

Chapter 16

Accepting Diversity Before Fighting for Inclusion: First Moments of the Family After the Disability Diagnosis

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ABSTRACT

Announcing the diagnosis of a disability constitutes a psycho-traumatic experience for parents. At the stage of diagnosis, the family experiences emotions that range from surprise and doubt to awareness of the situation. This chapter presents the case study of a family that receives the announcement of the diagnosis of their child with autism, which is automatically placed in the spectrum of diversity. At this point, it is worth noting that the social approach of disability places the individual in the context of the diversity so, adopting the above rationale, this chapter presents the diagnosis process in detail, the events as narrated by the parents but also the feelings that the parents had at that time. The results of this study demonstrated issues related to family stress levels, quality of life, the couple relationships, and a number of needs that arose.

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INTRODUCTION

Announcing the diagnosis of a disability is on the one hand a positive step for early intervention but at the same time, it constitutes a psycho-traumatic experience for parents. At the stage of diagnosis the family experiences emotions that range from surprise and doubt to awareness of the situation (Rosen et al., 2021; Russell et al., 2021). In some cases, there is a period of rejection of the child, which can be transformed into a positive framing when parents receive help and the necessary information and support from specialists. This chapter presents the case study of a family that receives the announcement of the diagnosis of their child with autism which is automatically placed in the spectrum of diversity. At this point it is worth noting that the social approach of disability places the individual in the context of the different Other and not to the one who is disadvantaged or problematic. Adopting the above rationale this chapter presents the diagnosis process in detail, the events as narrated by the parents but also the feelings that the parents had at that time. The results of this study demonstrated issues related to family stress levels, quality of life, the couple's relationship and a number of needs that arose. Indicatively, the issue of personalized management, the change of daily routine, psychological support and the supportive framework. The data of such qualitative approaches of individual cases can supply information and awareness to both professionals and families facing similar experiences.

BACKGROUND

Family schema is a dynamic living cell. Parents as caretakers play a vital role in mentoring and guiding their children's learning journey from early childhood into adulthood. Parental stress is an anxiety closely aligned with the significant role of being a parent. However, when it comes to parents of children with autism spectrum disorder (ASD), this role often starts as soon as their child is diagnosed (Foster et al., 2012). More specifically, parents of children with ASD very often face a plethora of difficulties regarding the educational opportunities focused on developing their skills and achieving a high quality of life (Efstratopoulou, Sofologi, Giannoglou & Bonti, 2021). In this vein, parents are faced with a range of emotional pressures as they attempt to learn about ASD and what this means for their child (Downes et al., 2021). Compared with parents of children with intellectual or other developmental disabilities, studies reveal that parents of children with ASD experience more psychological distress including depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic symptomatology.

Observing the Early Signs

For many years, much of what was known about the early signs of ASD was informed by parents' descriptions of their initial concerns, as well as analyses of early home videos. Rich insights from these data (complemented by experimental work that helped delineate key foundational processes impaired in ASD, such as affect sharing and joint attention) helped to inform the development of ASD-screening tools and surveillance efforts by community health professionals. Over the past decade, important advances in research have been made into the early development of ASD, incorporating prospective research designs and new technologies aimed at more precisely delineating the early emergence of ASD. Advances have

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