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ORIGINAL ARTICLE

Care needs of children with disabilities—use of the Pediatric Evaluation of Disability Inventory

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KEYWORDS

Health of individuals with disabilities;
Children with disabilities;
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Daily activities

Abstract

Objective: To describe the care needs reported by caregivers of children with disabilities going through the school inclusion process using the Pediatric Evaluation of Disability Inventory.

Methods: Cross-sectional study with 181 children aged 7–10 years with physical or mental disabilities, undergoing the inclusion process in elementary school in 2007. Location: 31 schools of the Regional Education Board–District of Penha, East Side the city of São Paulo. The children's care needs according to the caregivers were assessed in three areas—self-care, mobility and social function, using the Pediatric Evaluation of Disability Inventory, according to the following score: 5, Independent; 4, Supervision; 3, Minimum Assistance; 2, Moderate Assistance; 1, Maximum Assistance and 0, Total Assistance. For statistical analysis, we used Student's *t*-test and analysis of variance (ANOVA), with $p < 0.05$ being statistically significant.

Results: The lower means, with statistically significant differences, were observed for the items related to social function (55.8–72.0), followed by self-care functions (56.0–96.5); for all types of disabilities, except for children with physical disabilities, who had lower means for self-care (56.0) and mobility (63.8).

Conclusions: Social function was the area referred to as the one that needed a higher degree of assistance from the caregiver and the Pediatric Evaluation of Disability Inventory is a tool that can help identify these needs and develop a more targeted intervention.

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PALAVRAS-CHAVE

Saúde da pessoa com deficiência;
Crianças com deficiência;
Reabilitação;
Atividades cotidianas

Necessidades de assistência à criança com deficiência—Uso do Inventário de Avaliação Pediátrica de Incapacidade

Resumo

Objetivo: Descrever as necessidades de assistência referidas por cuidadores de crianças com deficiência em processo de inclusão escolar, por meio do Inventário de Avaliação Pediátrica de Incapacidade.

Métodos: Estudo transversal com 181 crianças de 7-10 anos com deficiências físicas ou mentais, que se encontravam em processo de inclusão escolar no ciclo Fundamental I, em 2007. Local: 31 escolas da Diretoria Regional de Ensino—Distrito Penha, Zona Leste do Município de São Paulo. Foram avaliadas as necessidades de assistência do cuidador da criança em três áreas—autocuidado, mobilidade e função social, por meio do Inventário de Avaliação Pediátrica de Incapacidade, segundo a seguinte pontuação: 5 Independente, 4 Supervisão, 3 Assistência mínima, 2 Assistência moderada, 1 Assistência máxima e 0 Assistência total. Para análise estatística, usou-se o teste *t* de Student e análise de variância (Anova) e foi significativo $p < 0,05$. **Resultados:** As menores médias, com diferença estatística, foram observadas para os itens relacionados à função social (55,8-72), seguidas das funções de autocuidado (56-96,5) para todos os tipos de deficiência, com exceção das crianças com deficiência física que apresentaram menores médias para autocuidado (56) e mobilidade (63,8).

Conclusões: A função social foi a área referida como a que necessita de maior assistência do cuidador e o Inventário de Avaliação Pediátrica de Incapacidade é um instrumento que pode contribuir para identificar essas necessidades e para o desenvolvimento de uma intervenção mais dirigida.

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Introduction

The inclusion of the disabled child is a process that starts within the family environment. This environment can be defined as a significant social unit within society, influences the determination of human behavior and the personality formation of its members.¹ The birth of a child with disability brings significant changes to the organization and structure of families and the decisive role that these have in the child's rehabilitation process is recognized, regarding the child's development as well as her independence in functional abilities.² In this process, the social support received by the caregivers of the child with disabilities is critical, as it lessens the parents' stress and promotes a more adequate bonding with the child.³ The family's response to this challenge depends on their previous experience, sociocultural aspects, family relationships and the existence of social support network for this condition, especially in the areas of education and health.²

The school, in addition to its traditional aim of promoting education and social integration, plays a key role in reversing exclusion situations by promoting awareness actions on the rights of individuals with disabilities.^{4,5} Inclusive education is defined as the set of educational processes belonging to articulated policies that preclude any type of segregation and isolation. These policies seek to increase access to regular school, broaden the participation and ensure the permanence of students, regardless of their characteristics. From a practical point of view, inclusive education guarantees that all children have access to elementary school education.⁶

In 1990, in Brazil, this program was supported by the accomplishments established in the Federal Constitution (1988), which guarantees equal access to education and permanence at school. It emphasizes the Government's responsibility for education, represented by obligatory elementary education that is free for all, including those that did not have access to it at an appropriate age, as well as specialized educational services for individuals with disabilities, preferably within the regular school system.⁷

Considering the difficulties of integrating children with disabilities, it is considered important that, using a validated assessment tool, information and subsidies be offered, which will support the school and families of these children during the inclusion process. The Pediatric Evaluation of Disability Inventory—PEDI—was developed in response to growing awareness that while the ability to participate in daily activities is the main goal for children with disabilities and their families, there were no tools that could efficiently measure these gains. According to Mancini,⁸ previously existing tools often emphasized the fact that the children had improved their performance in these activities, using as reference the performance of children without disabilities. The author states that the measurement should focus on improving the final outcome, regardless of the methods used by the child to develop them. The actual functional ability of children with disabilities was often underestimated and functional outcomes of interventions could not be fully assessed. The PEDI offers detailed information on disability and the need for caregiver assistance in the development of activities in three areas—self-care, mobility and social function.⁸

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