

ABSTRACT

The main aim of the dissertation is to analyze the form of shared care in families with a child with disabilities in the Czech Republic in the context of the current legislative frameworks from the perspective of family caregivers and to characterize the impact of informal care on caring parents. The theoretical framework of the thesis specifies the concept of formal and informal care in the principle of shared care, specifies the multidisciplinary approach in caring for a family with a child with disabilities and presents the primary legislative framework of care in the Czech Republic in the context of European provisions.

The research part is a qualitative research carried out using the grounded theory method. The research sample consisted of informal caring parents of children with disabilities aged 6 to 24 years who attended pre-school or school facilities for pupils and students with special educational needs or were educated inclusively with at least level I care allowance. Twenty individual semi-structured in-depth interviews were conducted with research participants between June 2021 and December 2023.

The research findings characterize five basic categories that frame the relationships of the defined phenomenon of shared care, which are the context of formal care, the family, the availability of care and its coordination, the competence of the main caring parent, and the demands of care.

The results of the study describe the form of shared care as a continuous, asymmetric interaction with health, education and social care professionals that is determined by the level of communication, relationships, available options in the long-term care system and the parents themselves. The impact of informal care in the long term is mainly reflected in the health status of the caring parents, family relationships and places demands on parents in terms of acquiring specific skills related to caring for a child with disabilities.

KEYWORDS: formal care, informal care, shared care, multidisciplinary care, family with a disabled child, special educational support