

**FAMILY ASSOCIATIONISM AND DISABILITIES: APPROACHES AND INTERVENTION STRATEGIES
A SCOPING REVIEW**

ASSOCIAZIONISMO FAMILIARE E DISABILITÀ: APPROCCI E STRATEGIE DI INTERVENTO UNA SCOPING REVIEW

Arianna Taddei

Università di Macerata
arianna.taddei@unimc.it

Abstract

Il presente contributo intende approfondire il fenomeno dell'associazionismo delle famiglie di figli con disabilità attraverso una Scoping Review che si è preposta, tra i suoi principali obiettivi, quello di individuare gli approcci e le strategie di supporto adottati dalle famiglie delle associazioni. I risultati si collocano in continuità con la prima parte dello studio presentata in un precedente lavoro dell'autrice (Taddei, 2021) che ha avuto il proposito di studiare i ruoli, le motivazioni e le finalità delle associazioni delle famiglie di bambini con disabilità, offrendo interessanti suggestioni e fattori di riflessione anche per il presente articolo.

I risultati di seguito descritti esortano la pedagogia speciale ad intraprendere traiettorie di ricerca che accendano riflettori sui processi pedagogici in evoluzione all'interno delle famiglie di bambini con disabilità, con particolare attenzione alla dimensione associativa. Gli approcci di *empowerment* e di resilienza così come le strategie di *coping* e di *parent to parent support* attribuiscono un ruolo strategico alla famiglia nella sua pluralità di voci, identità, bisogni e desideri che meritano di essere adeguatamente approfonditi.

This contribution intends to investigate the phenomenon of associationism of families of children with disabilities through a Scoping Review which has set itself, among its main objectives, that of identifying the approaches and support strategies adopted by the families of the associations. The results are in continuity with the first part of the study presented in a previous work by the author (Taddei, 2021) which had the purpose of studying the roles, motivations and purposes of associations of families of children with disabilities, offering interesting suggestions and factors for reflection also for this article.

The results described below urge special pedagogy to undertake research trajectories that turn the spotlight on the evolving pedagogical processes within families of children with disabilities, with particular attention to the associative dimension. The approaches of empowerment and resilience as well as coping and parent to parent support strategies attribute a strategic role to the family in its plurality of voices, identities, needs and desires which deserve to be adequately investigated.

Key-words

Scoping Review, Family Associations, Children with Disabilities, Approaches, Inclusive Strategies.

Scoping Review, associazionismo familiare, bambini con disabilità, approcci, strategie inclusive.

1. Theoretical introduction

The courage to associate among families and to stand alongside organisations for people with disabilities has been important in breaking an infinitely immemorial silence and bringing the needs of the families and their children with disabilities to the welfare policy table. While the political dimension has represented a founding element of associationism since the beginning, the pedagogical implications and meanings inherent in the practices adopted have gradually emerged through the development of these associations, arousing the interest in studying Special Pedagogy (Nocera, 2001; Mura, 2004, 2009). In fact, when families meet, the members share their experiences and activate formulas for mutual help with an important effect of mutual care, but sometimes with great difficulty.

In some cases, the opportunity for parents to talk about themselves represents a real rebirth, as well as the possibility to finally come out of a season of mourning – which was born from an unexpected diagnosis – in order to pursue trajectories and constructive strategies, which were functional to a less uncertain and more reassuring “after us” (Giaconi, 2015). The need to come out of isolation and to share one's experiences allows to give meaning to everyday life, for example, through storytelling (Crescimbeni & Amatori, 2019) or *coping* strategies. In fact, Amatori states that «the child's disability forces parents to implement synergistic and proactive actions, coping strategies which can reduce psychophysical stress» (2019, p.57).

Support and mutual trust, the sharing of objectives and needs and the motivation for a common project generate a condition of well-being for families with positive effects on the local community. Specifically, Verdugo et al. (2020) point out that the family role is crucial not only in the private sphere in terms of the well-being of children with disabilities, but also in the surrounding social and community context.

Surveys have shown a positive association between family support and the family's ability to increase resilient behaviours, to reduce stress and to promote quality of life in the household (Gardiner & Iarocci, 2014; Boehm, 2015).

In order to properly contextualise the relationships between family and disability, it should be emphasised that people are influenced by multiple micro- and macro-systems (Bronfenbrenner 1974, 2005; Cordoba, 2017) and, as it is known, the family micro-system is fundamental for human development, learning, autonomy and self-determination (Verdugo et al., 2020).

In particular, the construct of Quality of Life was used for studying families of people with disabilities, proving it to be decisive in overcoming a clinical or therapeutic approach focused on the problems of the family system (Fernandez, 2015) and pursuing an inclusive point of view. The concept of Family Quality of Life (FQoL) is defined as a dynamic condition of family well-being, which is determined at both a collective and individual level (Zuna, 2009). Several indicators, reflecting the five dimensions of the model (family interaction, parental role, emotional well-being, physical and material well-being, support for people with disabilities), highlight the importance of family relationships with the outside world, where we can place the experience of associationism with other families.

This contribution intends to examine the phenomenon of the associationism among families of children with disabilities by illustrating the second part of the results of a Scoping Review, which has been led by two research questions: the first one, object of a previous work by the author (Taddei, 2021), has aimed at identifying the roles assumed by associations today, the motivations and the goals underlying the activities of the associationism among families of children with disabilities; the second one, object of this article, aims at highlighting approaches and support strategies adopted by the associations of families of children with disabilities. The results of the first study have revealed significant gaps about this topic in the international

literature, despite the undeniable importance of the association phenomenon in the processes of inclusion and self-determination for people with disabilities and their families.

The state of the art, which also emerges from this in relation to approaches and support strategies, suggests interesting and unprecedented trajectories of investigation, reflection and pedagogical action for Special Pedagogy, nevertheless they have to be examined.

2. Methodological aspects

The literature review introduced below has made use of a *Scoping Review* methodology, which consists of a literature review aimed at pointing out the state of the art in terms of the scale and the examination of a phenomenon or a topic within a particular disciplinary field (Arksey & O'Malley, 2005; Levac et al., 2010; Colquhoun et al., 2014; Ghirrotto, 2020), as illustrated in the first part of the study¹.

From a procedural point of view, this review went by five steps (Arksey and O'Malley, 2005; Bhojti et al., 2016) consisting of: a) identification of research questions, b) identification of the studies through key concepts, c) selection of relevant studies, d) summary of research data into tables, e) analysis, interpretation and communication of results. The last two steps will be dealt with in paragraphs 3 and 4 respectively.

A faithful application of a Scoping Review should have included an additional step devoted to share the results with the insiders. The absence of this last step represents a variation on the original approach of the methodology adopted.

a) Identification of research questions

As explained in the previous work (Taddei, 2021), the overall review process has been led by two questions:

Q1. Which social roles do associations of families of children with disabilities assume and what are their motivations and goals at a national and international level today?

Q2. Which approaches and support strategies are adopted by associations of families of children with disabilities?

The results for question Q2 will be discussed below.

b) Identification of the studies through key concepts

The key concepts included in the databases (Proquest, EBSCO Host -Education Research Complete- ERIC) have been in Italian and English languages: Family Associations and Children with Disabilities; Parents of Children with Disabilities and Empowerment; Family Support Networks and Children with Disabilities; Families, Disability Practices and strategies. The search within the databases has been carried out by activating the boolean/phrase search mode, circumscribing the search period from 2000 to 2021 and resulting in 362 products.

c) Selection of relevant studies

After a further selection based on the presence of the concepts of family and generic or specific disability in the title and one of the key concepts referring to practices/strategies, family support and/or associationism in the abstract, 140 products have been selected. Finally,

¹ For more details about the methodological dimension, please see the article Taddei A. (2021). Associazione familiare e disabilità: ruoli, motivazioni e finalità. Una Scoping Review. In *Italian Journal of Special Education for Inclusion*, IX (2), pp.41-48.

the further review carried out on the basis of the contents which have specifically “informed” regarding to Q1 and Q2 has significantly reduced the number of products to 15 peer-reviewed articles and one monograph. In this article, the ones responding to the review question Q2 will be considered.

3.Scoping Review Results

The review results for Q2 are shown in Table 1 and described below.

a) Commentary to meta-data

The studies were carried out in the following countries: USA, Italy, Spain, China, Turkey, Jordan and Latin America.

The contributions can be categorised according to three methodological typologies: Qualitative, Quantitative and Mixed Methods. The first ones include literature review work, such as Systematic Review and narrative investigation through the use of interviews and case studies, while quantitative research has mostly used questionnaires or measuring scales. The Mixed Methods are the result for the integration of interviews, questionnaires, measuring scales. The studies analysed mainly used a qualitative approach and involved parents of children with different kinds of disabilities, which were not always specified. The reported ones range from autism spectrum disorder (the most frequently recorded disability) to FASD (foetal alcohol spectrum disorder), till complex disabilities.

Authors Year and Country	Objectives of the contribution	Study methodology ² and survey tools	Target
Mura A. 2004 Italy	Drawing up a state of the art regarding the associationism among families of children with disabilities from a pedagogical perspective	MM. - interviews and questionnaires	40 associations of parents of children with disabilities
McCabe H. 2008 China	Analysing the experiences of families of children with autism spectrum disorder in China	QL. - Interviews	Parents of 43 children with autism spectrum disorder
Bingham B. & Stephen W.S. 2010 Florida	Analysing the factors which should be considered when supporting families and their children with disabilities through coping strategies.	QL. - Literature review	Families of children with disabilities facing stressful situations

² The different research methodologies will be indicated in the table using the following acronyms: Quantitative=QT, Qualitative=QL, Mixed Methods=MM.

Latefa D. & Muayyad A. 2013 Jordan	Analysing coping strategies as mediators and moderators between stress and quality of life (QoL) in parents of children with autism spectrum disorder.	QT. – Parent stress Index	184 parents of children with autism spectrum disorder.
Ekas N., Timmons L., Pruitt M., Ghilain C., & Alessandri M. 2015 USA	Examining predictors of relationship satisfaction for mothers and fathers of children with autism spectrum disorder	QT. - questionnaire	67 couples of parents of children with autism spectrum disorder.
Arakelyan S., Maciver D., Rush R, O'hare A. & Forsyth C. 2019 USA	Summarising the empirical proofs and highlighting the factors which can foster participatory interventions for families with disabilities.	QL. – Systematic Review and Meta-analysis	Families with children aged from 5 to 12 with disabilities.
Sardohan Yildirim, A. E & Akçamete, A. G. 2019 Turkey	Analysing a family-centred training model for parents of children with multiple disabilities based on their needs	QL – Case Study	Three mothers of children aged from 0 to 8 with several disabilities.
Dettori G.F. & Tedde A. 2020 Italy	Understanding the extent to which remote, telehealth-based PMT (Parent Management Training) interventions during COVID-19 period have contributed to achieve the psycho-educational objectives set and to survey the parents' perceptions on the effectiveness of remote PMT	QL – Semi-structured interviews	10 families, including 10 mothers and 4 fathers of children and teenagers aged between 6 and 20 with Autism Spectrum Disorder.
Verdugo Alonso, M. Á., Córdoba Andrade, L. & Rodríguez Aguilera, A. 2020 Spain and Latin America	Studying the application of the Quality of Life Model to the relationship between family and disability.	QL. - Literature review	Families of children with disabilities.

Table 1. Summary of Scoping Review results for question Q2: *Which approaches and support strategies are adopted by associations of families of children with disabilities?*

b) Q2 Results

As a preface to the description of the results, it is underlined that some of the studies identified examine the issue of approaches and support strategies for families of children with disabilities in the specific context of associationism (Mura, 2004; McCabe, 2008; Sardohan, 2019), while others deal with this issue without any explicit reference to the associative

dimension, despite obvious connections (Bingham & Stephen, 2010; Latefa & Muayyad, 2013; Ekas et al., 2015; Arakelyan & Maciver, 2019; Verdugo et al., 2020; Dettori & Tedde, 2020).

Among the main actions carried out by associations, the study carried out by Mura (2004) highlights the training activities addressed to parents of children with disabilities through the teaching of a dialogue, which facilitates the understanding of oneself and the others and favours self-reflection. The initiatives are aimed at acquiring psycho-pedagogical skills. Other spheres of interest concern the legal protection rights for families and the development of personal autonomy for people with disabilities. The activities identified demonstrate how associations represent interactive learning contexts based on cooperation, interpersonal confrontation and helping relationships. In particular, families indicate *resilience and coping* strategies to deal with difficult situations caused by their children's disability situation, through the ability to manage complex situations and to adopt *accommodation* strategies in the face of new situations.

The educational intentionality represents the pedagogical premise which makes the choices implemented by associations *formative* towards care, solidarity and *empowerment*, which is developed through the recursiveness between practice-theory-practice.

The importance of training is also the subject of the studies by Sardohan (2019) and Dettori & Tedde (2020). Starting from the identification of the needs for parents of children with several disabilities since early childhood, the first one suggests a Family Centred Training Model, which is useful for fathers and mothers with similar needs. The second study (Dettori & Tedde, 2020) focuses on Parent Management Training (PMT), an intervention which aims at profitably modifying parents' behaviour towards children with behaviour disorder. The authors introduce a research carried out in Italy during the lockdown, using a narrative inquiry methodology, involving parents of children with autism spectrum disorder who took part in a telehealth parent training. The survey got positive feedbacks on parents' perceptions about distance learning, which offered individual and group support and ensured the achievement of psycho-educational goals. The experience fostered a sense of well-being among the participants and low stress levels by sharing experiences.

Latefa & Muayyad's study (2013) examines *coping* strategies. The two authors emphasise the importance of *coping* approaches in determining adaptive or maladaptive behaviours in relation to stressors. The researchers examine how these strategies can act as mediators and moderators between the dimensions of stress and Quality of Life in parents of children with autism spectrum disorder (ASD). *Coping* is defined as the set of constantly changing cognitive and behavioural efforts to master, to reduce or to tolerate a specific exceeding stressor compared to one's resources and abilities. The study shows that *the acceptance of responsibility* represents the strategy which can mediate the relationship between stress and Quality of Life conditions. The authors add that *seeking social support and avoiding escape from difficult situations* represent actions which moderate stress levels with positive repercussions on parents' quality of life. The study, which was carried out in Jordan, also offers an interesting reflection on how contextual (social, economic, cultural and gender) factors can influence the development of *coping* strategies: in the specific case of the study, the social configuration of the Arab world, which is characterised by high levels of solidarity, would facilitate the provision of support for families of children with disabilities.

Bingham & Stephen (2010) introduce a literature review and this contribution further emphasises the importance of *coping* strategies, pointing out that there are several stressors to be considered when trying to help families of children with disabilities. The results highlight that mothers usually have access to more support opportunities, while fathers are less likely to find spaces to share their emotional and psychological states. Stress often represents a *mainstreaming* condition throughout a family life cycle, so it becomes strategic to share one's experience with people facing similar difficulties in order to receive mutual help and to

promote family empowerment. In this perspective, it becomes strategic for families to become aware of their available resources, which can be divided into: natural supports (e.g. friends, relatives, local community members); informal supports (informal networks, parent-to-parent support programmes); formal supports (systematic day-to-day support in assisting families' needs).

A further support strategy, which is adopted by families and often included among the associations' practices is Parent to Parent Support (PtPS). McCabe (2008) introduces a survey on PtPS, which was carried out in China and adopted by 43 parents of children with autism spectrum disorder within a specific programme. From the parents' interviews during different steps of the programme, PtPS is perceived as a positive practice for the possibility of sharing similar conditions within a more equitable relationship than the others which were characterised by inequalities mainly determined by the absence of disability in family's daily life. Therefore, the experimentation of PtPS programmes represents a strategic step in order to create ways of supporting families, so that they can emerge from the isolation to which they are destined as a result of a culture who still discriminates against people with disabilities and their families.

The study by Ekas et al. (2015) involving parents of children with autism spectrum disorder is interesting, because it emphasises the effects of individual parental factors (such as optimism, *coping* styles and social support, including family associations) on the relationship between partners. The research emphasises on understanding the processes underlying the parents' positive adaptation in dealing with the growth of a child with autism spectrum disorder.

The study by Arakelyan & Maciver (2019) still pays attention to the relevance of family factors, specifically regarding to the social participation of children with disabilities. The way parents deal with these factors can have a negative impact on their well-being and behaviour and may also affect their children's level of participation. The authors make an interesting distinction between *family status factors* (socio-demographic and family structure factors) and *family process factors* (health and well-being, parental beliefs and values, perceptions, attitudes, family resources). The first ones are difficult to be changed, while the second ones can be the subject of interventions which place the family at the centre, such as initiatives which facilitate access to information, consulting services and support networks, including associations among families of children with disabilities.

Starting from a literary review about FQoL origins (Beach Center, 2001; Hoffman et al., 2006; Turnbull et al., 2007; Zuna, 2009), Verdugo et al. (2020) finally propose the Empoderamiento Familiar model, which adopts an eco-systemic approach, based on the development of people and family well-being, according to which each member plays a fundamental role in decision-making through a process of collective empowerment. The studies, which were carried out in Spain and Latin America through the adaptation of FQoL measuring scales, confirmed the importance of consolidating cooperation among professionals, each family and associations of families through an approach based on the principles of collaboration rather than intervention.

4. Discussion of results

A first consideration concerns the limited number of the studies which deal with approaches and family support strategies within an explicit contextualisation to the world of associations among families of children with disabilities, who are often left in the shadows of the analyses. The international literature mainly focuses its research interest on families (although the

number of contributions is still modest), but it does not examine the ways in which families interact and cooperate within the framework of associations yet (Carra, 2013).

Despite this premise, the results encourage important reflections from the point of view of Special Pedagogy. A transversal interpretation of the analysis results allows to identify recurring thematic questions regardless of the specificity of each study. The first topic concerns FQoL, which was particularly examined by Verdugo et al. (2020) at a theoretical and methodological level, but it is a mere interpretation for most of the contributions examined, confirming the fact that the approaches and the strategies adopted by each family or associations among families of children with disabilities affect the quality of family's overall well-being. Furthermore, FQoL framework reiterates the importance of analysing the contexts through a holistic-systemic perspective which considers: the causes of stress, the interactions between the psycho-physical conditions of each family member and the contextual factors and the possible psycho-pedagogic and/or rehabilitation actions.

It is important to emphasise that the relationship between the quality of life levels of parents and the social participation levels of their children with disabilities undeniably influences the course of the latter's life project. By reference to the concept of multidimensional well-being, FQoL model should be translated into actions and strategies aimed at responding not only to the families' needs, but also their desires, which are overwhelmed by the emptiness of often unmet primary needs. The space of desire opens up through the empowerment process, which represents a second recurring concept and has been identified as the pivot to which to anchor the processes of transformation of family dynamics and routines in the perspective of self-determination for people with disabilities. The empowerment process also represents the key to read the contexts in search of resources which can be activated to improve family quality of life.

The promotion of empowerment is also facilitated by training intervention, which has been dealt with in several studies (Bingham & Steffen, 2010; Dettori & Tedde, 2019; Verdugo et al., 2020), finding a privileged space in Mura's survey (2004) with a specific reference to associations. These activities are addressed to all the family members, who provide an important context for learning with and from others, but also for becoming aware of the situation and the difficulties they are facing and will be able to have. Awareness-raising training is a key element in the development of an empowerment process at an individual, family and associational level.

In this perspective, *coping* and *parent to parent support* strategies have a strategic meaning to make families able at activating adaptive behaviours and sharing experiences in order to face undeniably complex situations, where the temptation to run away or to stiffen behavioural responses seems the only feasible solution instead of empowerment and resilience, which can represent valid alternatives.

Finally, a last comment concerns the gender issue: on the one hand, there is a family cross-section where care processes are still mainly a responsibility for mothers; on the other hand, psychological and emotional support is not easily accessible for fathers. Despite the important cultural changes highlighted by several scholars' research on special pedagogy (Caldin, Cinotti, 2013; Visentin, 2020), fathers are still often perceived as figures on the margins of the family orbit.

5. Conclusions for planning the future

The last results inevitably urge special pedagogy to undertake research ways which will turn the spotlight on the evolving pedagogical processes within the families of children with

disabilities, with a particular attention to the enhancement of the associative family world. Empowerment and resilience approaches, as well as coping and parent-to-parent support strategies give a strategic role to a family in a plurality of voices, identities, needs and desires. Special pedagogy has the task of being able to listen to such a complexity in order to synthesise it into educational trajectories addressed not only to the family members directly affected by disabilities, but also the members who make up the support network in their daily struggles, without forgetting that families have often been irreversibly upset by unprecedented and unexpected changes which disability always takes with it. Therefore, experiences of mutual help among parents become strategic, by sharing their fears and uncertainties. It is often only by listening and storytelling that families are able to give birth to *old* pain in order to build *new* hope, which is nourished by the awareness that they are not alone. The possibility of rewriting future lies in equally sharing their experiences and expressing their family's wishes. Future needs to be nourished by the skills of both education professionals and families and their associations. At the time of pandemic, *education for empowerment and resilience* is more necessary than ever, in order to facilitate the reconstruction of family and individual identity, without ever reducing a person to his/her problems, but helping him/her to recover his/her potential, finding possible solutions within himself/herself in the interaction with the context and taking responsibility for the changes individually and collectively made.

In this perspective, experts should support family *coping* ability, which is fundamental «to create active adaptation to the children's disabilities. The more parents cohesively respond and privilege closeness and emotional communication, the more they manage to improve their resources in the face of the critical situation», as underlined by Giaconi et al. (2018, p.212). In order to offer effective responses, which are able to dialogue with social and cultural contexts, it would be equally important to undertake the following research trajectories:

- understanding how the sharing and mutual aid practices of families and associations with disabilities have been changed during the pandemic;
- examining FQoL paradigm in relation to associations among families of children with disabilities;
- studying how associations manage to catalyse family needs which evolve over time together with the age of children with disabilities, taking into account contextual differences and gender issue, which is still alive in the division of care roles between fathers and mothers.

Finally, we are well aware that disability is the product of a historically marked socio-cultural interpretation and, therefore, every strategic change and innovation needs time and “good contaminations” to undertake a *sustainable* path towards inclusion.

References

- Arakelyan, S., Maciver, D., Rush, R, O'hare, A. & Forsyth, C. (2018). Family Factors Associated with Participation of Children with Disabilities: a Systematic Review. In *Developmental Medicine & Child Neurology*, 61, pp.514–522. DOI: <https://doi.org/10.1111/dmcn.14133>
- Arksey, H. and O'Malley, L. (2005). Scoping Studies: Towards a Methodological Framework. In *International Journal of Social Research Methodology: Theory & Practice*, 8 (1), pp.19-32. DOI: <https://doi.org/10.1080/1364557032000119616>
- Beach Center (2001). Family Quality of Life Survey. Kansas, University of Kansas-Beach Center of Disability.

- Bhopti, A., Brown, T. and Lentin, P. (2016). Family Quality of Life: A Key Outcome in Early Childhood Intervention Services – A Scoping Review. In *Journal of Early Intervention*, 38 (4), pp.191-211. DOI: <https://doi.org/10.1177/1053815116673182>
- Bingham, B. & Steffen, W.S. (2010). Providing effective coping strategies and Supports for Families with Children with Disabilities. In *Intervention in School and Clinic*, 35 (5), pp.194-196.
- Boehm, T.L., Carter, E.W. & Taylor, J.L (2015). Factors associated with family quality of life during the transition to adulthood for youth and young adults with developmental disabilities. In *American Journal on Intellectual and Developmental Disabilities*, 120, pp.395-411. DOI: [10.1352/1944-7558-120.5.395](https://doi.org/10.1352/1944-7558-120.5.395)
- Bronfenbrenner, U. (1974). Developmental Research, Public Policy and the Ecology of Childhood. In *Child Development*, 32, 513-531.
- Bronfenbrenner, U. (2005). Making Human Beings Human. Bioecological Perspectives on Human Development. Oaks: Sage.
- Caldin, R. & Cinotti, A. (2013). Padri e figli/e con disabilità: vulnerabilità e resilienze. In *Studium Educationis*, Anno XV (3), pp.93-101.
- Carrà, E. (2013). L'Associazionismo familiare come fattore di coesione sociale. In *Studi di Sociologia*, n.3-4, pp. 245-247.
- Colquhoun, H.L., Levac, D.E. and O'Brien K.K. (2014). Time for Clarity in Definition, Methos and Reporting. In *Journal of Clinical Epidemiology*, 67 (12), pp.1291-1294. DOI: [10.1016/j.jclinepi.2014.03.01](https://doi.org/10.1016/j.jclinepi.2014.03.01)
- Córdoba, L. (2017). Calidad de vida, un modelo clave en la atención a personas con discapacidades intelectuales desde la perspectiva ecológica. In *Revista Electrónica de Educación Especial y Familia*, 8 (2), pp.6-13. DOI: <https://doi.org/10.16925/2382-3984.2020.01.01>
- Crescimbeni, M. and Amatori, G. (2019). Narrazione e associazionismo familiare: il potere trasformativo del raccontare l'esperienza familiare. In Giaconi C., Del Bianco N. e Caldarelli A. (eds). *L'Escluso. Storie di resilienza per non vivere felici e scontenti*. Milano, FrancoAngeli.
- Dettori, G.F. e Tedde, A. (2020). Educare bambini e ragazzi con Disturbo dello Spettro dell'Autismo attraverso la mediazione delle figure parentali: il Parent Management Training a distanza. In *Rivista di Educazione Familiare*, 2, pp.439-458. DOI: [10.13128/rief-9443](https://doi.org/10.13128/rief-9443).
- Ekas, N., Timmons, L., Pruitt, M., Ghilain, C. & Alessandri, M. (2015). The Power of Positivity: Predictors of Relationship Satisfaction for Parents of Children with Autism Spectrum Disorder. In *Journal of Autism and Developmental Disorders*, January 2015, 45 (7). DOI: [10.1007/s10803-015-2362-4](https://doi.org/10.1007/s10803-015-2362-4)
- Fernández, A., Montero, D., Martínez, N., Orcasitas, J. R. y Villaescusa, M. (2015). CVF: marco de referencia, evaluación e intervención. In *Siglo Cero*, 46(2), 7-29. DOI: <http://dx.doi.org/10.14201/scero2015462729>
- Gardiner, E. & Iarocci, G. (2014). Students with Autism Spectrum Disorder in the University Context: Peer Acceptance Predicts Intention to Volunteer. In *Journal of Autism and Developmental Disorders*, 44 (5), pp.1008-1017. DOI: [10.1007/s10803-013-1950-4](https://doi.org/10.1007/s10803-013-1950-4)
- Ghirotto, L. (2020). *La Systematic Review nella ricerca qualitativa. Metodi e strategie*. Roma, Carocci Editore.
- Giaconi, C. (2015). *Qualità della vita e adulti con disabilità. Percorsi di ricerca e prospettive inclusive*, Milano, FrancoAngeli.
- Giaconi, C., Del Bianco, N., Crescimbeni, M. & Rodriguez, M.B. (2018). Famiglie con figli disabili: il contributo della pedagogia speciale. In Giaconi C., Del Bianco N. (Eds). *In Azione. Prove di inclusione*. Milano, FrancoAngeli.
- Hoffman, L., Marquis, J., Poston, D., Summers, J. A. y Turnbull, A. (2006). Assessing Family Outcomes: Psychometric Evaluation of the Beach Center Family Quality of Life Scale. In *Journal of Marriage and Family*, 68(4), pp.1069-1083. DOI: <https://doi.org/10.1111/j.1741-3737.2006.00314.x>

- Latefa, D. & Muayyad, A. (2013). Coping Strategies as Mediators and Moderators between Stress and Quality of Life among Parents of Children with Autistic Disorder. In *Stress and Health*, 31, pp.5-17. DOI: [10.1002/smi.2513](https://doi.org/10.1002/smi.2513)
- Levac, D., Colquhoun, H. and O'Brien, K.K. (2010). Scoping Studies: Advancing the Methodology in *Implementation Sciences*, 5 (69). DOI: <https://doi.org/10.1186/1748-5908-5-69>
- McCabe, H. (2008). The Importance of Parent-to-Parent Support among Families of Children with Autism in the People's Republic of China. In *International Journal of Disability, Development and Education*, 55 (4), December 2008, pp.303–314. DOI: <https://doi.org/10.1080/10349120802489471>
- Mura, A. (2004). *Associazionismo familiare, handicap e didattica. Una ricerca esplorativa*. Milano, FrancoAngeli.
- Mura, A. (2009). Famiglie e associazionismo: il contributo al processo di integrazione. In Pavone M. (edited). *Famiglia e progetto di vita. Crescere un figlio disabile dalla nascita alla vita adulta*. Trento, Erickson.
- Nocera, S. (2001). *Il diritto all'integrazione nella scuola dell'autonomia*. Trento, Erickson.
- Sardohan Yildirim, A. E. & Akçamete, A. G. (2019). A Family Centered Training Model Proposal to Meet the Needs of Parents Having Multiple Disabled Child. In *International Journal of Early Childhood Special Education*, 11(2), pp.168-182. DOI: [10.20489/intjecse.670476](https://doi.org/10.20489/intjecse.670476).
- Taddei, A. (2021). Associazionismo familiare e disabilità: ruoli, motivazioni e finalità. Una Scoping Review. In *Italian Journal of Special Education for Inclusion*, IX (2), pp.41-48. DOI: [10.7346/sipes-02-2021-05](https://doi.org/10.7346/sipes-02-2021-05).
- Turnbull, A., Summers, J., Lee, S. H. y Kyzar, K. (2007). Conceptualization and Measurement of Family Outcomes Associated with Families of Individuals with Intellectual Disabilities. In *Mental Retardation*, 13(4), pp.346-356. DOI: <https://doi.org/10.1002/mrdd.20174>
- Verdugo Alonso, M. Á., Córdoba Andrade, L. y Rodríguez Aguilera, A. (2020). Calidad de vida en familias de personas con discapacidad. In *Pensando Psicología*, 16 (1), pp.1-23. Doi: <https://doi.org/10.16925/2382-3984.2020.01.01>
- Visentin, S. (2020). Essere padri di figli con disabilità intellettiva: l'autonomia come sfida educativa. In *L'integrazione scolastica e sociale*, 19 (1), pp.129-146. DOI: [10.14605/ISS1912012](https://doi.org/10.14605/ISS1912012)
- Zuna, N. I., Summers, J. A., Turnbull, A. P., Hu, X. e Xu, S. (2009). Theorizing about Family Quality of Life. In R. Kober (Eds.). *Enhancing the Quality of Life of People with Intellectual Disability: From Theory to Practice*. Nueva York, Springer.