

HAVING A CHILD WITH AUTISM: WHAT KIND OF NEEDS AND SUPPORT EXPECTATIONS FOR PARENTS?

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Background: Raising a child with an autism spectrum disorder (ASD) is a daily stressful experience implying changes in family functioning [1]. Parents are more likely to experience psychological and educational difficulties and their vulnerability is clearly described [2, 3]. Most studies deal with parental difficulties (medical, psychological...) whereas those focusing on parental self-reported support needs, related to ASD are lacking.

Objectives: The aim of this study was to investigate parents' needs and their support expectations in order to investigate needs priority.

Methods: Two parents groups of children aged between 3 and 10 years are compared (ASD or control group). Mothers and fathers were interviewed about unmet needs using The Parental Needs Questionnaire, developed for this study and semi-structured interview used to evaluate parents' needs in terms of quality.

Results: 141 parents were included, 57 with an ASD child and 84 with TD children. There are 6 need areas for ASD child parents as well as controls: materials, time management, information, education, psychological support and relational difficulties. Parents of ASD child describe priority information needs (89.5%), psychological (73.5%), material needs (71%) and education (58.5%). These needs are listed last in the control group (respectively 10.5%, 26.5%, 29%, and 41.5%).

Conclusions: Providing parental assistance should be based on three key dimensions to receive specific information, to have psychological and social support and to manage child disorder. In practice today only the third axis is often considered in programs [4]. So, we make relevant recommendations about support for parents of ASD child.