

PARENT-TRAINING TO SUPPORT PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

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Abstract. *Social inclusion necessitates educational efforts to be made to address everyday problems and difficulties. Researchers and practitioners widely emphasize the importance of training parents of children with special needs. Parents of children with Autism Spectrum Disorder have been successfully taught to improve their parent-child relationship, increase communication skills, and decrease inappropriate behaviors, as well as to reduce their psychological distress. This paper presents the results of a survey carried out within the two-year project EXEC (Extending Social Educators Competences) supported by the European Union.*

Keywords: *social inclusion, autism spectrum disorders, special needs education, parent-training, social educators', professionalization.*

Introduction

Developmental disability represents an alarming global issue for its implications on public health (Moeschler & Shevell, 2014), since poverty and disability are often mutually related (de Chenu, Dæhlen, & Tah, 2016; Flynn, 2019).

Autism Spectrum Disorder (ASD) is a specific developmental disability characterized by social and communication impairments, as well as by restricted interests and repetitive behaviors (American Psychiatric Association, 2013). Its median of prevalence, worldwide, is estimated at 62/10,000 (Elsabbagh et al., 2012).

Over the last few decades, the number of people diagnosed with ASD has increased significantly in those countries where prevalence studies have been conducted (Hansen, Schendel, & Parner, 2015). Furthermore, from recent research it emerges that there is a high rate of clinically significant psychiatric problems among children suffering from ASD. Anxiety and attention deficit hyperactivity disorder are the most frequently detected syndromes (Skokauskas & Gallagher, 2012).

Corresponding to the increasing number of individuals being diagnosed with autism, there is a growing demand for support to be provided throughout their lifespan (Jariwala-Parikh et al., 2019). Cross-sectional US studies have shown that ASD leads to extensive use of social services and high demands on healthcare (Croteau, Mottron, Dorais, Tarride, & Perreault, 2019). In this regard, it has been observed that the need for high-cost institution-based care may be reduced by developing interventions aimed at enhancing independent living skills and identifying and implementing less costly home and community-based alternatives (Cidav, Lawer, Marcus, & Mandell, 2013). On the other hand, a child with ASD creates several issues for families owing to behavioral crises that follow from changes to routines, as well as community and recreational restrictions.

Over 90% of parents of children with ASD experience situations of stress and anxiety (Nikmat, Ahmad, Oon, & Razali, 2008), and the literature demonstrates that this stress increases according to the level of severity of the child's disturbance (Osborne & Reed, 2009). Nevertheless, parents' behavior plays a fundamental role in facilitating cognitive, adaptive, and social development and adaptation of their children. Families are socializing agents and, as such, influence children's behavior through their actions, attitudes, and practices.

How, then, can one actively involve families as an element in developing interventions directed at children with ASD?

Might parent-training programs offer a means of supporting families to sustain the daily burden and enhance the creation of community-based services?

The importance of training parents is widely emphasized by researchers and practitioners (Wang, Lam, Kim, Singer, & Dodds, 2016), and there are many studies that argue the effectiveness of parent-focused interventions, for example to improve parent wellbeing (Rutherford et al., 2019), although a research effort is needed to determine the optimal parent intervention models.

Parent training

According to Callias, parent training refers to “educative interventions with parents that aim to help them cope better with the problems they experience with their children” (Callias, 1994, p. 918). However, other terms are used to address parent-training such as “parent education” (Schultz, Schmidt, & Stichter, 2011), “in-home training” (Seung, Ashwell, Elder, & Valcante, 2006), and “parent-mediated” (Ingersoll & Wainer, 2013).

There are many practical approaches to parent education for ASD. The main differences concern the program's format, intensity, location, duration, and target age (Steiner, Koegel, Koegel, & Ence, 2012).

According to Bearss, Burrell, Stewart, and Scahill, (2015), there are two broad categories of interventions that invoke the label parent-training: *Parent Support* and *Parent-Mediated Intervention* (PMI). Parent support includes programs intended to provide an indirect benefit to children by providing support to parents and increasing the parent’s knowledge about ASD. Parent-mediated interventions, on the other hand, encompass techniques where the parents are agents of change whilst children are the direct beneficiaries of treatment.

Figure 1 shows the taxonomy of parent training in the scope of ASD.

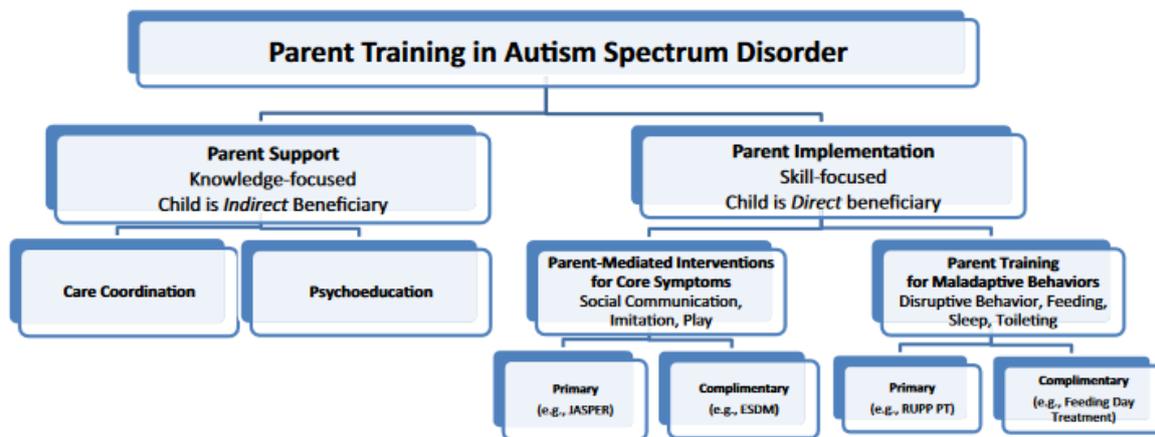


Figure 1 *Parent training in ASD* (source: Bearss, Burrell, Stewart, & Scahill, 2015, p.171)

There are many programs for parent-training in ASD that have previously been experimented, such as *Understanding Autism and Understanding My Child with Autism* (Farmer & Reupert, 2013), *RUPP Parent Training* (Bearss, Johnson, Handen, Smith, & Scahill, 2013), and *Transitioning Together* (Smith, Greenberg, & Mailick, 2014). In this paper, we present the results of a survey carried out within the scope of the two-year project ESEC (Extending Social Educators Competences) focusing on parent-training in ASD, which is supported by the European Union.

ESEC objective and research methodology

The ESEC project began in December 2018 and will end in November 2020. It involves partners from five European countries (Italy, Latvia, Greece, Spain, and Poland), and pursues the general objective of extending the current competence of social educators. More precisely, it will design and experiment an innovative parent-training program for parents of children with behavioral disabilities, focusing on those with ASD.

The expected results from the ESEC project are:

- drawing up evidence-based guidelines for designing, implementing, and running parent training programs in an online environment;
- running a pilot that addresses the key issues, both theoretical and practical, related to parent-training practices in the ASD field.

The project foresees two phases:

- Phase I, that includes desk research on parent-training in ASD, and a survey conducted in each of the participating countries;
- Phase II, that includes the design and running of a parent-training pilot in an online environment, as well as the analysis and discussion of the educational experience in order to provide advice and recommendations to social educators involved in ASD.

As at this time, Phase I is nearing completion, and the design of the online environment and the learning units has been initiated.

The desk research was based on a two-stage procedure. We first searched on online databases (Scopus, TR Web of Sciences, SAGE, Wiley Online Library, IEEE Xplore Digital Library, and Google Scholar), selecting a pool of candidate articles, projects, and initiatives relevant to the project aim. From this research, we used the selected material to support an analysis of the experimented parent-training programs and the current best practices.

The results of the desk analysis have been partially used to inform the discussion in the previous paragraphs. The survey was conducted with the view to understanding the context of the parent-training currently provided in the different participating countries, and to propaedeutically support the needs analysis for Phase II.

Cronbach's alpha test was performed to determine the internal consistency of the survey. Subsequently the Kolmogorov–Smirnov test was used for the data analysis whilst the Kruskal–Wallis test was applied to determine statistically significant differences. Finally, a five-point Likert scale has been employed for the structured interviews (1 for “I completely disagree”; 2 for “I somewhat disagree”; 3 for “I neither agree nor disagree”; 4 for “I somewhat agree”; and 5 for “I completely agree”).

Survey results

The comparative analysis of the surveys conducted in the project participating countries is ongoing.

Partial results corresponding to the survey conducted in Italy are presented as follows.

The survey was based on structured interviews carried out on three groups of respondents, namely 108 social educators, social workers, and teachers; 75 parents; and 32 stakeholders.

The survey analyzed two main dimensions:

1. The subjective importance given to parent-training practices;
2. The opinion of respondents regarding the skills (or abilities) and competences necessary for educators involved in parent-training.

The group of 108 social educators, social workers, and teachers was composed of 96 females and 12 males, distributed across 5 age classes, as follows: 18 – 25 years (5); 26 – 35 years (33); 36 – 45 years (14); 46 – 55 years (21); and over 55 years (35). Respondents had different educational levels: secondary school (7), bachelor’s degree (44), master’s degree (26), other (31). Table 1 and Table 2 report, respectively, the importance attributed by social educators/social workers/ teachers to parent-training practices, and the evaluation of the most relevant skills and competences required in parent-training.

Table 1 Evaluation of parent-training practices by social educators/social workers/teachers (Italy)

Statement	Mean
Satisfaction of the experience	1.57
Training methodology	1.49
Use of online tools	1.17
Socialization with parents	1.55
Effectiveness on parents	1.44
Acquisition of new knowledge	1.58
Impact on your personal awareness	1.62

Table 2 Skills or competences needed in parent-training practices according to social educators/social workers/teachers

Actual (Mean)	Ability/Competence	Importance (Mean)
3.01	Deep expertise in the area to train	4.31
2.68	Ability to work in a collaborative online environment	3.42
3.21	Competence in teaching parents new skills	4.26
3.73	Skills to accept suggestions/feedback from the parents	4.38
3.35	Competence in teaching parents emotional communication skills	4.42
3.36	Ability to analyze Parent Implementation and Provide Corrective Feedback	4.31
3.42	Strategies for Evaluating Parent and Child Progress	4.41
3.38	Fluency in Presenting Information and Giving Feedback	4.29
3.31	Knowledge of the Empirical and Conceptual Basis of Intervention	4.44
3.50	Teach by using concrete, positive examples; provide supporting materials to illustrate examples	4.44
3.39	Setting goals and selecting strategies for parent education	4.52

A statistically significant difference has been found between the evaluation that teachers and social workers attributed to the statement *Parent-training participation can be increased using online learning-tools* ($p=.018$). Teachers showed the highest value (Mean Rank 94.75), whereas social workers the lowest (Mean Rank 29.50). Another statistically significant difference concerns the gender of respondents. In general, females rank communication and socialization skills more positively than males. The group of 75 parents of children with neurodevelopmental disorders (especially ASD) comprised 46 females and 29 males, distributed across 5 age classes, namely: 18 – 25 years (4); 26 – 35 years (5); 36 – 45 years (14); 46 – 55 years (26); and over 55 years (26). Respondents held different education levels: secondary school (29); bachelor’s degree (3); master’s degree (12); other (31). In respect to employment, 16 respondents had no work experience; 3 had less than one year; 5 had from 1 to 5 years; and 51 had more than 5 years. Table 3 and Table 4 show, respectively, the importance attributed by parents to parent-training practices, and their evaluation of the most relevant abilities and competences that educators in parent-training programs should possess.

Table 3 Importance attributed by parents to parent-training practices

Statement	Mean
Satisfaction of the experience	3.12
Contents of the training	3.07
Competence of trainers	3.18
Socialization with other parents	2.84
Beneficial effects	3.00
Acquisition of new knowledge	3.05
Impact on personal awareness	3.07

Table 4 Abilities and competences of educators in parent-training programs (parents’ opinion)

Ability/Competence	Mean
Deep expertise in the area to train	4.52
Ability to work in a collaborative online environment	2.91
Competence in teaching parents new skills	4.27
Skills to accept suggestions/feedback from the parents	4.47
Competence in teaching parents emotional communication skills	4.52
Ability to Analyze Parent Implementation and Provide Corrective Feedback	4.41
Strategies for Evaluating Parent and Child Progress	4.25
Fluency in Presenting Information and Giving Feedback	4.09
Knowledge of the Empirical and Conceptual Basis of Intervention	4.13
Teach by using concrete, positive examples; provide supporting materials to illustrate examples	4.29
Setting goals and selecting strategies for parent education	4.04

The group of 32 stakeholders was formed of 22 females and 10 males, distributed between 4 age classes, being: 26 – 35 years (5), 36 – 45 (16), 46 – 55 (7), and over 55 years (4). Respondents had different education levels: bachelor’s degree (3), master’s degree (22), other (6), and one did not respond. One of them declared from 1 - 5 years of work experience and 31 more than five years. Table 5 and Table 6 show, respectively, the importance attributed by stakeholders to parent-training practices, and their evaluation of the most relevant abilities and competences with which educators in parent-training programs should be endowed.

Table 5 Importance attributed by stakeholders to parent-training practices

Statement	Mean
Parent-training aims at creating or improving competence of participants	4.53
Online learning-tools can increase parents participation	3.03
A parent-training process aims at improving the awareness of participants about their problematic situations	4.47
Parent-training participation can be increased using online learning-tools	3.25
The most important skills of a parent training trainer is the ability to communicate	4.47
Participants should socialize and work together	4.06
Parent training is a program in which parents actively acquire parenting skills through mechanisms such as homework, modeling, or practicing skills	4.25

Table 6 Abilities and competences of educators in parent-training programs (stakeholders’ opinion)

Ability/Competence	Mean
Deep expertise in the area to train	4.28
Ability to work in a collaborative online environment	3.44
Competence in teaching parents new skills	4.59
Skills to accept suggestions/feedback from the parents	4.72
Competence in teaching parents emotional communication skills	4.66
Ability to analyze Parent Implementation and Provide Corrective Feedback	4.56
Strategies for Evaluating Parent and Child Progress	4.44
Fluency in Presenting Information and Giving Feedback	4.53
Knowledge of the Empirical and Conceptual Basis of Intervention	4.50
Teach by using concrete, positive examples; provide supporting materials to illustrate examples	4.72
Setting goals and selecting strategies for parent education	4.78

Conclusion

The analysis of the research results is still in progress, since the project partners are currently carrying out a comparative analysis of data resulting from their research. However, the outcomes of the Italian survey broadly confirm what emerged from the desk research, namely that parents and stakeholders attribute

great importance to parent-training practices. Nevertheless, it should prove useful for a supplementary analysis to understand the different points of view of social educators, social workers, and teachers regarding parent training practices, as it seems that the different roles they play may affect their evaluation. Another question that should be investigated in depth is the openness of trainers and parents to using online training programs. Online training can considerably reduce the cost of parent-training practices as well as greatly expand the audience of participants. There are, however, many issues that must be considered when implementing effective online parent training programs, e.g., the structure and organization of learning units, the heterogeneity of the audience, their capability to use the technology, the participation of facilitators, etc. The above questions will be discussed between the ESEC partners as soon as Phase I of the project is completed.

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Extending Social Educators' competences

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References

- American Psychiatric Association. “Diagnostic and statistical manual of mental disorders”. *BMC Med*, 17. (2013). 133-137.
- Bearss, K., Johnson, C., Handen, B., Smith, T., & Scahill, L. (2013). A pilot study of parent training in young children with autism spectrum disorders and disruptive behavior. *Journal of Autism and Developmental Disorders*, 43, 829–840.
- Bearss, K., Burrell, T.L., Stewart, L., & Scahill, L. (2015). Parent training in autism spectrum disorder: What’s in a name? *Clinical child and family psychology review*, 18(2), 170-182.
- Cidav, Z., Lawer, L., Marcus, S.C., & Mandell, D.S. (2013). Age-related variation in health use and associated expenditures among children with autism. *Journal of autism and developmental disorders*, 43(4), 924-931.
- de Chenu, L., Dæhlen, D., & Tah, J. (2016). A critical comparison of welfare states and their relevance to people with an intellectual disability. *Journal of Intellectual Disabilities*, 20(4), 397-415.
- Croteau, C., Mottron, L., Dorais, M., Tarride, J.E., & Perreault, S. (2019). Use, costs, and predictors of psychiatric healthcare services following an autism spectrum diagnosis: Population-based cohort study. *Autism*, 3, 28. Retrieved from <https://journals.sagepub.com/doi/full/10.1177/1362361319840229>; last accessed on 01.04.2020.

- Elsabbagh, M., Divan, G., Koh, Y.J., Kim, Y.S., Kauchali, S., Marcín, C., & Yasamy, M.T. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism research*, 5(3), 160-179.
- Farmer, J., & Reupert, A. (2013). Understanding Autism and understanding my child with Autism: An evaluation of a group parent education program in rural Australia. *Australian Journal of Rural Health*, 21(1), 20-27.
- Flynn, S. (2019). Irish Intellectual Disability Services for Children and Austerity Measures: The Qualitative Impact of Recession Through Framework Method. *Child Care in Practice*, 1-17.
- Hansen, S.N., Schendel, D.E., & Parner, E.T. (2015). Explaining the increase in the prevalence of autism spectrum disorders: the proportion attributable to changes in reporting practices. *JAMA pediatrics*, 169(1), 56-62.
- Ingersoll, B., & Wainer, A. (2013). Initial efficacy of Project ImPACT: A parent-mediated social communication intervention for young children with ASD. *Journal of autism and developmental disorders*, 43(12), 2943-2952.
- Jariwala-Parikh, K., Barnard, M., Holmes, E.R., West-Strum, D., Bentley, J.P., Banahan, B., & Khanna, R. (2019). Autism Prevalence in the Medicaid Program and Healthcare Utilization and Costs Among Adult Enrollees Diagnosed with Autism. *Administration and Policy in Mental Health and Mental Health Services Research*, 6(6), 768-776.
- Moeschler, J.B., & Shevell, M. (2014). Comprehensive evaluation of the child with intellectual disability or global developmental delays. *Pediatrics*, 134(3), e903-e918.
Retrieved from
http://media.affymetrix.com/promotions/cma/documents/AAP_Pediatrics2014_Moeschler_peds.pdf; last accessed on 01.03.2020.
- Nikmat, A.W., Ahmad, M., Oon, N.L., & Razali, S. (2008). Stress and psychological wellbeing among parents of children with autism spectrum disorder. *ASEAN Journal of Psychiatry*, 9(2), 65-72.
- Osborne, L.A., & Reed, P. (2009). The relationship between parenting stress and behavior problems of children with autistic spectrum disorders. *Exceptional Children*, 76(1), 54-73.
- Rutherford, M., Singh-Roy, A., Rush, R., McCartney, D., O'Hare, A., & Forsyth, K. (2019). Parent focused interventions for older children or adults with ASD and parent wellbeing outcomes: A systematic review with meta-analysis. *Research in Autism Spectrum Disorders*, 68, 101450.
- Schultz, T.R., Schmidt, C.T., & Stichter, J.P. (2011). A review of parent education programs for parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 26(2), 96-104.
- Seung, H.K., Ashwell, S., Elder, J.H., & Valcante, G. (2006). Verbal communication outcomes in children with autism after in-home father training. *Journal of Intellectual Disability Research*, 50(2), 139-150.
- Skokauskas, N., & Gallagher, L. (2012). Mental health aspects of autistic spectrum disorders in children. *Journal of Intellectual Disability Research*, 56(3), 248-257.
- Smith, L.E., Greenberg, J.S., & Mailick, M.R. (2014). The family context of autism spectrum disorders: Influence on the behavioral phenotype and quality of life. *Child and Adolescent Psychiatric Clinics*, 23(1), 143-155.
- Steiner, A.M., Koegel, L.K., Koegel, R.L., & Ence, W.A. (2012). Issues and theoretical constructs regarding parent education for autism spectrum disorders. *Journal of autism and developmental disorders*, 42(6), 1218-1227.

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Wang, M., Lam, Y.W., Kim, J., Singer, G.H., & Dodds, R. (2016). Behavioral Parent Training as Evidence-Based Practices for Families of Children with Developmental Disabilities. *Supporting Families of Children with Developmental Disabilities: Evidence-based and Emerging Practices*, 73-154.