisive role in the life of its members; the family’s life project is crystallized in actions and attitudes

that become the pillars on which family life is built To talk about family life projects is to talk about common life projects that contemplate the goals that are to be achieved as a couple, the family model that is sought to live as, what is expected of the children according to the ideals and strategies that can be used in the educational process. Family life projects allow us to cope with natural adversities in life and marriage, life with a partner or the type of family that has been configured.

It should be mentioned that the construction of the family life project is not incompatible with the construction of personal projects. The construction of life projects at both the family and individual levels is directly related to the lifestyles, which respond to the living conditions of people and their possibilities and potential.

Methodological basis

The present study is descriptive, it is intended to say how a particular phenomenon is and is manifested, making the effort to specify important properties of the subject under analysis, seeking to measure various aspects, dimensions or components of the subject under review. Measuring from the social sciences approach is to try to link abstract concepts with empirical indicators. An appropriate measurement instrument is one that records the observed data and represents the variables that the researcher has in mind. In order to approach the reality of people with disabilities and their families, to describe different aspects of family life that influence the educational process of students with disabilities and to quantify the observed, we have made use of the qualitative technique.

The qualitative approach through focus groups gave a wide margin of expression to the families and allowed us to observe and therefore register the potentialities and weaknesses of parents and families of students with disabilities. Every good measurement must meet two essential requirements: reliability and validity, so the technique of the focal group, much used in the social



sciences, correctly applied with a selection of appropriate sample for the study, manages to meet the demands of all research. The selected sample was 554 parents of students with disabilities from 13 special education schools in the country of the *Costa, Sierra* and *Oriente*. The data collec-

tion was carried out by the teachers of the above mentioned special education institutions who were students of the curricular design continuing education course from a functional ecological perspective, a response to people with disabilities in the year 2015.

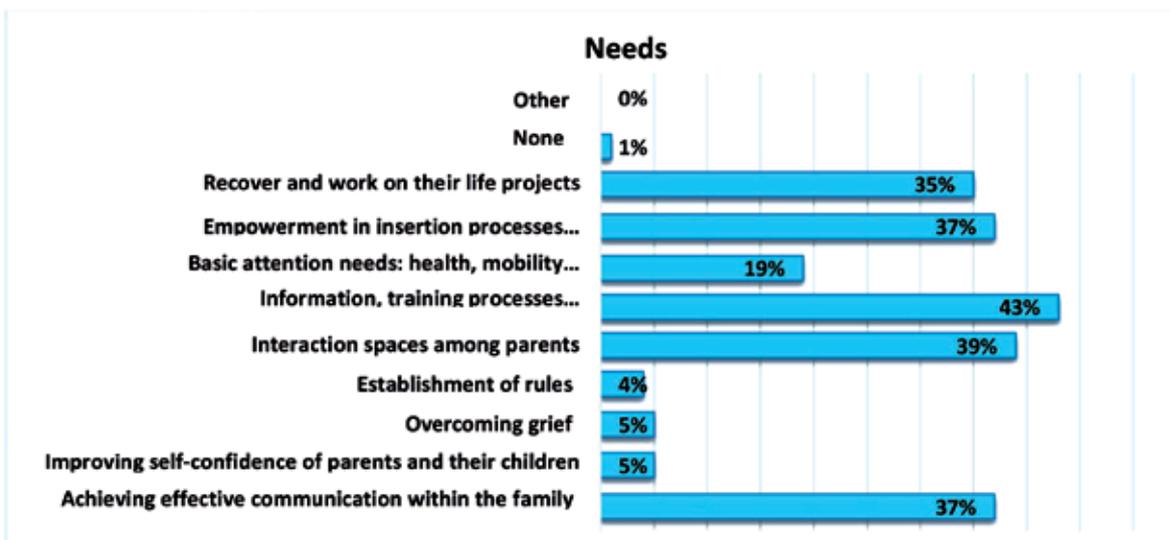
Chart1. Sample

Region	Province	N. School
Costa	Los Ríos	4
	Esmeraldas	1
	El Oro	1
	Guayas	1
	Santo Domingo de los Tsáchilas	1
Sierra	Pichincha	2
	Azuay	1
Oriente	Napo	2
Total		13

Source: GIE research group year 2016.
Own elaboration

Analysis and results

Figure 1. Needs of families of persons with disabilities attending special education institutions



Source: GIE research group year 2016
Own elaboration

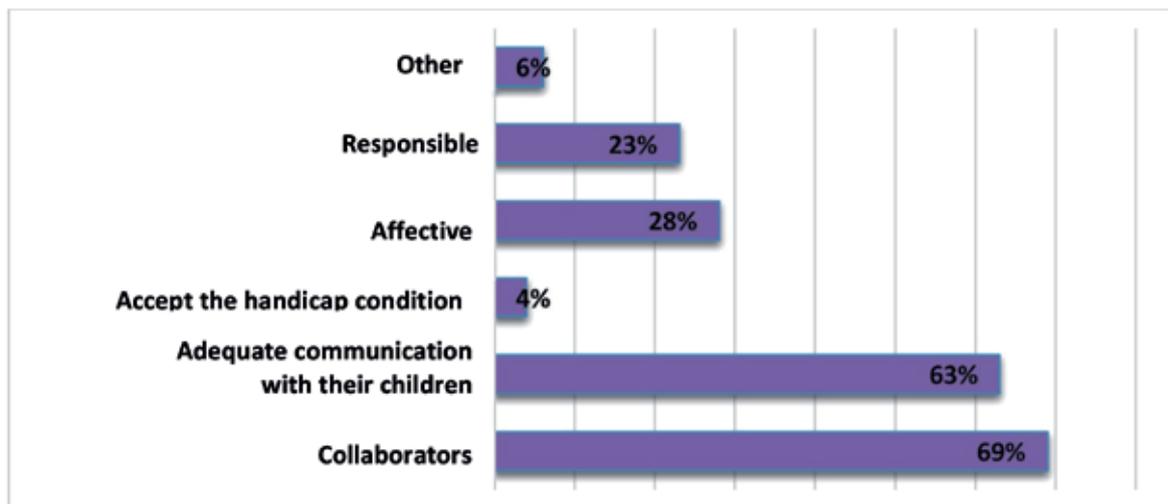


The most relevant needs expressed by the parents surveyed, as seen in the chart, place first the demand to receive information, training and accompaniment to understand and accept the limits and scope of the disability status of their children and their Influence on learning and their future life, this requirement reaches 43%. The second requirement with 39% is to have spaces for interaction between parents, support networks and family respite programs, the latter being understood as “a non-permanent support aimed at relatives who live with persons with Intellectual disabilities in order to facilitate the reconciliation of their personal, family and work life, providing temporary and short-term care to their disabled family member (FEAPS 2000, p.18).). Thirdly,

with 37%, there is the question of having support to work for the future of their children, above all clearing doubts about labor inclusion.

37% seek to achieve effective communication in the family and school environments. 35% of fathers and mothers state the need to recover and work on their personal life projects. 19% yearn to receive support in basic areas such as health, mobility, nutrition and economic support. A 5% expresses the desire to improve self-confidence in themselves and their children, 5% also need to establish rules in at home for better coexistence among the members of the family. Only 4% reveal the aspiration to overcome the grief that generates the loss of the expectations of life that the parents had about their son.

Figure 2. Strengths of the families



Source: GIE research group year 2016
Own elaboration

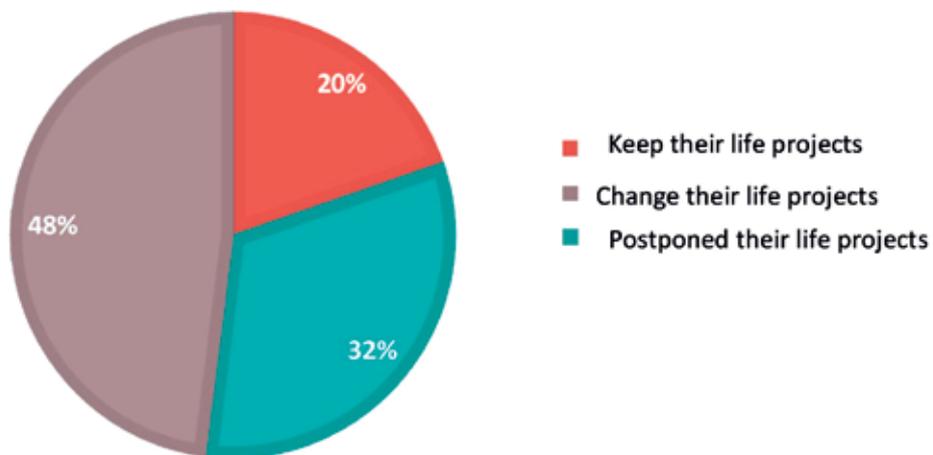
Among the strengths that parents identify to possess to support their children, we have a collaborative attitude with 69%; followed by 63% who feel they have as an element in their favor, an adequate communication with their children, these family strengths are the cornerstone of support to push the areas where parents find limitations.

4% affirm that they have accepted their child's disability status as opposed to 96% who do

not accept it or who are in the process of accepting it, this answer contradicts the answer given in the previous table that only 4% has not exceeded the stage of mourning that the parents live when facing the birth of a child with disability, this data can be related to the lack of knowledge that the parents and teachers have on this process or this term.



Figure 3. Influence of disability on the life projects of parents

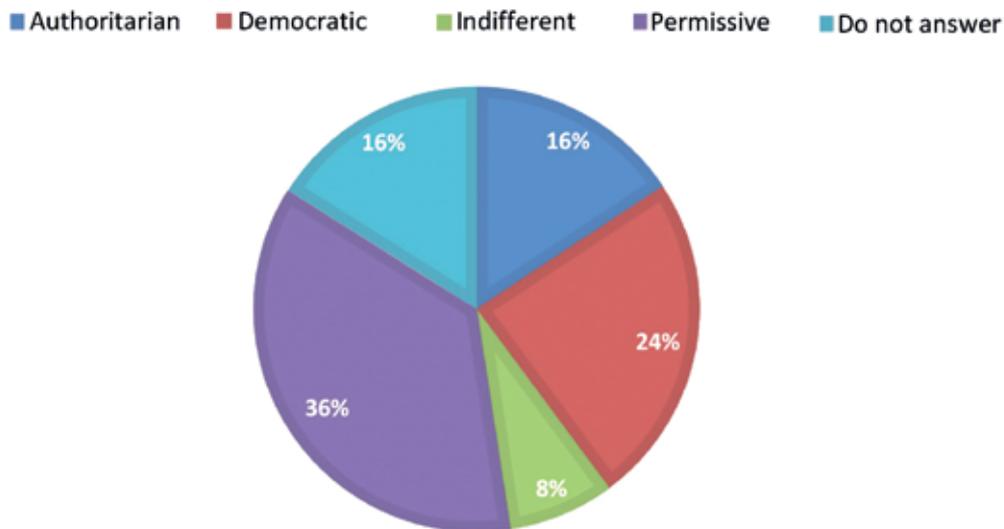


Source: GIE research group year 2016
Own elaboration

A relevant fact in this research is the percentage of parents who changed the project of personal life and / or delayed them for the near future, the figure reaches 68%, is a high percent-

age, which confirms the influence of the presence of a disabled child in the personal lives of parents and the family.

Figure 4. Types of relationships established by parents with their children



Source: GIE research group year 2016
Own elaboration

The style adopted by the parents determines the type of relationship that they maintain

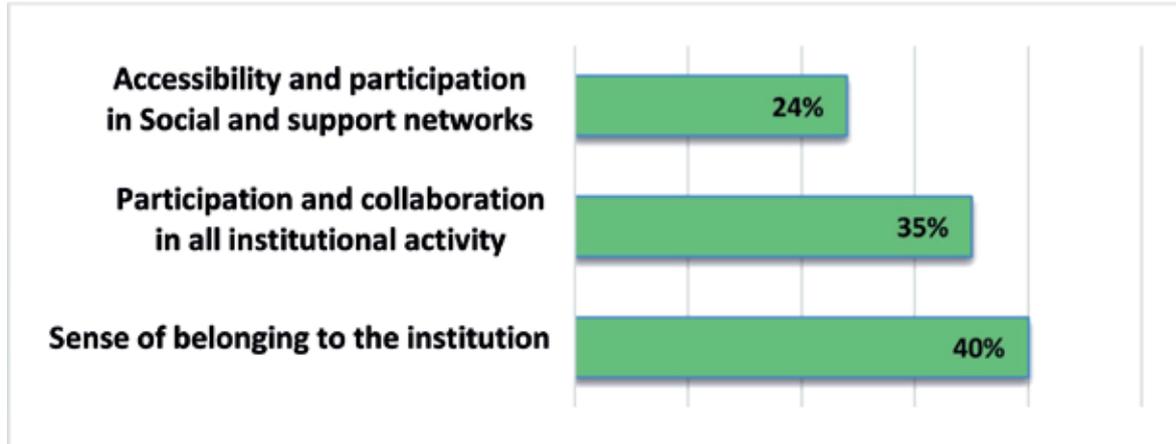
with their children, the parents mark a tendency that establishes the behaviors of the family. Of



all the ways of being of the father or mother, the democratic style is the one that has shown to bring more benefits for the development of the children. Parents who express this style, in addition to being affectionate, establish clear and coherent rules in the home, guide the behavior of their children and promote their autonomy, as we saw in the previous table, 24% of parents state that they are democratic, compared to the 36% that is recognized as permissive, this data is related to the weaknesses that can generate in the parents the presence of a member with disability,

the style of permissive parents is characterized by being affectionate and communicative but do not limit the behavior of their child, making it difficult to control its behavior. 16% of the parents say they maintain a style of authoritarian relationship, show little affection and communication, they control rigidly the behavior of their child. The 8% recognize themselves as indifferent and unfriendly. The 16% do not answer; it has not defined its predominant tendency in the style of relation with their child.

Figure 5. Commitments of parents with the educational institution to which they belong



Source: GIE research group year 2016
Own elaboration

The commitment that the parents assume with the school was investigated; of the 100% of parents, 40% maintains a sense of belonging to the institution, that is, identifies with it; 60% state that at school there is no comprehensive response to their needs. 35% participate in all activities of the institution, 65% do so sometimes or never. Regarding parental involvement in support networks and accessibility to social networks, only 24% say they have this possibility.

Discussion and conclusions

The findings of this research will allow teachers and administrators of the Special Education Institutions of Ecuador to establish strategies to meet the demands of the family, implementing an educational model focused on the involvement of the family as the main support of students with disabilities, and thus achieve to enhance their capabilities. It is necessary to cover the demands expressed by families: receive information, support and accompaniment. This would



be in compliance with what is stated in Article 23, paragraph 3, of the Convention on the Rights of Persons with Disabilities:

States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

The lack of information that the family receives on how to assume their own situations that originate from their child's disability status, limits their duties and responsibilities, and affect the educational processes of a child, affecting the harmonious relationship between the members of the family.

Faced with an unexpected event such as the birth of a child with a disability, a high percentage of families find obstacles and limitations to develop their personal goals and dreams, they become less important, educational programs do not establish actions that allow the family to resume and / or conclude their life projects, ignoring that the support that parents receive in this area is vital for the development of student's autonomy and directly influences the increase of the confidence and abilities of the children.

Highlighting the strengths of the parents is a lever to overcome the weaknesses of both their children and them with and without disabilities, fostering a more harmonious family life. In specialized education institutions, spaces are not created to support the family in their personal growth, emphasis is placed on the responsibility and problems that the child with disabilities generates, but it is forgotten that parents also have dreams and goals to fulfill. According to the Organic Law on Disabilities (OLD) in article 31 on training and education to the educational community, states that the national education authority will propose and implement training programs related to disabilities at all levels and

modalities of the education system. On the other hand, articles 35 and 37 on co-participative education and the demand for special educational institutions to involve the family as part of the educational community, establish the participation of the educational and training processes developed to favor the Transition in the different life cycles.

Article 37.- Formation of transition.- The national educational authority, will develop programs according to the age stages of life for people with disabilities who are trained in special and regular education centers; and, they will execute programs oriented to favor the transition of a person who acquires a disability at any stage of its life.

In the aforementioned institutions, it is important to motivate parents to opt for a democratic style of relationship with their children because this style fosters autonomy and encourages the construction of their personal life project, which contributes to the transition to adult life and is compatible with the dreams of the disabled person and mitigates the family's concern for the future of the disabled child, since having a life project allows eliminating the barriers that prevent their full realization.

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