Editorial of the Special Issue on Disability and the Family

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Nowadays, the important role of the family in the treatment and the integration of their children with disability is widely recognized. Many studies of the specialized literature uphold the need for parental involvement and similar recommendations come from international bodies, such as the World Health Organization, and from laws on disability that have been issued in a number of nations (WHO, 2001; Luckasson et al., 2002; Nota & Soresi, 2004; Soresi & Nota, 2004; Soresi, Nota, & Wehmeyer, 2011).

The services and the experts of the sector should clearly and continuously offer families two attentions: a) the first, as Soresi, Nota and Ferrari (2006) have underlined, refers to the personalized supports that must be guaranteed to all family members to help them cope with the daily problems they encounter; b) the second concerns the right to actively participate in the choice and realization of treatments that should be collaboratively considered suitable and collaboratively decided upon.

The parents of children with disability have to deal with particularly complex situations that often demand more energies and resources than those required of parents of non-disabled children (Soresi, Nota, & Ferrari, 2006). Think for example of the harrowing moment when they are told, often not in an appropriate way, that their baby has been diagnosed with disability, and of their deep distress and suffering when they experience the first impact with a disability and with the health and social services (Case, 2001).

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The birth of a child involves revision of roles and reexamination of tasks and activities between the partners, reorganization of financial resources, and a variety of new behaviors in order to cope with the needs of a baby. When the child is born with disability, the need for changes and adjustments becomes so urgent and stressful that one can think of this event as a turning point, a moment in time when life takes a significant course change (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). When their children with disability experience the changes typical of adolescence, these parents and these families will find themselves having to cope with the issues associated with their sexual development, with their participation in social and working life, and their transition to adult life. In most cases these individuals, especially those with restricted levels of autonomy, live with their parents and continue to attend occupational day centers or sheltered workshops/cooperatives for eight hours a day. Their limited levels of autonomy and social and community participation are often associated to low social abilities, while feelings of loneliness and depression may persist or even worsen, and mental health problems related to early aging are likely to emerge (Cooper, 1997). Their parents also find themselves having to deal with their own aging, their own declining physical and motor abilities and a higher incidence of chronic illnesses that can make caring for their child more difficult (Bigby, 2000).

This special issue collects together some important contributions whose main aim is to concentrate the focus of disability service providers and scholars on some thorny questions that have not been considered in the past with the depth and attention they deserve. A brief presentation of the authors is included in Appendix 1.

The first two contributions are from Italian colleagues and focus on the parental couple by involving both fathers and mothers of schoolchildren with intellectual disabilities. Cuzzocrea and colleagues examine the factors that characterize global family functioning, while Di Nuovo and Azzara address the relationship between family functioning and children's global developmental level. The third contribution is by Vera Noriega and colleagues and analyzes the functioning of Mexican families considering the point of view of mothers and fathers. The Authors emphasize the role of factors like parental support, family resources and family sense of coherence and underline the significance of these variables regardless of cultural context. The fourth contribution is by Scorgie and Wilgosh and shifts the attention on the transition from childhood to adulthood and how a group of Canadian parents experience this, highlighting parents' worries about it and the types of supports necessary to favor quality transitions.

In the fifth contribution Everri and colleagues carry out a deep qualitative analysis on the relationship between parents of children with disability and health and social service providers, emphasizing ways of interaction that may favor family resilience. The final contribution is by Wehmeyer, Palmer,

Davies and Stock. They examine the use of technology in family settings where a member has a disability, shedding light on an issue which is little investigated but which could yield precious indications on how to increase the independence of individuals with disability and the quality of life of their families.

References

- Bigby, C. (2000). Moving on without parents. Sydney: Maclennan & Petty.
- Case, S. (2001). Learning to partner, disabling conflict: Early indications of an improving relationship between parents and professionals with regard to service provision for children with disabilities. *Disability and Society*, 16, 837-854.
- Cooper, S. (1997). Deficient health and social services for elderly people with learning disabilities. *Journal of Intellectual Disability Research*, *41*, 331-338.
- Luckasson, R, Borthwick-Duffy, S., Buntinx, W. H., Coulter, D. L., Craig, E. M., Reeve, A., et al. (2002). *Mental retardation: Definition, classification, and systems of supports*. Washington, DC: American Association on Mental Retardation.
- Nota, L., & Soresi, S. (2004). Social and community inclusion. In J. Rondal, R. Hodapp, S. Soresi, E. Dykens, & L. Nota (Eds.), *Intellectual disabilities: Genetics, behavior, and inclusion* (pp. 157-192). London: Whurr Publishers Limited.
- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impact of parenting a child with disabilities. *American Journal on Mental Retardation*, 106, 265-286.
- Soresi, S., & Nota L. (2004). School inclusion. In J. Rondal, R. Hodapp, S. Soresi, E. Dykens, & L. Nota (Eds.), *Intellectual disabilities: genetics, behavior, and inclusion* (pp. 114-156). London: Whurr Publishers Limited.
- Soresi, S., Nota, L. & Wehmeyer, M.L. (2011). Community involvement in promoting inclusion, participation, and self-determination. *International Journal of Inclusive Education*, 15, 15-28
- Soresi, S., Nota, L., & Ferrari, L. (2006). Family setting in Down syndrome. In J. A. Rondal & J. Perera (Eds.), *Down syndrome, neurobehavioral specificity* (191-211). Chichester: Wiley.
- WHO (2001). International classification of functioning, disability and health (ICF). Geneva: World Health Organization.

APPENDIX 1. Authors of this special issue

Giovanna Azzara is psychologist. She has done research at the Psychology Faculty University of Catania. Her interests focus on Family psychology with specific reference to disability and autism, in collaboration with the rehabilitation services operating in these areas.

Roberto Baiocco is researcher of Developmental Psychology at the Department of Developmental and Social Psychology at the Sapienza, University of Rome. He is a family therapist and his research interests include the study of family functioning and the roles of early social experience and parenting in children's socio-emotional and personality development.

Patricia Barrientos Mendoza is professor, in the Department of Human Development. Her areas of interest include family and disability, resilience, parental training.

Sebastiano Costa is a PhD student in "Psychological Sciences" at the University of Messina, Italy. He is particularly interested in the study of parenting style and discipline management in families with disabled children and adolescents. Specifically he deals with measuring and evaluating the various aspects involved in parental and family functioning.

Francesca Cuzzocrea is researcher in Developmental and Educational Psychology at the University of Messina, Italy where she teaches "Psycho-Educational intervention in life cycle" and "Methodology of psychological research". She has developed a specific interest in the methodological aspects of research in educational and clinical psychology both, basic and applied.

Daniel K. Davies, MA, is president and founder of AbleLink Technologies, Inc in Colorado Springs, CO. His interest is in the research and development of technology to support independent functioning and quality of life for people with cognitive disabilities.

Santo Di Nuovo is professor of Psychology and President of the Psychology teaching facilities at the University of Catania. He is in charge of the Vocational Guidance and Counseling Services at the same University. His scientific production focuses on the psychometric and methodological aspects of psychological research and their applications in educational, clinical and rehabilitation settings. He collaborates with many Italian and foreign institutions.

Marina Everri is research assistant in Social Psychology and member of CAVI (Centro Video Analisi delle Interazioni) at the Department of Psychology, University of Parma, where she does research on family relations and methods for the analysis of interactions. She is also a couple and family psychotherapist.

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Maira Fernanda Hurtado Abril is post graduate student in Psychology. Her areas of interest include health, family and disability.

Rosalba Larcan is full professor in Developmental and Educational Psychology at the University of Messina, Italy, where she coordinates the course degree in Psychology and a PhD in Psychological Sciences. She has published extensively on behavioural analysis applied in educational contexts. She focuses on the study of parents of disabled people and families at risk. Specifically, she has designed and set up some parent training to improve the parents' basis of behavioural management skills.

Susan B. Palmer, PhD, is a research professor at the University of Kansas, affiliated with the Beach Center on Disability, the Kansas University Center on Developmental Disabilities, and the Department of Special Education. She is interested in self-determination and access to the general curriculum for students of all ages.

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Steven E. Stock, MA, is Vice President of AbleLink Technologies, Inc. in Colorado Springs, CO. His research has been primarily in the areas of developing assistive technologies to support independence for individuals with developmental disabilities, traumatic brain injuries and aging and dementia issues.

José Ángel Vera Noriega is social psychology, PhD, researcher in human development and social welfare. His areas of interest include child rearing, educational evaluation, and quality life.

Michael L. Wehmeyer, PhD, is professor of special education, director of the Kansas University Center on Developmental Disabilities, and senior scientist and associate director at the Beach Center on Disability, all at the University of Kansas. His research focuses on self-determination, access to the general education curriculum for students with severe disabilities, and technology use by people with cognitive disabilities.

Lorraine Wilgosh, PhD, is a professor emeritus at the University of Alberta, in Edmonton, Alberta, Canada. While retired, Dr. Wilgosh remains involved in writing research papers and making conference presentations.