

Quality of Life for Families with Children/Youth with Autism Spectrum Disorder

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Abstract : This research aims to analyze the impact of autism spectrum disorders (ASD) in families with children and youth (0-25 years) with ASD in Portugal. The impact will be evaluated on a multidimensional perspective, following the work on the concept of quality life from WHOQOL Group (UN). The study includes quantitative and qualitative methodology. It correlates statistical sources and other information with the data obtained through a survey of a sample of about 100 families with children/youth with ASD (October and November 2013). The results indicate a strong impact of autism on the quality of life for families in all study dimensions. The research shows a negative impact on quality of life for families in material and financial conditions, physical and emotional well-being, career progression, feelings of injustice, social participation and self-perception of happiness. The quality of life remained in the relationship with the family and the spouse, interpersonal relationships and beliefs about himself. The ASD improved the quality of life aspects such as interest, knowledge and exercise of rights on disability, autonomy to make decisions and be able to deal with stress. Other dimensions are contemplated: a detailed characterization of the child/young with ASD and all family members (household composition, relationship status, academic qualifications, occupation, income, and leisure) the impact of diagnosis in the family wellbeing, medical and therapeutic processes, school inclusion, public support, social participation, and the adequacy and implementation of legislation. The study evaluates also the strengths and weaknesses of the Portuguese public rehabilitation system and demonstrates how a good law-in-theory may not solve the problems of families in practice due to the allocation of insufficient public resources, both financial and human resources.

Keywords : autism, families, quality of life, autism spectrum disorder

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