

Access to the care network by children and adolescents with special health needs

Acesso à rede de atenção por crianças e adolescentes com necessidades especiais de saúde

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ABSTRACT

Objective: to understand the access to the care network for children and adolescents with special needs from the perspective of professionals. **Methods:** qualitative study carried out in an Association of Parents and Friends of Exceptional Children. The semi-structured interview was used, with representation through the cloud of words. Participated in the research 11 professionals who work in health care and special education. **Results:** from the professionals' perspective, the access to the network of care for children and adolescents comes from the special care and education offered by the Association. The participants highlighted the difficulties of access of children and adolescents to health services and the diversity of activities used so that they can socialize, interact, and form bonds. **Conclusion:** the access of children and adolescents to the attention network occurs through the services of the Association, represented by the clinic for health care and the school for development and social inclusion.

Descriptors: Health Services Accessibility; Disabled Persons; Child Health; Adolescent Health.

RESUMO

Objetivo: compreender o acesso à rede de atenção de crianças e adolescentes com necessidades especiais na perspectiva de profissionais. **Métodos:** estudo qualitativo realizado em uma Associação de Pais e Amigos dos Excepcionais. Utilizou-se a entrevista semiestruturada com representação por meio da nuvem de palavras. Participaram da pesquisa 11 profissionais que atuam na assistência à saúde e educação especial. **Resultados:** na perspectiva dos profissionais, o acesso à rede de atenção de crianças e adolescentes advém dos atendimentos e da educação especial oferecidos pela Associação. Os participantes evidenciaram as dificuldades de acesso de crianças e adolescentes aos serviços de saúde e à diversidade de atividades utilizadas para que elas possam socializar, interagir e formar vínculo. **Conclusão:** o acesso de crianças e adolescentes à rede de atenção ocorre por meio dos serviços da Associação, representados pela clínica para os cuidados de saúde e da escola para o desenvolvimento e inclusão social.

Descritores: Acesso aos Serviços de Saúde; Pessoas com Deficiência; Saúde da Criança; Saúde do Adolescente.

Introduction

Improved quality of life and increased survival of medically fragile children due to perinatal injuries, chronic diseases, and trauma are the result of technological and scientific advances in pediatrics. Technological advances in neonatology and pediatrics resulted in the emergence of the classification of children dependent on technology and health care, called by the international literature as Children with Special Health Care Needs (CSHCN), which in Brazil came to be called Children and Adolescents with Special Health Care Needs⁽¹⁻²⁾.

Children and adolescents with special health needs have been classified as a group that presents special health conditions and requires complex and continuous care, temporary or permanent, to maintain their survival. They need a network of specialized health services at different levels of complexity and care by different professionals, in addition to the care actions required by children and adolescents in general⁽³⁾.

Regarding access, it is related to the use of the service, regardless of the health problem affecting children or the number of times they seek the service. Children and adolescents require access to the different levels of complexity and devices that make up the network of articulated and intersectoral care, to ensure comprehensive and continuous care at different levels of support⁽⁴⁾.

Although Primary Health Care should be the main gateway for users of the health care network, when it comes to children or adolescents with special needs, many scenarios show a disarticulation of the health care services that serve this population, since the gateway often ends up being the hospital or specialized outpatient services⁽⁵⁻⁶⁾.

However, regarding the attention, education, assistance, and inclusion of people with any kind of special need, the emergence of the Association of Parents and Friends of Exceptional Children in the 1950s stands out as an institution that promotes the recep-

tion, socialization, and care of CSHCN (especially those who have some physical and/or intellectual disability, or some chronic illness that requires special care). From the birth of the Association, children, adolescents, and families had the possibility to have access to specialized health and education services, through activities that aim at autonomy, development, and socialization⁽⁷⁾.

In view of that, it is important to know how the professionals of this service perceive the access of children and adolescents to the health care network available for their care and socialization. Health and education professionals are subjects involved in the daily work of this service. They know their weaknesses and strengths, they experience the daily challenges of caring for children, adolescents, and their families, they develop bonds, they move the network, and they accumulate experiences while developing their work. Therefore, the perceptions woven by these individuals offer perspectives to understand how access happens in the care network.

Given the above, the question is: How the access of children and adolescents with special needs in the network of care is perceived by professionals of the Association of Parents and Friends of Exceptional Children?. Thus, it was defined as an objective to understand the access to the attention network of children and adolescents with special needs from the perspective of professionals.

Methods

This qualitative study was carried out at the Association of Parents and Friends of Exceptional Children located in the northwest region of southern Brazil. The team is made up of 24 employees who work in assistance, health, and special education, i.e., some are in health assistance, others are assigned to the Association's school.

The inclusion criteria were: being a professional of the Association in the areas of care, health and special education and working with children and

adolescents with special needs for at least six months. Those who were on vacation or on leave of absence of any kind were excluded.

Of the 24 collaborators, 20 met the inclusion criteria and five were on vacation. Thus, 15 possible participants could be invited to compose the study. The invitation occurred randomly according to the availability of professionals to participate in the interviews. The criterion of data saturation was used when no new information was added⁽⁸⁾, thus 11 professionals participated in the study.

The data were produced between December 2019 and January 2020. The initial contact was made with the institution and the professionals, when the research objectives were explained and those who met the established criteria could be invited. Because there were no refusals, it was decided to schedule the dates according to the availability of the participants and the interviews were conducted in a room attached to the institution.

Firstly, socio-occupational data was collected (gender, age, education, place of work within Association of Parents and Friends of Exceptional Children). Then, an in-depth interview was conducted by means of a semi-structured script composed of 11 questions referring to the access of children and adolescents to the Association and to the work developed by the professionals. The interview was carried out by a student in the last year of the Undergraduate Nursing Course, previously trained. They lasted an average of 20 minutes and were audio recorded with the consent of the participants.

Data were transcribed in Microsoft Word and later submitted to thematic content analysis, classified into three phases: pre-analysis; exploration of the material and treatment of results; and inference and interpretation⁽⁹⁾. The process of analysis of the research data resulted in the construction of two thematic categories: The access of children and adolescents in the care network: The Association of Parents and Friends of the Exceptional as a meeting and welcoming space and Strategies of care and education as pa-

ths for strengthening the access and welcoming in the Association of Parents and Friends of the Exceptional.

To contribute to data analysis, a tool called word cloud was used, which is characterized by the formation of a figure with different words, based on their mention in the text⁽¹⁰⁾. The cloud was built through a website (WordClouds®).

In order to maintain the participants' anonymity, the letter "P" referring to the participant was used, followed by a numeral corresponding to the order of the interviews. The study began after the project was approved by the Ethics and Research Committee of the Federal University of Santa Maria under opinion number 2,632,767/2018 and Certificate of Ethical Appreciation Submission number 86186518.5.0000.5346.

Results

Participated in this study 11 professionals who worked with children and adolescents in the Association and ranged in age from 22 to 58 years old. There was a predominance of female professionals: nine women and two men.

In relation to the professional category of the collaborators, nine teachers/pedagogues, one physical therapist, and one occupational therapist stand out. As for the education of these professionals, all had undergraduate degrees and four were specialists in their areas of training. Regarding their work in the Association, seven worked in special education, three in assistance, while one worked in both areas.

The access of children and adolescents to the care network: the Association of Parents and Friends of the Exceptional as a place for meeting and welcoming

Figure 1 shows the word cloud, which consists of the grouping and graphic organization of words according to their frequency, making it possible to clearly identify which are the keywords in this category.



Figure 2 – Word cloud referring to category 2. Palmeira das Missões, RS, Brazil, 2019/2020

Regarding the care strategies used by health and education professionals, playful, music, and diversified activities that can instigate curiosity and are accessible to the needs of this population group stand out: *Different techniques to develop the activity for them, I try to organize the activities that they will develop everything in the best possible way, that they will be happy doing, developing activities in a playful way!* (P1). *I bring several images, drawings to color, they like to color a lot. And they also like things that are fun, that catch their attention...* (P2). *My work is in recreation, more the playful, more their socialization...* (P7). *They really like the playfulness, the educational games that work on physical motor coordination, hand-eye coordination, and attention! A small number of students can read, and the digital introduction for them is a part of inclusion, to turn them into a little more independent and autonomous human beings!* (P8).

The speeches show that the professionals who work in the Association's clinic and school seek constant updating and adapt to the reality of special children and adolescents. All the activities are planned according to the health condition, participation and interaction possibilities of the children and teenagers: *We always try to do different activities, here at the school we have the mirror room that they do taekwondo, we have art class, we have computer class, so we try not to let it fall into routine... I bring a lot of pictures, drawings, playful activities that they can participate in...* (P2). *One day you do one thing, the next day you see what didn't work. The next day you change the working practice, to make them more comfortable to participate* (P3). *I must let them free, I have to offer games, and then bring the activities that I want to develop with them, there must be a management with special children and adolescents!* (P7). *We always try to reinvent ourselves to become attractive to*

them in some way! (P8). *I try to work on activities that make them feel pleasure in doing the activity, that make them feel good, that work on their reasoning, that stimulate them to live well, to defend themselves in society, these are the basic orientations for life!* (P10).

Finally, the enunciations emphasize the importance of the work that is done by the Association professionals, reinforcing the affection and care that they have with this public, seeking to keep them always involved and motivated.

Discussion

As limitations of the study, we highlight the small sample size and the fact that the collection was developed only in a certain context.

The results obtained contribute to unveil aspects related to the access of children and adolescents with special health needs and their families to the Association of Parents and Friends of the Exceptional, from the perspective of health workers who are actors deeply involved in the working dynamics of this institution. Therefore, the look and experience of these professionals bring information about the weaknesses and challenges, as well as about the prospects for inclusion and improved access. This provides subsidies for understanding how public policies have been put into effect in the daily life of services.

The enunciations of the participants reveal the difficulties of insertion of children and adolescents in the services of the municipal care network, the professionals revealed the lack of knowledge of other reference services for this population, showing the disarticulation of the care network. The family caregivers have a long trajectory to access health services for the care of CSHCN due to the destitution of the health care network⁽¹¹⁾.

Improving the health status of people living with chronic conditions (in other words special health needs that require special care by the family and a multi-professional team) requires transforming the health care system so that it can respond to health needs in a proactive, integrated, and continuous way,

emphasizing the child and/or adolescent and their family for health promotion and maintenance⁽¹²⁾.

The care of children and adolescents must be offered at an appropriate time, providing access to services and technological resources needed through the coordination of primary care, resulting in comprehensive actions and practices⁽¹³⁾. Primary care must act as the gateway to receive and continue the health care of children and adolescents with special needs⁽¹⁴⁾.

Through the statements of the interviewees, it was found that the network of services was weakened, which ends up overloading family members and/or caregivers of this population that presents diverse and complex demands related to rehabilitation and reduction of complications arising from their health care needs. The itinerary of the family caregivers of CSHCN is formed by the pilgrimage in health care networks in search of assistance and resoluteness⁽¹⁵⁾.

The participants brought information that, besides the access to health services, this public needs to socialize, interact, and form bonds with the community and other children and adolescents. The family, besides being key in the socialization and adaptation process of children and adolescents with special health needs, is responsible for the insertion of these children in the several spaces where they live. The community is one of the environments in which this population moves and promotes movements, games, and relationships with other people to establish ties and bonds⁽¹⁶⁾.

It also highlights the care received by children and adolescents with special needs at school, since it is the space that strongly seeks to promote socialization and interaction with people qualified to provide care and pass on their teachings. Education professionals need to be willing and able to provide care, and for this, it is necessary to have knowledge about the health needs to ensure the safety of the child or adolescent⁽¹⁶⁾.

It is also observed, based on the statements, that the Association acts as the main service of attention for children or adolescents with special needs,

being several times the only institutional and social support. Similar findings are highlighted in relation to the Children and Adolescents with Special Health Needs, in which 77.7% had needed specialized institutional attention in the last 12 months. These children were statistically more likely to need these services than those who did not have special needs⁽¹⁷⁾. This reinforces that the Association represents, in Brazil, an important device for the continuity of unique health care for this population.

Furthermore, the findings show that family participation is essential in the process of inclusion and development. In this sense, it is noteworthy that family participation contributes significantly to the development of children using the Association, while families that do not accompany the process of care and education lead to losses for the child⁽¹⁸⁾.

Thus, the institutional network of children or adolescents with special needs is directly linked to the social support network, being represented by family members, friends and professionals who are part of their daily lives. In view of this, it is considered that families need social, emotional, and affective support to preserve life and to maintain the care of this population, seeking to constitute the social support network and make their individuals empowered⁽¹⁴⁾.

The results show that health and education professionals of the Association use play, music, and other diversified activities as care strategies with children or adolescents, to instigate them to meet their unique needs. The use of playfulness contributes significantly to the teaching-learning process as a facilitator and builder of knowledge within the inclusion process, especially for children and adolescents with special needs⁽¹⁹⁾.

The statements showed that professionals always seek to develop their work aimed at rehabilitation and reduction of complications arising from the health conditions of each child or adolescent with special needs. Aware that this population requires extended care and an institutional health network composed of a multi-professional team, the professionals

involved need to be able to promote access to care and comprehensive, interdisciplinary and intersectoral assistance, in favor of rehabilitation and social inclusion⁽¹⁴⁾.

The results reinforce the understanding that it is essential to ensure access to specialized care for children and adolescents with special health needs and their families⁽¹⁷⁾. The effectiveness of these services requires understanding about their needs, so that it is possible to connect them to the resources they need⁽²⁰⁾. Thus, it is inferred that the work developed by professionals working in the Association of Parents and Friends of Exceptional Children aims to improve the promotion of health and well-being of children and adolescents, seeking to meet whenever possible, welfare, health, and special education issues in favor of the development of their autonomy and guarantee of their rights.

Conclusion

From the perspective of the professionals who participated in this study, the access of children and adolescents to the care network occurs through the services offered by the Association, represented by the clinic for health care and through the school for development and social inclusion. Thus, the Association is a powerful reference of the health care and specialized education network for the population with special needs.

Authors' Contribution

Conception and design, data analysis and interpretation, writing of the article, relevant critical review of the intellectual content, and final approval of the version to be published: Bueno TV.

Writing of the article, relevant critical review of the intellectual content, and final approval of the version to be published: Silveira A.

Relevant critical review of the intellectual content and final approval of the version to be published: Centenaro APFC, Cabral FB, Costa MC.

References

1. Góes FGB, Cabral IE. Discourses on discharge care for children with special healthcare needs. *Rev Bras Enferm.* 2017; 70(1):154-61. doi: <https://dx.doi.org/10.1590/0034-7167-2016-0248>
2. Monnerat CP, Silva LF, Souza DK, Aguiar RCB, Cursino EG, Pacheco STA. Health education strategy with family members of children in continuous medication. *Rev Enferm UFPE on line [Internet].* 2016 [cited Jan 19, 2021]; 10(11):3814-22. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/11461>
3. Prece ML, Moraes JRMM, Pacheco STA, Silva LF, Conceição DS, Rodrigues EC. Educational demands of families of children with special health care needs in the transition from hospital to home. *Rev Bras Enferm.* 2020; 73(Suppl 4):e20190156. doi: <https://dx.doi.org/10.1590/0034-7167-2019-0156>
4. Nunes CK, Olschowsky A, Silva AB, Kantorski LP, Coimbra VCC. Mental health in children and adolescents: vision of the professionals on challenges and possibilities in building up intersectoral networks. *Rev Gaúcha Enferm.* 2019; 40:e20180432. doi: [10.1590/1983-1447.2019.20180432](https://doi.org/10.1590/1983-1447.2019.20180432)
5. Chavez GM, Rennó HMS, Viegas SMF. The interrelation of demand and accessibility in the Family Health Strategy. *Physis Rev Saúde Coletiva.* 2020; 30(3):300-20. doi: <https://doi.org/10.1590/S0103-73312020300320>
6. Neves ET, Okido ACC, Buboltz FL, Santos RP, Lima RAG. Accessibility of children with special health needs to the health care network. *Rev Bras Enferm.* 2019; 72(Supl 3):65-71. doi: <http://dx.doi.org/10.1590/0034-7167-2017-0899>
7. Silveira A, Alves BTG, Elauterio MP, Silva FO, Costa YS, Souza NS. Development of children and teenagers with special health needs. *Rev Cont Saúde [Internet].* 2020 [cited Jan 19, 2021]; 20(38):185-90. Available from: <https://www.revistas.unijui.edu.br/index.php/contextoesaude/article/view/10006>
8. Nascimento LCN, Souza TV, Oliveira ICS, Moraes JRMM, Aguiar RCB, Silva LF. Theoretical saturation in qualitative research: an experience report in interview with schoolchildren. *Rev Bras Enferm.* 2018; 71(1):228-33. doi: <http://dx.doi.org/10.1590/0034-7167-2016-0616>

9. Bardin L. *Análise de conteúdo*. São Paulo: Edições 70, 2016.
10. Prais JLS, Rosa VF. Clouds word and conceptual map: strategies and technological resources in pedagogical practice. *Rev Nuances*. 2017; 28(1):201-19. doi: <https://doi.org/10.14572/nuances.v28i1.4833>
11. Lima H, Oliveira D, Bertoldo C, Neves ET. (De) constitution of the healthcare network of children/adolescents with special health care needs. 2021; *Rev Enferm UFSM*. 11:e40. doi: <https://doi.org/10.5902/2179769248104>
12. Nóbrega VM, Silva MEA, Fernandes LTB, Viera CS, Reichert APS, Collet N. Chronic disease in childhood and adolescence: continuity of care in the Health Care Network. *Rev Esc Enferm USP*. 2017; 51:e03226. doi: <http://dx.doi.org/10.1590/S1980-220X2016042503226>
13. Silva RMM, Toso BRGO, Neves ET, Moura CB, Viera CS. Longitudinality in child health care in the context of primary care. *Rev Enferm UFPE on line [Internet]*. 2017 [cited Jan 25, 2021]; 11(5):1909-17. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/23340>
14. Silveira A, Nicorena BPB. Speaking map of children with special needs in the voice of mothers caregivers. *Rev Cont Saúde [Internet]*. 2020 [cited Jan 21, 2021]; 20(40):181-8. Available from: <https://www.revistas.unijui.edu.br/index.php/contextoesaude/article/view/10654>
15. Luz RO, Pieszak GM, Arrué AM, Gomes GC, Neves ET, Rodrigues AP. Therapeutic itinerary of families of children with special health needs. *Rev Rene*. 2019; 20:e33937. doi: <https://doi.org/10.15253/2175-6783.20192033937>
16. Oliveira SM, Gomes GC, Xavier DM, Pintanel AC, Montesó MP, Rocha LP. Contexts of care for children/adolescents with diabetes mellitus: a socio-environmental approach. *Aquichan*. 2018; 18(1):69-79. doi: <https://doi.org/10.5294/aqui.2018.18.1.7>
17. Huang L, Freed GL, Dalziel K. Children with special health care needs: how special are their health care needs? *Acad Pediatr*. 2020; 20(8):1109-15. doi: <https://doi.org/10.1016/j.acap.2020.01.007>
18. Ferreira T, Falcão A, Oliveira A, Rolim RO, Pereira V. Intervenção precoce e a participação da família: relato de profissionais de APAES. *Rev Educ Esp*. 2019; 32:1-20. doi: <https://doi.org/10.5902/1984686X31866>
19. Resende DCP. A importância da ludicidade na educação especial inclusive. *Pedag Ação [Internet]*. 2018 [cited Aug 2, 2021]; 10(2):71-82. Available from: <http://periodicos.pucminas.br/index.php/pedagogiacao/article/view/16845>
20. Roman SB, Dworkin PH, Dickinson P, Rogers SC. Analysis of care coordination needs for families of children with special health care needs. *J Dev Behav Pediatr*. 2020; 41(1):58-64. doi: <https://doi.org/10.1097/DBP.0000000000000734>



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