

Mothers' Experiences of Children in the Autistic Spectrum in Greece

Loukisas, Theodoros D.; Papoudi, Despina

DOI:

[10.1080/1034912X.2015.1111304](https://doi.org/10.1080/1034912X.2015.1111304)

License:

None: All rights reserved

Document Version

Peer reviewed version

Citation for published version (Harvard):

Loukisas, TD & Papoudi, D 2016, 'Mothers' Experiences of Children in the Autistic Spectrum in Greece: Narratives of Development, Education and Disability Across their Blogs', *International Journal of Disability, Development and Education*, vol. 63, no. 1, pp. 64-78. <https://doi.org/10.1080/1034912X.2015.1111304>

[Link to publication on Research at Birmingham portal](#)

Publisher Rights Statement:

This is an Accepted Manuscript of an article published by Taylor & Francis in *International Journal of Disability, Development and Education* online on 8th January 2016, available online: <http://www.tandfonline.com/10.1080/1034912X.2015.1111304>

Checked Jan 2016

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Mothers' Experiences of Children in the Autistic Spectrum in Greece: Narratives of development, education and disability across their blogs

Theodoros D. Loukisas^{a*} and Despina Papoudi^b

^aHead of Public Vocational Training Institute of Avlona, Attica, Greece;

^bDepartment of Disability Inclusion and Special Needs (DISN), School of Education, University of Birmingham, Birmingham, United Kingdom

Autism occupies a prominent place in scientific research both as a medical and as a socio-cultural phenomenon. Autism is studied as a disorder and a diagnostic label, as an experience of people with autism, their parents and their supporters, and finally as a disability related to stigma and rejection. The purpose of this article is to describe the posted experiences on personal blogs of five mothers who have school-aged children in the autistic spectrum in Greece. The qualitative method of content analysis is used for analysing the personal narratives across their blogs because this method focuses on describing and understanding the presented experiences and acknowledges the central role of the researcher in describing and signifying the issues discussed. The results of the content analysis show that the mothers seem to view autism through a developmental perspective and as they lead efforts for their child's developmental timeline they are worried about their child's developmental course and tend to experience high levels of anxiety, depression and burnout. The mothers act as practical scientists and co-therapists, taking an active role in educating and raising their children, finding a school and selecting appropriate interventions. The mothers struggle to obtain quality in education and services, while faced with the absence of technical infrastructure and understaffing in schools, lack of funding, covert or overt practices of acceptance and rejection of people with disabilities in the educational system, the attitudes and ignorance of some educators, and the high cost of private services. These mothers, at first, view autism as a tragedy and within their social environment they face covert or overt rejection since their children are stigmatised as "abnormal". Later on, the mothers accept their child's disability as a prerequisite for gaining a new life experience. It seems that the mothers have a mixed perception of disability, which sometimes tends to be closer to the medical model, sometimes to the hybrid model, while other times to the social model of disability.

* Corresponding Author. Email: tloukisas@yahoo.gr

Keywords: autism; mothers of children in the autistic spectrum; blogs; disability; education; social model of disability; narratives; content analysis; online research

Introduction

Research on autism is associated with social representations, cultural and personal experiences of different groups, scientific developments and social changes. The research involves a multitude of studies and it is performed on many levels, ranging from the organic to the social dimension of autism (D’Auria, 2010; Fisher, 2006; Ortega, 2009; Panopoulou-Maratou, 2010; Papoudi, 2008; Sawchuka & Clarke, 2015; Sinclair, 2010; Solomon, 2010).

Autism is the object of thorough research and attracts scientific interest on so many levels and from so many different approaches because it is a versatile developmental disorder, which involves special characteristics and disabilities requiring a versatile treatment (Panopoulou-Maratou, 2010). In terms of severity, the cognitive and language impairments as well as the disturbance of the individual’s ability to relate to other people, rank autism at the top of pervasive developmental disorders (Papoudi, 2008).

Autism, which is often compared to a “puzzle” or “labyrinth”, is even more complex as a social phenomenon and covers the sphere of politics, medicine, ethics and, above all, education. Whether viewed as a clinical category (Brownlow, 2010a; D’Auria, 2010; Shah, Dalton, & Boris, 2007), or as a sociocultural phenomenon (Oliver, 1996; Ortega, 2009; Sinclair, 2010), autism holds a prominent, albeit controversial, position in social research and in the constant search of the humanities concerning empathy, inter-subjectivity and cognitive functions (Solomon, 2010). At the same time, autism is linked to social changes and directly affects families, services and schools (Fisher, 2006; Myers, Mackintosh, & Goin-Kochel, 2009). The

struggle for public schools that will offer quality educational programs for autism with teaching methods based on empirical data seems to be at present the only way out of the “labyrinth” of autism for families (Fisher). It is, therefore, of great interest to discover how mothers present their experiences of the educational system and its services for children in the autistic spectrum.

When looking at the experiences of parents of disabled children of school-family cooperation, in the light of the social model of disability approach in Greece, research revealed a sense of personal tragedy experienced by the majority of parents, lack of cooperation with specialists, lack of support structures and difficulties in communication with education professionals. The same research has also highlighted the struggle of families to convince the teaching staff to allow their disabled children to enroll or continue their attendance in schools, the intolerance and inability of the educational system to differentiate itself from the medical model of education and treatment of a disabled student, as well as the shift of all responsibility from organisations and education professionals to parents of disabled children as part of the individual model of disability approach (Zoniou-Sideri & Deropoulou-Derou, 2008). In addition, educational services do not take responsibility for their role and they act with formalism, bureaucracy, non-acceptance of disability and treat disability like an illness (Boutskou, 2008; Phtiaka, 2008). The shift of responsibility to parents as well as the difficulties in communication with education professionals are themes previously discussed by Dreuth Zeman, Swanke, & Doktor (2011b).

Greek sociocultural evidence refers to a “hybrid” model of approaching disability as opposed to the medical and social model of disability. On the one hand, the medical model of disability focuses on diagnosis and labeling the individual, and, on the other hand, the social model of disability focuses on the social construction of disability (Zoniou-Sideri, 2011). The

proposed “hybrid” model of disability is based on “common sense”, an approach that combines individual and social elements, views the disabled individual as the ‘other’ and disability as a personal matter, sometimes even as a “personal tragedy”, with a philanthropic attitude, but accepting the need for equal treatment as well as for the human and social rights of the disabled. Furthermore, it is argued that disability is a popular subject in the media, with a preference for personal success or failure disability stories, as well as for the shortcomings and failures of the state and its services with reference to citizens with disabilities (Zoniou-Sideri, Karayianni, Deropoulou, & Spandagou, 2006).

The present article examines the discourse of the experiences of mothers who have a child with autism, as posted on their personal blogs, by using a qualitative methodological approach. A thorough review of the literature showed the relevant research to be very limited so far at an international level (Fleischmann, 2004, 2005) while absent at a national level. The studies conducted are based on narratives of parents’ personal websites (Fleischmann, 2004, 2005) but a study of the blogs is under examined with the exception of a few scholars (Dreuth Zeman, Swanke, & Doktor, 2011a; Dreuth Zeman et al., 2011b). Nevertheless, the blogs are much more interactive compared to static websites, usually facilitating communication among bloggers and readers, thus promoting the building of social networks (Boyd & Ellison, 2007). Additionally, parents of children in the autistic spectrum are using the virtual social networks to communicate, get support and gather information (Dreuth Zeman et al., 2011a). Therefore, the objectives of this article are: (a) to describe and present the mothers’ experiences of school-aged children in the autistic spectrum as narrated through their reports on their personal blogs, and (b) to investigate the discourse of mothers about autism in relation to the current dominant models of disability in the autism field. This is extremely important because the Internet is used more widely nowadays;

parents mediate for their children's rights and act as advocates (Jordan, 2010; Ryan & Runswick-Cole, 2009).

Methodology

Research Questions

In order to explore the mothers' experiences and to collect meaningful and significant data, the following questions were explored according to the mothers' reports on their blogs.

1. How are children in the autistic spectrum presented on their mothers' blogs?
2. How are the school and its services presented as part of the educational system which is aimed at families and children in the autistic spectrum?
3. How is autism and disability presented and perceived by mothers in their social environment?

Research Context and Research Participants

The data were collected from blogs created by mothers of children in the autistic spectrum on Greek websites. The research participants were five mothers of children in the autistic spectrum who had published their views and experiences on their blogs (Table 1). The term "children in the autistic spectrum" used in this research applies here to children diagnosed with "Asperger Syndrome", "autism" and "pervasive developmental disorder". The mothers' age was roughly estimated through their reports to be within the age group of 35-45 years. The mothers and authors of those blogs were middle-class, married, working women of Greek origin, residing in Athens, with the exception of one woman living in the provinces. On average they had two children each, although in one case there was a mother with three children (a child with autism and twin boys). They all lived in the same house with their husbands and children, and were mostly graduates of Higher Education. On two occasions the mothers' educational backgrounds

were not mentioned, and on another occasion a mother's employment status was not reported. Three out of the five mothers (60%) took an active part in associations for parents of children in the autistic spectrum or other similar organizations. All mothers had in their blogs links to Greek and international organizations for autism, special needs and disabilities, to websites with autism materials, as well as to homepages of an informative nature and to websites from people and public or private sector bodies with content relevant to autism.

[t] Insert Table 1 near here/[t]

The children in the autistic spectrum were all boys with an average age of 8.4 years, ranging from six to twelve years old. Two of the children were diagnosed with autism, two with Pervasive Developmental Disorder (PDD) and one with High-Functioning Autism—Asperger syndrome. All the children in the autistic spectrum had a formal diagnosis from agencies of state, were capable of speech, lived at home with their parents and studied in special primary schools, except for one child who studied in a common primary school (Table 1).

Data were collected through the Google web search engine by entering keywords such as “mothers of children in the autistic spectrum”, “families / parents of people with autism”, “autism and blogs”, “parents’ views on autism”, “child with autism”. The selection criteria in order to include a blog in the sample are as follows:

1. The blog is written in Greek for the most part.
2. The blogger is a mother of a child with autism according to her statement. No distinction is made between the informal and formal diagnostic categories and definitions of autism (e.g. pervasive developmental disorders, autism, high-functioning autism, Asperger Syndrome).

3. The blog contains personal narratives and experiences of the author—the mother—which relate to the child with autism and her experience as a parent.
4. The blog extends to more than 20 pages (separate pages posted by the same author, which can be accessed from the blog's home page through links sorted chronologically or thematically).
5. The blog can be freely accessed by anyone, not requiring registration or any other authorisation in order to view the blog.

There is a need to take into account that the actual state of being the mother of a child with autism, the demographic characteristics, the existence of a child in the autistic spectrum and an accurate diagnosis cannot be certified in an official way. Although all of the above were personal statements of the mothers on their blogs, it is obvious from the discourse on their blogs that the mothers were indeed the authors, as they often uploaded photos of their child and their family, snapshots from their everyday life and useful material related to their child's education and activities. Furthermore, it should be pointed out that the content and narratives from the blogs examined are not necessarily representative of the experiences of other mothers of children in the autistic spectrum.

The practice of conducting research online is evolving and so are the ethical issues relating to privacy, informed consent and confidentiality. The decision on how to address the issue of informed consent depends on how public a research environment is (Rodham & Gavin, 2006). In the present research the blogs were public, anyone could access them without any restrictions and this was a sample selection criterion. Moreover, the blogs were indexed and thus locatable by search engines. It can be safely argued that the mothers' expectations about privacy were mediocre as their blogs were open to the public, and opinions, and facts and photos were

disclosed as if in a physical public location. Moreover, it became obvious during the course of the analysis that the mothers used their personal blogs to express ideas, narrate experiences, connect with others and struggle against stigma and rejection of their children. Therefore, they are likely to have higher expectations of publicity instead of privacy. It could also be argued that blogging could be a way of relating and giving support to others outside the family (Heisler & Ellis, 2008).

Following the British Psychological Society (2007) guidelines for ethical practice in psychological research online, the issues of identity verification, anonymity and confidentiality of participants, as well as data protection, were properly addressed in the present research. In order to maintain anonymity, the blogs' addresses are not cited in the text or listed among the references. Although the identity of participants could not be verified in any official way, it is obvious from the blogs that the writers were mothers who uploaded material related to their families and children in the autistic spectrum. For the purposes of anonymity and confidentiality their names are not cited, and any personal data were securely protected and replaced with general categories without identifiable information. Moreover, the research strived to adopt a self-critical stance towards the key role of the researchers themselves and apply the ethical code of conduct, abiding by the 'do not harm' principle as argued in the relevant literature (Rodham & Gavin, 2006).

Selection of Research Method

Robson (2011) profiles narrative analysis as a valid form of research and arguably, to accept personal accounts as reliable sources of information may prove particularly insightful. The qualitative method of content analysis was selected in order to analyse the mothers' written narratives, because it focuses on description and understanding of the text, and acknowledges the

main role of the researcher in the way the issues are described and signified. Through the construction of thematic categories, the text is deconstructed, analysed, interpreted and theorised. The analysis focuses on concepts, meanings or issues recalled with respect to the focus of study and how information on the topic is gathered, as well as on how this is perceived by individuals or groups (Kyriazi, 2001).

Findings

The mothers, through their narratives on their blogs, constructed a representation of children in the autistic spectrum by referring to their child's development and disability, education, family and wider social environment. The main thematic categories of analysis formed within the current research design were selected and constructed on the basis of the methodological considerations developed above, and are as follows: (1) reference to the growing child and his disability, (2) reference to education and services as part of the educational system, and (3) reference to autism and disability within the social environment.

Reference to the Growing Child and his Disability: From disorder to development

Mothers referred to the image of children in the autistic spectrum by adopting a developmental perspective, which included many examples of the special characteristics and qualitative differences of social interaction. A mother writes for her son in the autistic spectrum: "He is repeatedly asking the same question, obviously in an effort to (a) ask for more information, (b) initiate social interaction, (c) kick off some stress or solve a difficult problem or perhaps he is just trapped in a routine trying to find his way out of it." This view is very close to the view of advocates of people with autism who have expressed in public their personal experience and perception of autism. For example, Sinclair (2010) views the image of people with autism through the abundance of differences from individuals without autism, presenting many

examples relating to a continuum of neurodevelopmental diversities characterised by qualitative differences in communication, restricted interests, and stereotypic patterns of behaviour. However, his view on autism points out that it is a different way of perception, behaviour and existence within the social environment rather than a disorder. Furthermore, Grandin acknowledged to Sacks (1996) that in her social interactions with people, she feels like “an anthropologist on Mars”. Grandin refers to the uniqueness of each person with autism and the many differences between people with autism. Moreover, the same author notes her own sensory difficulties over time, tantrums, obsessions, overstimulation, anxiety and nervousness, stereotypic behaviour, as well as her taking advantage of her obsessions and turning them into professional skills, and the essential role of teachers in the integration of students with autism (Grandin & Scariano, 1996). In this way the “voices” of people with autism seem to construct an “inside” representation of individuals with autism. Acknowledging the uniqueness of her son, a mother is writing: “I came to realise that his obsessions were a means of expressing himself, of achieving happiness. For a while I was trying to deprive him of his personality.”

A similar effort seemed to be made by the participating mothers by their examining of the uniqueness of the developing child with autism, the diversity and qualitative differences in various aspects of development, and the ways in which these can form a single representation. The image of developing children in the autistic spectrum—as presented in the blogs—was the product of the mothers’ experiences with their children, and contributed to constructing the representation of autism through the maternal relationship and the characteristics, difficulties and behaviour of the child. Furthermore, references were made to specific issues such as epilepsy, drugs, sexuality and the diagnosis itself. The aforementioned issues were identified and discussed repeatedly by mothers viewing the disorder from a developmental perspective. In this

way the experience of autism was communicated through the mothers' descriptions, which covered a wide range of behaviours and offered a wealth of information about the child and its development. The shift of focus from the difficulties faced by the child because of his developmental disorder to the functional skills that will enable him to meet the demands of family, school and social environment is the goal of mothers who are making efforts to this end.

"In the beginning was the diagnosis" a mother wrote, as the diagnosis is the beginning of all efforts. The diagnosis constitutes a painful introduction of the representation of autism to the individual and family life, and marks the deprivation of "normality" (Russell & Norwich, 2012). The first period after the diagnosis was made, was characterised by severe shock, anger and sadness; some mothers compared this period to a "tombstone", "the torture of Sisyphus" and "the end of happiness". The mourning for the loss of the "normal" child was apparent in the narratives of mothers, but it would be inappropriate to conclude that this is continuous or permanent. Mothers reported that they experience anxiety, concern, uncertainty, puzzlement, threat, shock, sadness, distress, anger and the diagnosis and differential diagnosis are presented as time-consuming and quite demanding procedures. As a result, precious time is wasted for the family and child, targeted interventions and provision of education are delayed and parents experience additional emotional and financial problems because of this delay in diagnosis (Fleischmann, 2005; Larson, 1998; Midence & O'Neill, 1999). The participating mothers not only recognised the importance of early diagnosis and the consequences of late diagnosis, but also claim the creation of an organised institutional framework for autism in Greece and its treatment by the state as an existing and frequent disorder of development. By expressing these requests, mothers adopted a model that views disability as a "crusade". The "crusade" model uses medical concepts and practices to explain the disability, but at the same time takes action by

reacting to some extent to the “personal tragedy” model employed by professionals and claims full participation of children with disabilities instead of the “normalisation” promoted by the medical model (Seligman & Darling, 2007 in Ryan & Runswick-Cole, 2009). In this regard, a mother writes that “... the sooner you receive and accept the diagnosis, the faster you go along ... you must search and study as well as avoid confusion, false promises and scams.” Moreover, another mother supports the notion of early diagnosis of autism as “the only way to help children and their families through Early Intervention” adding that “we, parents, must demand that all children in Greece should be screened for autism early in their lives.”

The emotional, linguistic and psychosocial aspects of child development were those that concerned all of the mothers the most. Within this context, the characteristics of autism were described, as well as the skills the child had conquered in each area of development. The findings show that the mothers were not limited to a simple description of disabilities and special characteristics of children in the autistic spectrum, but seemed to be concerned about the cause and effect relationship and the developmental progress of children, the comparison with the expected behaviour, the typical course of development and the skills acquired by the child in each developmental stage. The various characteristics were thus associated with the development and functionality of each child, behaviour, skills, school performance and relationships with others, providing a sense of continuity. Thus a mother comments upon her son’s new skill: “Since he learned how to read, a whole new world has been opened up in front of us ... he’s been asking to read many times a day ...”

Mothers appeared to set goals and take action and initiatives, approaching the roles of therapists, educators, special educators, psychologists, speech therapists and other specialists without however, substituting for the actual professionals. Dealing with a child with autism

meant they had to go beyond the traditional maternal role of child rearing, to acquire more dimensions and to include specialised skills and interventions. Indeed, the skills developed by these mothers were not the usual skills found in mothers of children without autism. The mothers studied books about autism, referred to websites of scientific associations and professionals, worked alongside their child's therapists, learned from each other, participated in seminars and conferences, and by developing a critical view of the interventions applied they managed to apply themselves to some elements of those interventions. As a mother indicates, "it is worth remembering that development does not progress in a linear fashion but in uneven steps, so don't become obsessed with the developmental milestones." It also seems that they acted as co-therapists by applying problem-solving skills adapted to the family's daily routine and way of life. A necessary condition for this to happen was that they themselves acquired sufficient understanding of the issues related to the development, personality, weaknesses and preferences of the child, and that they were able to combine these in a creative way in order to solve problems as "practical scientists" and develop the child's functional skills by achieving progressive goals. A mother dealing with her son's sexuality issues writes: "Unwanted sexual behaviours (like stripping in public areas and masturbating, touching strangers or children, etc.) are treated as unwanted behaviour problems, namely by teaching the right thing to do (using pictures for example), interrupting (not verbally) the unwanted behaviour and practicing again and again." Previous scholars (Dreuth Zeman et al., 2011b) focused on mother bloggers acting not only as parents, but as therapists and advocates as well, depicting their fight for quality services to their children.

In the current study, sexuality seemed to be the area of development the mothers knew less about and this was a cause of anxiety, especially as their children approached puberty. The

majority said they were not familiar with the subject and they felt unprepared, although they realised that they would have to deal with it in the near future. It seems that they faced their child for the first time as a person with gender and the sexuality related to that gender. However, the prospect of addressing the issue without proper support and guidance was frightening and stressful for them. A mother notes that “Puberty in autistic people looks like a bomb ready to explode at any moment.” Additionally, the issue of companionship, human intimacy and coexistence was discussed with reference to specific examples, and was associated with sexuality and the needs of people with disabilities which are not covered by the current life model.

Some mothers were also particularly preoccupied about epilepsy and medication, along with the side effects that accompanied these medical conditions. One of them describes epilepsy as “a hit below the belt. I can deal with autism but I find it impossible to deal with epilepsy.” The existence or lack of quality health services as well as the parents’ right to be informed and choose their child’s treatment are key issues that have been addressed extensively. Mothers argued that they have the right to be informed and choose the treatment of their children themselves, opposing the medical model that deems professionals as experts who decide and parents as passive recipients of medical decisions. One of them is clearly stating that “I do not intend to sacrifice my son putting him on medication that causes him to suffer all those strong side effects.”

Mothers did not have a very clear understanding of what autism is, and it seemed that they were puzzled whether autism constituted a separate representation quite distinct from the representation of the child and which are the boundaries of the two representations. In one instance, the brain of the person in the autistic spectrum appears as a messy suitcase, unlike the neuro-typical person’s brain that corresponds to a tidy suitcase, while a “wise” person with

autism resembles a suitcase having inside only one thing—that thing which the person with autism excels at. Another mother referring to the minds of some of the people in the autistic spectrum writes that “Autistic minds are definitely the strongest ones ... That boy with IQ higher than Einstein, couldn't have been but autistic.” These efforts, through often simplistic metaphors, romantic representations and extreme examples, are essentially the mental processes which show the mothers' attempts to understand autism through the variety, complexity and the challenges it presents, to create fantasies that mentally satisfy them and representations that eventually reconcile fantasy with external reality. Thus, a mother describes her son as “... my little star, my Little Prince, who lives so far away from my world and I need to learn the rules of his world ...”

Reference to Education and Services as Part of the Educational System: A long-lasting struggle

From the analysis of the research findings, it seems that mothers' experiences in relation to the education and provision of services for children in the autistic spectrum are narrated at three levels: The first level concerns the structures and operation of the schooling system and the curriculum and private services, the second level deals with politics and its impact on education, and the third level is about the culture, attitudes and the hidden value system of the educational system.

The mothers were mainly concerned with finding an appropriate educational setting; the lack of appropriate educational structures for children in the autistic spectrum in Greece was common knowledge to all mothers. The mothers expressed their concern about the existing schools due to the problems in both infrastructure and staffing. It is argued that the lack of structures and the lack of experts justify the continuous requests of parents for the improvement of the educational system and the adequate staffing of schools (Kontopoulou & Tzivinikou,

2004; Vlachou & Mavropalias, 2008). Due to these problems in the infrastructure, a number of children in the autistic spectrum were forced to remain at home without attending school. Moreover, it seems that the children with more severe difficulties, i.e. those who cannot perform on their own the tasks of everyday life, the “itchy”, the hyperactive, those who have apparent behavioural and social adjustment difficulties, the ones who find attending school more difficult, are faced with “waiting lists” and “staff shortages”, while parents are often driven, directly or indirectly, to other schools or private frameworks. All the mothers reported using costly private services for their autistic children, which included interventions by specialists after school either by individuals at home or in organised intervention centers. This is a financial burden for all parents because the Greek National Insurance Service covers only a small amount of the expenses. A mother gave the title “... of a lesser god ...” when she described the treatment received by disabled students in the Greek educational system. Another mother felt deeply disappointed when the kindergarten teacher informed her that all children were expected to be independent in the bathroom and fully trained before enrollment: “I couldn't bring myself to admit that he wasn't potty-trained yet and of course we never returned to that school again.” This veiled culture of rejection denies disabled children's rights to education and is perpetuated through a system of hypocrisy by turning a blind eye to the inadequate educational system.

The rejection of the child with autism has thus become a status quo which parents must accept and abide by, under threat of punishment for the child and themselves. A mother describes a scene where an angry school teacher shouts at her: “Shame on you, why did you do that? Don't you watch TV? People are getting genetic tests nowadays, are you that ignorant?” Hostile relationships between members of the staff and the mother were also described by scholars in the States, when the mother tried to convince the staff members to provide services

for her child (Swanke, Dreuth Zeman, & Doktor, 2009). According to Boutskou (2008), teachers in special schools perceive parents with deficiency models, while education officials with the personal tragedy model. Data from the present study support this argument and show how the whispers of teachers “construct” parents. The veiled culture of rejection that underlies these models gradually becomes evident and runs through the entire spectrum of education.

Furthermore, the mothers experienced the bureaucracy, formalism and lack of taking responsibility which characterises the attitude of the Greek educational system. Similar findings have been reported in other studies that examined the experiences of a small sample of parents with disabled children in the Greek educational system (Zoniou-Sideri & Deropoulou-Derou, 2008). Another aspect found in the Greek educational context is the minimal implementation of the laws regarding special education and disability rights (Zoniou-Sideri, 2011). In this vein, a mother uses the term “state with special needs” to show how the students with autism and their families are forced to adjust to the needs and deficiencies of the social system, which uses the medical model as an excuse to project its own weaknesses and errors onto citizens with disabilities. Therefore, it is extremely important to take into account and redefine shortcomings, failures and negative examples, and to emphasise the positive examples and good practices identified by mothers in order for these to emerge, be cultivated and constitute not only objects of analysis but also role models.

The mothers were mostly concerned with the future prospects for their child with autism and narrated their worries about their child’s independence, adulthood, employment and the social effects of financial crisis on education, health care and disability. Some of them seemed to consider future in the short term while others adopted a longer-term perspective. A mother described the dead-end faced by another mother who was trying to secure closed care for her

adult son with autism before she died: “Because of the cancer she can barely take care of herself, let alone her son ... But what she fears most is not death rather than leaving him alone and helpless ...” The mothers were largely concerned about the future of their children in the autistic spectrum in the event that they were no longer alive to take care of them because there is a minimal provision of services for adults with autism in Greece. All of them highlighted their concern about the existing institutions, their appropriateness and the conditions that operate because the quality of services provided to people with autism is low and they have a profit orientation. It is not by chance that Goffman (1963) describes institutions as landfills for the dumping of people and that Timmons (2008) argues that the separation in institutions leads to loss of humanity and dignity as the staff focus mainly on their duties rather than on the children. In this regard, a mother who has visited several such institutions considers them “as dumping grounds for forgotten people”.

Reference to the Social Environment: Acceptance-rejection, stigma and struggle against discrimination and social exclusion

Overall, the mothers discussed issues of acceptance, rejection, stigma and struggle against discrimination. Some mothers reported loneliness and isolation as a consequence of rejection by the social environment, an actual experience of social exclusion, and some reported loss of friends and social life. The study of Dreuth Zeman et al. (2011b) also reported feelings of isolation between cyber mothers, mainly relating to the home-school environment and the lack of support. Others referred to the limitations unavoidably experienced in their social lives and to the negative reactions of strangers. Some of them experienced not only rejection and stigma in their environment but also inside themselves. Others challenged those around them to address their prejudices and accept diversity. Some mothers mentioned disability and political discourse, mass media discourse, and the discourse arising from public figures.

The social environment often poses control and discipline issues for the children in the autistic spectrum and their families. The mothers experienced negative comments and rejection by the social environment due to their children's behaviour, especially when outside, in situations involving contact with other people in public places such as the church, playground, restaurant or shops. One mother reported feelings of anger caused by comments, advice and aggressive suggestions of others on the behaviour of her child. In another instance, a mother became obviously angry with those who characterised and addressed her child as a "problem". It appears as if the physical substance of the child with autism is registered in the social context and acquires its importance in society, where the physical body becomes a social body and is treated as a "problem". According to Makrinioti (2004), this happens to bodies that differ, i.e. those bodies that disrupt the daily routine, cause bewilderment, challenge the standard boundaries of the body and raise issues of control and discipline. During these social interactions, according to Milton (2012), certain behavioral indicators linked with differences in neurology are not only producing differences in sociality, but are used to construct the notions of autism as a "lack" and "social deficit".

In addition, one mother's concern stood out in her narrative about whether the teacher would treat her child with dignity, whether his classmates would laugh at him, whether the older kids would beat him up again and whether just being different would cause social problems at school. The school environment is presented as hostile towards the student with autism who appears to deviate from the socially accepted standard (Storey, 2007). As children in the autistic spectrum find it difficult or do not meet the culturally and socially defined expectations of behaviour (Solomon, 2010), it seems inevitable that they are rejected by the social environment,

and these acts of rejection cannot be easily disputed. “People need to know that autism relates to diversity, not deficit” states a mother.

While the notions of inclusion and diversity are echoed in the mothers’ discourse, the depiction of autism and disability in the media seems to reinforce negative stereotypes. The vicious cycle includes the negative reactions of others towards children in the autistic spectrum which are partly due to their ignorance about autism and which favour in turn the isolation of children in the autistic spectrum within the confines of their home.

Conclusions

The mothers’ narratives of their children in the autistic spectrum build a “mosaic” of views, experiences and emotions which could describe the actual experience of being the mother of a child with autism. By reconstructing the image of children in the autistic spectrum through the blogs of mothers, one could reach the conclusion that autism is experienced by mothers: (a) as a diagnostic category and disorder within a developmental context (Panopoulou-Maratou, 2010; Shah et al., 2007), whose symptoms are connected with the course of development and affect many aspects of it (Papoudi, 2008); (b) as a struggle for quality education and services within the educational context (Boutskou, 2008; Zoniou-Sideri & Deropoulou-Derou, 2008); and (c) as a disability within the social environment associated with rejection, stigma and the struggle against discrimination and social exclusion (Goffman, 1963; Gray, 2002; Makrinioti, 2004). These mothers challenged the constructs of autism as a developmental disorder, as special educational needs and as a disability which all appear as separate models in the autism field.

The struggle of the specific mothers for the education of children in the autistic spectrum seems to hold a prominent position among the conclusions of this research. Autism constitutes a childhood disorder involving special characteristics and disabilities that lead to exclusion from

learning, and social exclusion (Panopoulou-Maratou, 2010). The lack of support structures, the reluctance, the intolerance and the inability of the educational system to differentiate itself from the medical model of education, shift all responsibility from organisations and education professionals to parents of disabled children (Zoniou-Sideri & Deropoulou-Derou, 2008). It appears, therefore, that children in the autistic spectrum and their parents undergo the covert culture of rejection by the educational system that treats them according to the deficiency and the personal tragedy models (Boutskou, 2008). Instead of ensuring the rights of children in the autistic spectrum, these are questioned through bureaucracy and formalism and are violated by the educational services not taking responsibility for educational provision (Phtiaka, 2008; Zoniou-Sideri & Deropoulou-Derou, 2008). The mothers were not able to ensure their autistic child's right to education, and their efforts to access the education services were a constant struggle with many frustrations, stress and anxiety (Zoniou-Sideri & Deropoulou-Derou, 2008). These mothers dream of ensuring quality education in public schools, supplemented by private services for children in the autistic spectrum, and for all children with or without disabilities.

The participating mothers also narrated the practices of rejection, stigmatization and charitable attitude towards people with disabilities, and addressed disability by adopting either the medical or the hybrid model (Zoniou-Sideri et al., 2006). But they also asserted the rights of children in the autistic spectrum, reacting to rejection and stigmatisation and acting as advocates for their children's rights, a finding also supported by the research of Zeman et al., (2011). It seems that the mothers had a mixed perception of autism, adopting views and borrowing ideas from the medical model of disability, from the hybrid model and from the social model of disability.

The written narratives of mothers having children in the autistic spectrum, as presented through their posts on their personal blogs, provide a view of autism both as a clinical category and as a sociocultural phenomenon associated with educational and social challenges, as a disorder and diagnostic category from a developmental perspective, as an educational challenge, and finally as a disability associated with stigma and rejection. The use of the personal blogs gave the mothers the opportunity to express their views publicly and narrate their experiences, which constitutes a context of informal “treatment”. In this way, the Internet served as a vehicle to develop links with other parents, receive and provide help and support, but also to act against stigma and rejection of their children by becoming role models themselves.

Further research needs to be undertaken in order to explore in-depth and enlighten the ways in which families with children in the autistic spectrum experience their everyday life, and the obstacles they face in meeting the individual needs of their children. The majority of published papers (Myers et al., 2009; Ryan & Runswick-Cole, 2009, Sawchuka & Clarke, 2015) are from countries in which diagnostic services and educational provision are well developed, but we are lacking information from diverse socio-cultural backgrounds. In order to gain a better understanding of autism, professionals should listen not only to their own voices but also to the voices and experiences of people with autism and their families worldwide.

Acknowledgement

There was no research funding for this study, and no restrictions have been imposed on free access to, or publication of, the research data.

Disclosure Statement

No potential conflict of interest was reported by the authors.

References

- Boutskou, E. (2008). Creating 'the parents': Whispers of special teachers. In H. Phtiaka, (Ed.), *Drop by for a coffee. School-home relationships at the edge of diversity* (pp. 197-215). Athens: Taxideutis [in Greek].
- Boyd, D. M., & Ellison, N. B. (2007). Social network sites: Definition, history, and scholarship. *Journal of Computer-Mediated Communication*, 13(1), 210-230. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/j.1083-6101.2007.00393.x/full>. doi: 10.1111/j.1083-6101.2007.00393.x
- Brownlow, C. (2010a). Presenting the self: Negotiating a label of autism. *Journal of Intellectual & Developmental Disability*, 35(1), 14-21. doi:10.3109/13668250903496336
- D'Auria, J. (2010). Autism on the Web: "Oh, the places you'll go!". *Journal of Pediatric Health Care*, 24(6), 11-15. doi:10.1016/j.pedhc.2010.07.007
- Dreuth Zeman, L., Swanke, J., & Doktor, J. (2011a). Measurable successes for children with ASD: Perspectives from mothers' virtual journals. *School Social Work Journal*, 36(1), 61-78.
- Dreuth Zeman, L., Swanke, J., & Doktor, J. (2011b). Strengths classification of social relationships among cybermothers raising children with autism spectrum disorders. *School Community Journal*, 21(1), 37-51.
- Fisher, J. T. (2006). Strange new worlds. *Commonweal*, 133(4), 30-32.
- Fleischmann, A. (2004). Narratives published on the internet by parents of children with autism: What do they reveal and why is it important? *Focus on Autism and Other Developmental Disabilities*, 19(1), 35-43. doi: 10.1177/10883576040190010501
- Fleischmann, A. (2005). The hero's story and autism: Grounded theory study of websites for parents of children with autism. *Autism*, 9(3), 299-316. doi: 10.1177/1362361305054410

- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Grandin, T., & Scariano, M. M. (1996). *Emergence: Labeled autistic*. New York: Warner Books.
- Gray, D. (2002). Everybody just freezes. Everybody is just embarrassed. Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*, 24(6), 734-749. doi:10.1111/ 1467-9566.00316
- Heisler, J. M., & Ellis, J. B. (2008). Motherhood and the construction of “mommy identity”: Messages about motherhood and face negotiation. *Communication Quarterly*, 56(4), 445-467. doi:10.1080/01463370802448246
- Jordan, C. J. (2010). Evolution of autism support and understanding via the World Wide Web. *Intellectual and Developmental Disabilities*, 48(3), 220-227. doi: 10.1352/1934-9556-48.3.220
- Kontopoulou, M., & Tzivinikou, S. (2004). Critical review of a “new” institution in the area of special education: The parents’ perspective. *Review of Pedagogy*, 38, 110-126 [in Greek].
- Kyriazi, N. (2011). *Sociological Research*. Athens: Pedio /in Greek/.
- Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science & Medicine*, 47(7), 865-875. doi: 10.1016/S0277-9536(98)00113-0
- Makrinioti, D. (2004). Introduction. In D. Makrinioti (Ed.) *The limits of body: Interdisciplinary approaches* (pp. 11-73). Athens: Nisos.
- Midence, K., & O’Neill, M. (1999). The experience of parents in the diagnosis of autism. *Autism*, 3(3), 273-285. doi: 10.1177/1362361399003003005
- Milton, D. E. M. (2012). On the ontological status of autism: The ‘double empathy problem’. *Disability & Society*, 27(6), 883-887. doi:10.1080/09687599.2012.710008

- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3(3), 670-684. doi:10.1016/j.rasd.2009.01.004
- Ortega, F. (2009). The cerebral subject and the challenge of neurodiversity. *Biosocieties*, 4, 425-445. doi:10.1017/S1745855209990287
- Panopoulou-Maratou, O. (2010). *Child psychopathology: Social and learning exclusion*. Lectures in the Master of Arts Program in Special Education, Faculty of Early Childhood Education, National and Kapodistrian University of Athens, Athens, Greece [in Greek].
- Papoudi, D. (2008). The inclusion of children with Asperger in the mainstream school. *Greek Review of Special Education*, 1, 195-207.
- Phtiaka, H. (2008). The inclusion of children with special needs in mainstream schools through the eyes of the parents: successes, problems and cooperation amongst family and school. In H. Phtiaka (Ed.), *Drop by for a coffee. School-home relationships at the edge of diversity* (123-168). Athens: Taxideftis [in Greek].
- Robson, C. (2011). *Real world research*. Chichester, West Sussex: Wiley and Sons Limited.
- Rodham, K., & Gavin, J. (2006). The ethics of using the internet to collect qualitative research data. *Research Ethics Review*, 2(3), 92-97. doi:10.1177/174701610600200303
- Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Child Psychology and Psychiatry*, 17(2), 229-245. doi:10.1177/1359104510365203

- Ryan, S., & Runswick-Cole, K. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 43-53. doi:10.1111/j.1468-3148.2008.00438.x
- Sacks, O. (1996). *An anthropologist on mars: Seven paradoxical tales*. New York: Vintage.
- Sawchuka, D., & Clarke, J. (2015). Representations of autism and autism spectrum disorder (ASD) in the North American Roman Catholic print media, 1990-2013. *Journal of Disability & Religion*, 19(2), 146-167. doi:10.1080/23312521.2015.1024910
- Shah, P. E., Dalton, R., & Boris, N. W. (2007). Pervasive developmental disorders and childhood psychosis. In R. M. Kliegman, R. E. Behrman, H. B. Jenson, & B. F. Stanton (Eds), *Nelson Textbook of Pediatrics* (18th ed., pp. 173-180). Philadelphia, PA: Saunders Elsevier.
- Sinclair, J. (2010). Cultural commentary: Being autistic together. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1075/1248>
- Solomon, O. (2010). Sense and the senses: Anthropology and the study of autism. *Annual Review of Anthropology*, 16(2), 241-259. doi:10.1146/annurev.anthro.012809.105012
- Storey, K. (2007). Combating ableism in schools. *Preventing School Failure*, 52(1), 56-58. doi:10.3200/PSFL.52.1.56-58
- Swanke, J., Dreuth Zeman, L., & Doktor, J. (2009). Discontent and activism among mothers who blog while raising children with autism spectrum disorders. *Journal of Maternal Health and Well-being*, 11(1), 199-210.
- The British Psychological Society. (2007). *Report of the working party on conducting research on the internet: Guidelines for ethical practice in psychological research online*. Retrieved from

http://www.bps.org.uk/sites/default/files/documents/conducting_research_on_the_internet_guidelines_for_ethical_practice_in_psychological_research_online.pdf

Timmons, V. (2008). Towards inclusive education in Canada. In L. Barton, & F. Armstrong (Eds.), *Policy, experience and change: Cross-cultural reflections on inclusive education* (pp. 133-147). London: Springer.

Vlachou, A., & Mavropalias, T. (2008). Education and school inclusion of children with disabilities: The Parents' perspective. In H. Phtiaka (Ed.), *Drop by for a coffee. School-home relationships at the edge of diversity*. Athens: Taxideftis [in Greek].

Zoniou-Sideri, A. (2011). The necessity of inclusion: Current questions and perspectives. In A. Zoniou-Sideri (Ed.), *Current inclusive perspectives* (pp. 29-53). Athens: Pedio [in Greek].

Zoniou-Sideri A., Karayianni, P., Deropoulou, E., & Spandagou, I. (2006). Inclusive discourse in Greece: Strong voices, weak policies. *International Journal of Inclusive Education*, 10(2), 279-291. doi:10.1080/13603110500256046

Zoniou-Sideri, A., & Deropoulou-Derou, E. (2008). Cooperation between school and family: Analysis of the experience of disabled children's parents. In H. Phtiaka, (Ed.), *Drop by for a coffee* (pp. 69-86). Athens: Taxideutis [in Greek].

Table 1. Characteristics of the sample.

Blog	Children in family	Gender	Age	Diagnosis	Mother's education	Mother's employment status
1	3	Male	12	HFA—Asperger Syndrome	Not mentioned	Not mentioned
2	2	Male	8	Autism	Higher Education	Employed
3	2	Male	8	Autism	Higher Education	Employed
4	2	Male	8	PDD	Higher Education	Employed
5	2	Male	6	PDD	Not mentioned	Employed