


Stress and Resilience of parents and caregivers of children with disabilities

Estresse e Resiliência de pais e cuidadores de crianças com deficiência

Estrés y resiliencia de los padres y cuidadores de niños con discapacidades

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RESUMO

Objetivo: Avaliar a resiliência de pais e cuidadores de crianças com deficiência e os fatores associados segundo a literatura científica e entender a importância da qualidade de vida, aspectos emocionais, estresse e cuidados dos pais e cuidadores de crianças e adolescentes com deficiência. **Método:** Trata-se de uma revisão bibliográfica realizada na biblioteca eletrônica Scientific Electronic Library e nas bases de dados Literatura Latino Americana e do Caribe em Ciências Sociais e da Saúde. Para a busca, foram utilizadas as palavras-chave: crianças com deficiência; inclusão escolar e social; políticas públicas; deficiência mental; família; políticas públicas; deficiência mental; família; estresse cuidador. **Resultados:** O maior desafio e assegurar que as crianças com deficiências tenham voz ativa na população, procurando uma sociedade para que eles possam se envolver na vida social, uma série de barreiras limita sua capacidade de acessar serviços sociais (como educação e saúde) e se envolver em suas comunidades. Esses incluem: barreiras físicas como prédios e banheiros que não tem acesso para cadeirantes, bullying, livros didáticos indisponíveis em Braille ou anúncios de saúde pública entregues sem interpretação em linguagem de sinais e todos esses aspectos impactam na vida dos pais e cuidadores. **Conclusão:** as crianças com deficiência enfrentam desafios múltiplos e muitas vezes complexos na realização de seus direitos, inicia-se pelo acesso à educação em casa, as crianças com deficiência têm menos probabilidade de ser incluídas ou ouvidas em quase todas as medidas. Com muita frequência, as crianças com deficiência são simplesmente abandonadas.

Descritores: Crianças; Inclusão escolar e social; Políticas públicas; Deficiência.

ABSTRACT

Objective: To evaluate the resilience of parents and caregivers of children with disabilities and the associated factors according to the scientific literature and to understand the importance of quality of life, emotional aspects, stress and care of parents and caregivers of children and adolescents with disabilities. **Method:** This is a bibliographic review carried out in the Electronic Library Scientific Electronic Library and in the databases Latin American and Caribbean Literature on Social and Health Sciences. For the search, the following keywords were used: children with disabilities; school and social inclusion; public policies; mental disability; family; public policies; mental disability; family; caregiver stress. **Results:** The biggest challenge and ensuring that children with disabilities have an active voice in the population, looking for a society so that they can get involved in social life, a number of barriers limits their ability to access social services (such as education and health) and engage in their communities. These include: physical barriers such as buildings and bathrooms that do not have wheelchair access, bullying, textbooks unavailable in Braille or public health announcements delivered without interpretation in sign language and all these aspects impact the lives of parents and caregivers. **Conclusion:** children with disabilities face multiple and often complex challenges in realizing their rights, starting with access to reading education at home, children with disabilities are less likely to be included or heard in almost all measures. Too often, children with disabilities are simply abandoned.

Descriptors: Children; School and social inclusion; Public policies; Deficiency.

RESUMEN

Objetivo: Evaluar la resiliencia de los padres y cuidadores de niños con discapacidad y los factores asociados de acuerdo con la literatura científica y comprender la importancia de la calidad de vida, los aspectos emocionales, el estrés y el cuidado de los padres y cuidadores de niños y adolescentes con discapacidad. **Método:** Se trata de una revisión bibliográfica realizada en la Biblioteca Electrónica Científica y en las bases de datos Literatura Latinoamericana y del Caribe en Ciencias Sociales y de la Salud. Para la búsqueda se utilizaron las siguientes palabras clave: niños con discapacidad; la inclusión escolar y social; políticas públicas; discapacidad mental; familia; políticas públicas; discapacidad mental; familia; estrés del cuidador. **Resultados:** El mayor desafío y garantizar que los niños con discapacidad tengan una voz activa en la población, buscando una sociedad para que puedan involucrarse en la vida social, una serie de barreras limitan su capacidad para acceder a los servicios sociales (como educación y salud) y participar en sus comunidades. Estos incluyen: barreras físicas como edificios y baños que no tienen acceso para sillas de ruedas, intimidación, libros de texto no disponibles en Braille o anuncios de salud pública entregados sin interpretación en lenguaje de señas y todos estos aspectos impactan la vida de los padres y cuidadores. **Conclusión:** los niños con discapacidad enfrentan múltiples y a menudo complejos desafíos para realizar sus derechos, comenzando con el acceso a la educación lectora en el hogar, los niños con discapacidad tienen menos probabilidades de ser incluidos o escuchados en casi todas las medidas. Con demasiada frecuencia, los niños con discapacidad simplemente son abandonados.

Descritores: Niños; Inclusión escolar y social; Políticas públicas; Deficiencia.

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Introduction

First, it is necessary to clearly define the term "disability", to avoid common distortions when dealing with this area of knowledge. By law effect, deficiency is considered "any loss or abnormality of a psychological, physiological or anatomical structure or function that generates incapacity for the performance of activities, within the standard considered normal for the human being".¹

A disabled person is considered to have physical, auditory, visual and mental disabilities. The association of two or more of these deficiencies is characterized as multiple disability. Thus, autistic, hyperactive, people with syndromes, mental suffering and the gifted, for example, do not fall into this category. These are currently called people with special needs, terminology that, although new, has been questioned by some experts, because of its generic character, because it does not say much about the subject it intends to characterize.¹

Fifteen percent of the world's population at least one billion people have some kind of disability, whether present at birth or acquired later in life. Almost 240 million of them are children. The Convention on the Rights of Persons with Disabilities defines living with disabilities as one who has a long-term physical, mental, intellectual or sensory disability that in interaction with the environment prevents participation in society on an equal footing with other people.²

The birth of a disabled child causes significant changes in the organization and structure of families is recognized the decisive role they play in the rehabilitation process of the child, both in terms of their development and independence in functional skills.³

In this process, the social support received by caregivers of children with disabilities is essential, as it relieves the stress of mothers and fathers and promotes more appropriate bonding with their child. The family's response to this challenge depends on their previous experience, sociocultural aspects, family relationships and the existence of a social network to support this condition, especially in the areas of education and health.⁴

According to the research, there is a concern for the health of parents and caregivers of children with disabilities, research indicates that families and caregivers of children with disabilities have different responses.

Method

The present study is a bibliographic review of the literature, which seeks to synthesize results of previously published research and draw conclusions from thus leading to the contribution of discussions on methods and research results, as well as to provide reflections that offer future investigations.⁵

Data were collected from September to November 2022 in the Scientific Electronic Library Online (SciELO) electronic library and in the Latin American and Caribbean Literature in Social and Health Sciences (LILACS) databases. For the search, the following keywords were used:

children with disabilities; school and social inclusion; public policies; mental disability; family.

We included articles published in Portuguese (Brazil) available online and in full, as well as dissertations, books, book chapters, reviews and theses. Those previously found in the same database and those without relevance to the theme were excluded. In addition, books, texts available in the libraries of public and private institutions were consulted.

Initially, an exploratory reading of the titles and abstracts was carried out to recognize the articles that met the eligibility criteria. Then, the previously selected articles were read in full, and they were resubmitted to the inclusion and exclusion criteria. Finally, the selected materials were extracted from the selected materials, title, objective, results and conclusion in order to obtain the data relating to the object of this review.

Results and Discussion

Thirty-three publications related to the theme were found, 8 of which were eliminated by the initial reading of the titles, in the reading of the abstracts of the remaining articles according to inclusion/exclusion criteria, 5 articles were eliminated because they were not related to resilience in higher education, 2 because they had no direct relationship with the theme, and 1 because it was not related to the health area. The remaining 17 articles were read and used in the final sample of the text.

Stress of parents and caregivers of children with disabilities

These are pertinent and constant doubts on the part of families with disabilities: the level of education that will be achieved by these people, the degree of autonomy they will achieve, the type of affective-sexual relationships they will establish, the possibilities of insertion in the labor market and even the concerns about the provision of their own needs when they reach old age, when parents may no longer be able to take care of them.⁶

The path to full acceptance and adjustment to the child's diagnosis is long, arduous and tortuous. Receiving the comfort of family and friends when knowing the diagnosis can serve as a consolation and meet the need for acceptance, minimizing the feeling of helplessness and loneliness of the parental couple. Fathers, especially mothers, can blame themselves for having had a child with a peculiar developmental condition.⁷

Studies addressing the family relationships of children with development problems point to a high level of stress in fathers, especially mothers, of children with disabilities and a greater tendency of these parents to develop depression.⁸

Often, people who propose to educate and care for these children feel lost and distressed, either because of the difficulty in their relationship, or because of the distortions and prejudices arising from

the lack of information about disability and its consequences on the child's development and learning, and may even be judged unable to take on this task efficiently.⁹

It is already well documented that the burden experienced by families has a negative impact on the health and well-being of parents, resulting in high levels of stress, which need to be carried out through specific strategies to reduce their deleterious effects.⁷

In relation to family changes, these are mainly related to employment; in particular, the mother's employment. The literature points out that the changes, inevitable in the face of the birth of a child, particularly of a child with special educational needs, can be perceived, in a positive or negative way. There may be cases in which some relationships are strengthened and in other cases, this relationship can be of intense suffering, in which one of the parents suffers in isolation and in his way the situation.¹⁰

Parents and caregivers of children with disabilities or with a disabling condition can develop the "stress of the caregiver" since the routine of these parents and caregivers are very tiring and intense, both physically and psychologically. Signs of the syndrome are irritability, fatigue, excessive sadness and irritability. Some studies show that caregivers have a predisposition to develop some mental disorder that they are: depression; anxiety; burnout syndrome; alcohol abuse; drugs and thoughts of high extermination.¹¹

School and social inclusion of children with multiple disabilities

The school plays a key role at this moment, both in understanding the reactions of parents and supporting them emotionally and guiding them on the best way to conduct the child's learning, pointing out the need for stimulation in some area, the most effective means of teaching it, the complementary care indicated and the existing support network in the community for your case.¹²

Inclusion can bring undeniable benefits to the development of the person with disabilities, provided that it is offered in the regular school, necessarily a Special Education that, in a broader sense, "means to educate, sustain, accompany, leave marks, guide, conduct."¹²

The effort to include disabled people in society, as well as those with special needs, must begin from birth or from the moment the disability is found, because otherwise what the author calls "subaltern inclusion", a perverse model in which it is first excluded and then included in a lower plane, depriving individuals of the rights that give meaning to their social relations.¹³

In the field of education, the legislation in force points to the school inclusion of children from the first stage of basic education, by advocating, in the Law of Guidelines and Bases of National Education (LDBEN), Article 29, Section II, that special education, a modality of school education offered to students with special needs, including the disabled, should be offered during Early Childhood Education, which "aims at the integral development of children up to six years of age, in

its physical, psychological, intellectual and social aspects, complementing the action of the family and the community".¹⁴

Parents of the disabled child may be afraid to leave their children in daycare or school because they believe that they are not mature enough to face this experience or that people will not be prepared to receive them at the institution, shows the extent to which the attitudes of parents and educators towards schooling of disabled children can affect the expectations created in relation to their ability to adapt to the school environment.¹⁵

It is a consensus that the person with special educational needs benefits from the social interactions and culture in which he is inserted, and that these interactions, if developed in an appropriate manner, will be driving mediations and conflicts necessary for the full development of the individual and the construction of superior mental processes.¹⁶

Conclusion

In the proposal of inclusive education, the need for educational institutions to modify their conceptions and attitudes towards special students, to make methodological and curricular adaptations and to empower education professionals to deal with disabled children is seen as a primary factor. But school inclusion goes beyond the walls of institutions and bumps into social and political issues.

The school's partnership with the family and the community is another important factor to be considered, even for strengthening the bonds that will favor the child's learning and development. However, this will only be possible if the school and the family establish a relationship based on dialogue, respect and mutual trust.

Society, in turn, must combat every form of prejudice, discrimination and segregation that goes against the democratic principles of justice, equality and equal opportunities.

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