

A intervenção com pais e cuidadores enquanto estratégia de atendimento a pessoas com necessidades especiais

Intervention with parents and caregivers as assistance strategy for persons with special needs

La intervención con padres y cuidadores como estrategia para la asistencia a personas con necesidades especiales

Gilsiane Maria Vasconcelos Marques¹; Neirielle Almeida dos Santos²; Francisco Gilmário Rebouças Junior³; Georgia Maria Melo Feijão⁴; Cynthia de Freitas Melo Lins⁵

How to quote this article:

Marques GMV; Santos NA; Junior FGR; et al. Intervention with parents and caregivers as assistance strategy for persons with special needs. Rev Fund Care Online. 2018 abr/jun; 10(2):374-378. DOI: <http://dx.doi.org/10.9789/2175-5361.2018.v10i2.374-378>

ABSTRACT

Objective: This study aims to present the intervention possibilities toward parents and caregivers as an assistance strategy for individuals with special needs. **Methods:** For this purpose, it was performed an experience-based report on working with Health Psychology in a support institution for people with special needs in *Fortaleza* city (Ceará, Brazil), and also a narrative review of the literature. **Results:** Dealing with a handicapped person requires specific care, dedication, and also the family engagement in order to provide a better quality of life for all involved. By caring for the exceptional people, it also includes caring for the family, who often may not be prepared to welcome them in the best way. With that in mind, it is important the integration of the multiprofessional team towards the relatives and caregivers, aiming to a better handling in both the adaptation and attention processes, then working together the autonomy of the disabled people and favoring their development. **Conclusion:** Therefore, the psychologist must realize that it is not only the child with special needs that is in need of care, but also the entire family structure, which is a fundamental part of the treatment process.

Descriptors: Intervention towards the handicapped person's parent, psychological intervention, groups with parents and caregivers of handicapped people.

¹ Psychology Graduate by the Faculdade Luciano Feijão. E-mail address: gilsianemarques@gmail.com.

² Psychology Graduate by the Faculdade Luciano Feijão. E-mail address: neirielleas@hotmail.com.

³ Psychology Graduate, Master's Degree in Family Health, Professor of the Psychology Department at Faculdade Luciano Feijão. E-mail address: gilmariojr@gmail.com.

⁴ Psychology Graduate, Master's Degree in Psychology, Professor of the Psychology Department at Faculdade Luciano Feijão. E-mail address: georgiafeijao@hotmail.com.

⁵ Psychology Graduate, Doctor's Degree in Psychology, Professor of the Psychology Postgraduate Program at Universidade de Fortaleza. E-mail address: cf.melo@yahoo.com.br.

RESUMO

Este artigo teve sua gênese durante o Estágio Supervisionado em Psicologia da Saúde II, realizado na instituição APAE. Tem por objetivo investigar novas possibilidades de intervenção com pais e cuidadores de pessoas com necessidades especiais, buscando oferecer um suporte e esclarecimentos sobre o desenvolvimento dos seus filhos. O cuidado com os excepcionais também inclui o cuidado com a família, que muitas vezes pode não estar preparada para acolhê-los da melhor maneira, e por isso é importante a integração da equipe multiprofissional aos familiares e cuidadores, haja vista um melhor manejo no processo de adaptação e de atenção, trabalhando juntos a autonomia das pessoas deficientes e favorecendo seu desenvolvimento. Este trabalho foi elaborado baseado em artigos com referência no tema, através de levantamento bibliográfico, e também por meio de relato da experiência de estágio e o projeto de intervenção voltado para este público.

Descritores: Intervenção com pais de excepcionais; Intervenção psicológica; Grupo com pais e cuidadores de excepcionais.

RESUMEN

Este artículo tuvo su génesis durante la pasantía supervisada en Psicología de la Salud II, que tuvo lugar en la institución APAE. Su objetivo es investigar nuevas posibilidades de intervención con los padres y cuidadores de personas con necesidades especiales, tratando de proporcionar un apoyo y clarificación del desarrollo de sus hijos. El cuidado con el excepcional también incluye el cuidado de la familia, que a menudo no pueden estar preparados para acoger de la mejor manera, y por lo que es importante integrar el equipo multidisciplinario a las familias y cuidadores, dada una mejor gestión en el proceso de la adaptación y la atención, trabajando en conjunto para potenciar a las personas con discapacidad y favorecer su desarrollo. Este trabajo fue realizado en base a los artículos con referencia en la materia, a través de la literatura, y también a través de experiencia en el escenario informe y proyecto de intervención enfocada para este público.

Descriptor: la intervención para los padres de excepcional; La intervención psicológica; Grupo con los padres y cuidadores excepcionales.

INTRODUCTION

Along with the coming of a newborn, the parents' plans and expectations about the future of their child are also born. Already during the process of pregnancy, it is common for fathers and mothers to design fantasies about the child's sex, their development in school, their professional career, their sexual orientation and even on the family that will constitute a day, as well as other aspects common to the growth human. With that in mind, what to expect when all these expectations of a "perfect" child are confronted with the birth of a disabled child? The time has come to abandon the plans of the future for this child and give a brand new meaning to the experience of parenthood. They will go through a process of overcoming until the acceptance of the condition of the child with a disability and they will have to offer an inclusive environment that encourages them to develop within their limitations.¹

For some, the person with disabilities may be seen as weak and incapable, for others, as a being of great courage

and capacity for development. Deficiency brings both visions, still, a "strong emotional load" to all involved in this process (parents, children and other family members), requiring not only a restructuring of the family routine, but a change in all its dynamics.²

The influence of the family on the social development of the disabled is analyzed from two perspectives, as follows: facilitating or preventing the integration of persons with disabilities into the society, and integrating them into their family environment. These are interdependent aspects, since the more the family is integrated, the more natural and "normal" the disabled will be treated, then enabling them to access the resources and services available in the community, and expanding both their acceptance and integration into the society and the family.³

The participation of both parents and caregivers in this development process is extremely important because they are the first people with whom the special needs person comes to have contact and learn to socialize. So this family needs to be adapted to the presence of this member with special needs, preparing for the transformations within the family, as well as those of external forces, that must be confronted; overcoming prejudice and stereotypes imposed upon them. Faced with the social exclusion that many people with disabilities face, it happens that marginalization affects their family, which also becomes stigmatized, and therefore many families choose to isolate their children and reinforce the patterns of overprotection, aggravating the special condition of this subject, making it impossible to develop their abilities and skills.³ On the other hand, when the family members are properly oriented, they can both help and encourage the integration of the disabled person, since it constitutes their primary social group, so professionals should not underestimate the importance of family dynamics in the process of social integration of the disabled.²

Family Relationships and the Adaptation Process

Through a research carried out with relatives and caregivers of people bearing disabilities, they were able to enumerate seven characteristics peculiar to all who live the process of giving a new meaning and adaptation to the coexistence with a disabled person. At first there is the experience of the difficulty in receiving the diagnosis of the deficiency in the child, hitherto idealized in a totally healthy way by the parents, where the feelings of sadness, denial, humiliation and guilt are mixed; feelings that may hinder interaction with the child. The second factor is to avoid talking about the deficiency, in which the family has difficulties to live with prejudice and social stigma, or act in this way as an escape from the reality in which they live in order to minimize their suffering; another reason to avoid talking, would be the lack of knowledge of the disability, which constitutes another obstacle to the development of the child. The third aspect concerns the difficulty of having

the support of family and friends, showing that many are frustrated that they cannot act. The fourth category is living with the disabled child, where many caregivers organize their lives and routines to better serve their special children, some even either quit or decrease attention to other activities and relationships; among those surveyed, it was possible to verify the marital commitment after the birth of the disabled child, since the mothers dedicate themselves to the care with the child and reduce the time for the couple. The fifth aspect is to surrender to social isolation, where they are often deprived and annulled, because they cannot go to certain places with the special child and because they fear that the children present some need that will not be met in that environment. The sixth category is related to their own desires, where many parents present their desires and still have the motivation to conquer them, contradicting the hypothesis of the researcher who believed that they only possessed the desires of the disabled children. And finally, the desire for a personal moment, where the subjects of the research affirmed their desire in activities that give them attention, with new experiences, different from what they already have. Parents of the disabled also have concerns for the rest of their lives, such as who will care for their child in their absence and about their aging (p. 117),³ the integration of a parent is not the same as living in function of the child, because to integrate a disabled member is "to let him occupy a space into the family, neither greater nor less than the others," so it will require the family to be restructured in order to better take care of the disabled person.¹

Given the aforementioned, it is necessary to have early intervention programs with families of the disabled, focused on support, information, balance and sensitivity, as they can help significantly in the adaptation of these parents during the first years of life of the special child.

The way that each family overcomes and adapts to this experience depends a lot on its resources and the intensity of the event. At such times growth, the strengthening of bonds and the maturity and risk of psychic disorders must coexist, and factors will determine how that experience will be traversed by the family, such as beliefs, how they face change, the environment in which they live, their expectations, communication between family members, socio-cultural and economic level, whether there is a support network and whether it provides support, the family's ability to seek help, among other factors. No research indicates that a child with disabilities will lead to conflicts in the family, even though these families are at risk, but nothing confirms that the risk is certain to materialize.¹

According to the experience lived through the experience in Health Psychology in association of support to exceptional family members, all the aforementioned aspects are verified in the speeches of parents and caregivers that are attended daily. There is thus the need for greater and better visibility of those people who are so directly related to the institution's disabled. In this experiment, two parallel projects were

developed to meet this demand, where one is dedicated to the care of mothers and caregivers who are in the waiting room because the children are in care, and the other one dedicated to parents and caregivers of adolescents and young people, in order to take care of parents' guidance on sexual development and the autonomy and independence of their children. Both aim to bring clear and objective information, safety and attention, to take better care of their children with disabilities, to take better care of their relationship with them, so that they can think and understand the development of their children, and thus improve their interpersonal relationships.

The Process of Insertion and Education of Parents and Caregivers of Persons bearing Disabilities

Based on the fact that in order to the individual bearing a disability gets socially integrated he needs to be integrated into his own family, then the early intervention in the family is of utmost importance in a way as useful and necessary as the direct care for the disabled, in other words, specialist professionals should focus on family care.³

The existence of a multiprofessional team in support networks and services for disabled people facilitates the exchange of knowledge and the construction of a dialogue between the different areas of knowledge. It is necessary that each professional may have its value and its space within the intervention process, thus applying the interdisciplinary knowledge and experiences. Therefore, the teams formed in the association in question have psychologists, pedagogues, physiotherapists, physicians, occupational therapists, physical educators, social workers, nutritionists, among other professionals, in order to attend to every aspect of the subject's development. This same team also assists in the process of care and support to families and caregivers of the handicapped person.

The psycho-education process varies according to the assumptions and goals of each professional, yet its role is to educate parents and caregivers of the disabled about their children's disability and how to deal with their development. A psycho-education group is one of the main devices to modify the negative aspects and to work on the understanding and provision of information to parents and caregivers, enabling them to better understand and deal with their children, and adhere to the treatment to assist in the family dynamics.⁴

A support network and services for the treatment and follow-up of people bearing disabilities should contribute to the family adaptation process, taking care of them with adequate resources and professionals, and these health professionals need to relate to family members and caregivers.¹ Many parents still suffer from the treatment of some health professionals, because they do not show respect when giving them the news of the child's disability, which is another aspect to be worked on in these professionals. A

point also to be addressed concerns, as mentioned previously, the psycho-education of these parents and caregivers, where the majority coexist with the precarious information about their children's disability, and the more they know about their children's disability, the better they can give a new meaning to the idealization process, then reducing the anxiety involved. The guidance of these parents also allows them to better educate and train their other children so that they can coexist satisfactorily with the handicapped sibling.

As health professionals, it invites us to minimize the feelings of isolation and overprotection of families, and to guide and clarify the real capacities of this special child, provoking a look at these parents about themselves.³ And even if they are not psychologists, they should make room for these parents to bring their doubts, frustrations and anxieties to be worked and not immobilized. It is also necessary to provide this family with accurate and up-to-date information about their child's condition so that they can find other alternative care and know how to deal with everyday situations.

As a better way of working with families that have disabled members, the psychologist needs to recognize the importance of the presence of this family environment, which is fundamental for the development of the child; realizing that families with handicapped children will not be problematic, as long as they have conditions such as family, economic and social support; and lastly, treating these families with a lot of respect and sensitivity, so that they can trust the services and collaborate with the treatment developed.

Hence, the professionals need to understand parents as active and meaningful partners when working with children, disabled or otherwise. Parents know their children very deeply, and psychologists need both to respect and use this knowledge as an aid to the therapeutic process (p. 244).¹

In this experience it was possible to note some urgent demands that require intervention, among them, the fact that when parents or caregivers are in care, a specific care is not available to them, in a way that their anxieties, their lack of knowledge about the child's disability, his achievements and challenges encountered throughout the creation of the handicapped child; as well as the presence of a formed discourse of some parents, which gave the impression that they prefer to educate their children within a protective ring, without encouraging them to continue developing and performing normal tasks in the life of any person, without encouraging them to seek autonomy and independence before their managers and other professionals and services; and finally, the demand for sexual education of these users, coupled with the awareness of parents for this same education, so that they are aware that the discovery of sexuality normally occurs in any subject, regardless of whether or not they are disabled.

The need to form a group with parents and caregivers of these users is the way to gather everyone and freely debate the biggest complaints of their children, without breaking the

secrecy of individual care or being placed in an embarrassing situation before others there gifts. The idea arises to try to offer this therapeutic space to parents who have doubts about how to educate their special children, given that they cannot either control or modify their behavior.

It is perceived that it goes beyond just caring or teaching how to educate that child, there is a need to strengthen ties between parents and children, understanding how difficult this relationship can be, since most of these mothers and fathers have other children to care for, educate and pay attention. Which brings us to the following question: who is this mother or father, what expectations and what the wishes that they had in relation to this long-awaited child, involved in so many hopes? The family is the first contact that is had as subjects, where they become social and belonging to a social group, where they develop the personality, culture, attitudes and the way of living together, through the exchange of affections, open the space for these parents to talk about their achievements and difficulties, will be given the beginning of the possibility of being worked ambiguous feelings towards the children.

As long as these parents are well oriented and sensitized to these situations, they can positively influence their children's self-confidence in developing their abilities. They can also become better prepared to deal with their emotions, expectations, values and beliefs wrapped around the condition that their child was born. And family support, in addition to reducing exclusion, minimizes the anxieties that the exceptional needs to deal with, creating a more welcoming environment and enabling coping with everyday problems.³

It is significant to say that for the professionals involved with the families of people bearing disabilities, it is of the extreme importance that they have the best possible knowledge of the dynamics through which these families pass to be emotionally and rationally set, since literature has emphasized the need that these parents receive as much information as possible, that they have their doubts clarified so that they can decide with greater certainty the resources and primordial conducts for the good development of his son.⁵

CONCLUSION

The psychologists must be always attentive to their abilities and skills, so that they can perform their work with better efficiency and sensitivity. The psychologist's role, within an association for supporting the families of exceptional people, is to serve not only disabled people but also parents and caregivers by providing them with better guidance (appropriate information, programs and groups addressing this demand) so that they can live together in this context, and also help their children to have a healthy and adequate development, aiming the coexistence in a society of total inclusion. Once the parents' anxiety about the development process of the disabled child has been

worked out, they will be allowed to live harmoniously with the family and society. It is necessary, in the first place, that the parents understand the emotional, intellectual reactions, the importance of a social, psychological reeducation so that the person with the disability can develop their capacities.

The psychologist is responsible for having the perception that it is not only the child who is in need of care, but also the entire family structure, which in most cases did not expect the birth of this child with limitations that will require more attention. The psychologist should bring information with a clear and objective language, so that they learn to deal with situations even from prejudices that may have occurred, or through information related to the health of their children, helping them to take better care of them and providing adequate development.

In this context, the psychologist must do the follow-up and also assist families during the process of building a more flexible and healthy coexistence, offering the disabled member greater security to live socially, because when a family reaches a good level of integration, this will serve as a base in order to transform the conception of family care.³

It is to recognize that parents and caregivers are key players in the health care of those with disabilities, especially in chronic and long-term situations. Furthermore, it was possible to conclude that there is a need for better care practices toward these parents and caregivers, in a way that these people can bring up their expectations and their experience and thus be a fundamental part in whole caring process along with the multiprofessional team, always aiming to improve the treatment of their special children.

REFERENCES

1. Fiamenghi, GAJr., Messa, AA. Pais, Filhos e Deficiência: Estudos sobre as relações familiares. *Psicologia Ciência e Profissão*. 2007;27(2):236-245.
2. Barros, CF, Montilha, RCI. Cuidadores de pessoas com deficiência atendidas em instituição filantrópica: Características, percepções e participação de intervenção em grupo. Congresso Brasileiro Multidisciplinar de Educação Especial; 2011; Londrina; Brasil. Londrina, 2011.
3. Glat, R. O papel da família na integração do portador de deficiência. *Revista Brasileira de Educação Especial*. 1997;2(4):111-119.
4. Freire, S. Grupo de cuidadores: um olhar na integralidade das relações familiares. Rio Grande do Sul: Universidade Federal do Rio Grande do Sul, Instituto de Psicologia; 2012. Disponível a partir de: <http://www.lume.ufrgs.br/handle/10183/62378>
5. Brunhara, F, Petean, EBL. Mães e filhos especiais: reações, sentimentos e explicações à deficiência da criança. Ribeirão Preto; 1999. Disponível a partir de: <http://www.scielo.br/pdf/paideia/v9n16/04.pdf>.

Received on: 12/10/2016

Reviews required: 09/03/2017

Approved on: 31/03/2017

Published on: 10/04/2018

Author responsible for correspondence:

Cynthia de Freitas Melo
Universidade de Fortaleza, Programa de Pós-Graduação
em Psicologia. Avenida Washington Soares, nº 1321, Bloco
N, Sala N13, Edson Queiroz, Fortaleza/CE, Brazil
ZIP Code: 60811-341
E-mail address: cf.melo@yahoo.com.br
Telephone number: +55 (85) 3477-3219