

# Experiences of disabled children's families concerning school-family collaboration

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The role of families in the education of disabled children is one of the prominent factors influencing their educational course. Parents' aspirations for their children, their expectations and their experiences are determinant factors in the education of their disabled children. In the Greek context the role of familial environment appears reinforced since historically the majority of society has considered education as an individual responsibility of families. The scope of this study is the exploration of the experiences of a group of disabled children's parents concerning school-family collaboration in relation to the functioning of the special educational structures following discourse analysis approach. The exploration of the experiences of disabled children's families took place using semi-structured interviews. The analysis of parent's experiences follows the social model of disability, which is contrasted with the clinical model and the theory of personal tragedy. The discourse analysis approach reveals a growing number of incidents concerning the feeling of personal tragedy. The experience of personal tragedy appears more often at the level of collaboration with structures and professionals from the educational context, projecting the individual model approach of disability at the level of school-family collaboration.

## Introduction

The way disability and its multi-complex structure are perceived has changed over the last decades. The multi-complex structure of the concept of disability is presented by the social model of disability (Oliver, 1996) and its derived approaches: materialistic feministic social model (Thomas, 1999· Corbett, 1994), cultural approach of disability (Lane, 1995· Aull Davies & Jekins, 1997), psychoanalytical approach of disability (Shakespeare, 1994) etc.

It is supported that the traditional medical individual approach of the various economical and social limitations of disabled people and their families has been surpassed, as the socio-cultural model of disability gradually dominates (Brett, 2002). On the other hand, the necessity of publication and redefinition of parent's opinions and experiences about the needs concerning the educational and social inclusion of their disabled children has emerged lately (Brett, 2002· Bjarnason, 2002· Read, 2000). It seems that families with disabled children do not participate equally in the decision-making about the education, the intervention programs or the supportive structures.

The scientists do not use parent's experiences, although parents are the nearest to the disabled child source of information, experience and knowledge (Brett, 2002· Case, 2000· Jones & Swain, 2001).

This fact explains the doubt expressed by a disabled child's mother about the scope and the interest that can be caused by a series of interviews given by disabled people's parents.

Parents and their disabled children form a "disabled" entity within the social structure of a medical orientated modern society and the severity and the kind of disability determine the possibilities of the education and sociability of the child. The medical model of disability views the behavior and the state of a disabled person as a disease and consequently focuses on the diagnosis and treatment of the disabled person. This point of view is opposed to the view of the social model of disability (Thomas & Peirson, 1996).

This fact leads family to be trapped in the suffocating experience of personal tragedy and perceive every challenge of their child's educational procedure as a personal responsibility, guilt or failure. The theory of personal tragedy proceeds from the medical model of disability according to which disability is perceived as a "problem" at individual (physical-intellectual) level (Barnes & Mercer, 2003). Nevertheless, in the present paper is independent of the medical model and forms a

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distinct experience of disability. This point of view agrees with the psycho-emotional dimensions of disability that attempt to harmonize the experience of impairment with the conceptual expression of disability (Thomas, 1999, 2004).

Parents bound to the individual model of disability perceive the birth of a disabled child as a personal matter and responsibility, appear weak and dependent on the medical model of disability that controls and determines their child's and their own life course on the basis of the adjustive possibilities of disability (Oliver, 1996, Shakespeare et al., 1999).

The social construct of disability displaces the responsibility from the diagnostic image of disability to the rigidity and irreconcilability of social structures that constrict even the average majority -that determines the widely and socially accepted values and principles - and exclude groups few in number from attained collective rights and institutions such as the right of education, sociability, work etc (Oliver & Sapey, 1999· Barnes & Mercer, 2003). Under such a social state, disabled people's families are labeled, although they are not, as disabled families, are restricted and excluded as a disabled unity from the right of participation (at the level of substantial activation) in the social-political institutions (Barton, 1993).

The social view of disability focuses more on the study of conception (concept of social context) and less of the subject (family and disabled child) aiming at the revision of given values, attitudes and structures (Dowling & Dolan, 2001).

The social model of disability as it is shaped in the 21<sup>st</sup> century preserves its dynamic power and functioning in the movement of disabled people as a way of expression and giving meaning to their experiences (Tregaskis, 2002).

The present study presents parents' experiences concerning the educational course of their disabled children and specifically the present school-family collaboration. By means of the analysis of experiences and the social model, it attempts to show the domination of the individual model of disability and the diffusion of the experience of personal tragedy that parents face at the level of school-family collaboration.

The publication of their experiences aims at the reinforcement of their role in the educational course within the context of an equal and active participation that focuses on making their attribute of "disabled children's parents" a matter of public concern, hence weakening the feeling of personal responsibility and the experience of personal tragedy.

### **School-Disabled children's family collaboration within the Greek educational context**

We study the collaboration between school and disabled children's family at the macro-level of educational policy as it is practiced according to the law, with its final receivers being school and family.

At first we will comment on the Public Law 1566/1985 concerning the structure and functioning of primary and secondary education including issues related to special education. This law will be commented because it was standing and influenced families' first experiences about their children's educational course. Continuously, we will refer to the standing Public Law 2817/2000 that regulates the issues of special education and contains paragraphs concerning collaboration. The decisions of the Department of Education about the regulations of the duties and responsibilities of educational staff and special educational staff of Special Education School Units will also be presented, as they have a direct relation to school-family collaboration.

It is widely known that the first Public Law concerning regular education that contained regulations about special education was the Law 1566/1985. In the issues related to special education, there was a paragraph (ΦΕΚ 1566/1985, Article 32, paragraph 6, passage st) about collaboration issues. It anticipated the formation and functioning of parents' associations that collaborate and participate in issues concerning special education and special vocational education along with the Department of Education without giving further explanations and elucidations.

The Centers of Mental Health and the Medical-Pedagogical Centers functioned under the supervision of the Department of Health and Social Insurances and were responsible for the diagnosis, enrollment and attendance of all disabled children in special education or special vocational education schools and for the consulting of educators, parents and disabled people (ΦΕΚ 1566/1985, Article 33, paragraph 1, passage a, b, c, d). It is noted that the Department of Health was responsible for the most essential issues, while disabled children's parents did not have an active or legislated role in decision-making related to education.

Fifteen years later the Public Law 2817/2000 is enacted referring exclusively to special education issues. The standing Law, as the previous one, preserves the collaboration between the Department of Education and parents' associations relating to the act of education (Article 1, paragraph 20, passage i and ia) introducing into the collaboration a new

member, the Division of Special Education of Pedagogical Institute in order to "offer consultative and supportive services to parents of children with special educational needs" (Article 1, paragraph 20, passage i and ia, p. 1568).

Moreover the responsibilities of Centers of Diagnosis, Evaluation and Support of children with special educational needs, a new institution that functions under the supervision of the Department of Education (they undertake the previous role of Centers of Mental Health without abolishing them) include "the organization of informative and training programs for students' parents" (Article 2, paragraph 3, passage d, p.1568).

Furthermore, in the recently published Disabled Citizen's Guide (2007) there is an extensive reference to the consultative and supportive programs for parents organized by Centres of Diagnosis, Evaluation and Support, as parents are invited to "participate actively and in collaboration with all the involved structures in order to succeed the equal integration of disabled people/ people with special educational needs in school and society" (p.160).

In the most recent decision published on the 3<sup>d</sup> of April 2007 concerning the responsibilities of educators and special staff of special education schools there is an extensive reference to the collaboration between special education teachers and parents as follows:

*"(Special education teachers) collaborate with parents and facilitate collaboration with school staff. Organize informative meetings for parents, teachers, special education staff or other involved structures concerning issues of common interest" (ΦΕΚ 449/2007, paragraph 7, p.9389).*

As far as teachers of special schools are concerned it is noted that they are responsible to guide parents to issues of special education and home support (ΦΕΚ 449/2007, p. 9390). The collaboration between inclusive classes' teachers and parents is also defined and it is noted that "no student can be excluded from attending an inclusive class, if parents wish so, even if there is no diagnosis from an official diagnostic structure" (ΦΕΚ 449/2007, p. 9390).

Finally, emphasis is given on the collaboration between school psychologists, social workers, speech therapists, specialists in vocational guidance and mobility of blind students and specialists in sign language of special schools' deaf students and students' parents (ΦΕΚ 449/2007, pp. 9391-9394).

From this short review of the legislative context, it is obvious that there is no legislative deficit concerning collaboration. Specifically, the standing Law 2817/2000 and the legislated functioning of Centers of Diagnosis, Evaluation and Support project and defend the active school-family collaboration. It is a fact that during the last seven years the necessity of this

institution is overemphasized by laws and legislative decisions. On one hand the importance of school-family collaboration is declared, but on the other hand the way educators will offer consultative and supportive services to families is not defined and foresighted, as the pre- and post-graduated programs of universities do not prepare teachers for this role.

In the latest legislative decision 449/2007 school-family collaboration is defined, but without any proposals for collaboration policies between structures involved in the educational procedure. The policies for collaboration presuppose the training and preparation of school staff for the reinforcement of collaboration by means of in-service training, organization of conferences, comprisal of a collaboration period with the family in the school program, creation of centers for the reinforcement and support of parents within the schools, home visits and creation of action research groups aiming at the improvement of the conditions for collaboration. A functional collaboration also presupposes the improvement of conditions for communication between social services, health centers and school.

It seems that all the precedent policies are omitted or applied partly as they demand structural changes of the educational system and the ways of collaboration, presupposing intention and willingness from the part of the educational policy concerning the reconstruction of conditions in the domain of school-family collaboration.

### **Scope and questions of the study**

The scope of this study is the exploration of the opinions of disabled children's parents about the Greek educational system, based on their past or present experiences in school-family collaboration.

The study attempts to show parent's opinions and experiences, aiming at the best possible understanding of issues proceeding from the education of disabled children. The analysis of experiences has a much more descriptive than interpretative character as it is a tool for problem understanding and solution and does not aim at an objective presentation of "reality". The present study lies between two levels: parents' experiences and opinions and disability studies (Goodley & Tregaskis, 2006).

The basic question that emerges from the present study refers to the kind and level of school-family collaboration within the modern Greek educational reality and the way family has experienced and experiences the present situation.

### **Methodology**

The present study adopts an analytic context of methodological approach and applies the narrative approach (Bryman, 2004) and discourse analysis for two main reasons: a) the

analysis attempts to give meaning to parents' experiences and comprehend the way that families approach disability and b) the way someone approaches disability is a matter of discussion and influences the formation of social relations and social structures and consequently the organization of education (Potter, 1996· Wood & Kroger, 2000· Scior, 2003).

The study took place in the presence of researchers in families' residence after a telephonic arrangement using the methodological tool of semi-structured interviews. The average duration of recorded interviews was forty five (45) minutes. Researchers were familiar with the family cases due to previous collaboration. This fact reinforced the feeling of intimacy and trust between parents and researchers.

Interviews' analysis followed thematic approach (Meason, 2003) and focused on the collaboration between school-educational structures and family (collaboration with the Department of Education, diagnostic structures, educational and school administrations, educators from special and regular education) while they were trying to find a school and while their child was attending a school.

### Sample

Four disabled children's families that reside in Attiki participated in the study. In three cases mothers were interviewed. Both parents were invited to participate in the interviews.

Researchers acknowledge that the number of families is limited. It must be noted though that semi-structured interviews are only a part of a series of multi-methodological case studies, which are not presented in the present text.

Researchers were familiar with the families that participated in the study due to past professional collaboration. Family cases are very interesting as they have conflicted with the educational system in various ways and their children's disabilities are not *accommodated* by special education. It is possible that these cases' dynamic reveals the challenges Greek educational system faces concerning the education of disabled students.

Moreover the fact that these families have a long educational experience since their children have passed through all educational levels or attend the higher educational levels gives us the possibility of forming a much more complete view of the educational course and the ways of school-family collaboration.

The first case involves a girl with Down syndrome. She is the youngest child of a six-member family and she is twenty five (25) years old. Both of her parents are graduates of secondary education.

The second family has a sixteen (16) year old adolescent girl with multiple disabilities (deafness and learning disability). She is the youngest child of a five-member family. Both parents are graduates of post-secondary

education. This family is a case of educational immigration. The mother and the disabled child moved to Athens in order to find the most appropriate educational setting for the child.

The third family has a fourteen (14) year old boy with multiple disabilities (deafness and autism). The family has three members and both parents are graduates of secondary education. The fourth case involves a four-member family that has a twelve (12) year old boy with mild multiple disabilities (microcephaly, hyperactivity, mild learning disability, hard of hearing). Both parents have a university degree.

### **Families' experience of personal tragedy within the context of disabled children's education: The role of educational structures involved in school-family collaboration**

The role of structures involved in disabled children's education and the way parents perceived their attitudes are presented in the following units. The experience of personal tragedy is dominant.

#### *The Department of Education as Pontius Pilate*

In the first case the mother of the child with Down syndrome reports her first experience concerning pre-school education in the late 80's. The mother reports that the Department of Education suggested that she enrolled her child in the regular pre-school education setting of the neighborhood according to the Public Law 1566/11985 that legitimized the enrollment and education of disabled children in the public educational structures.

The Department applies the law without preparing regular schools for applying it too. The following extract from the mother's discussion is revealing:

*I went to the Department of Education, I asked and they told me that I had every right, as every Greek citizen, to enroll my child in the public pre-school educational setting of our neighborhood ...*

But when she went to the school, the teacher told her:

*...The Department was right telling you to enroll your child in the school. If you wish we will enroll your child, but we inform you that things will become worst...*

The family of the child with multiple disabilities (deafness and autism) reports their experiences concerning their collaboration with the Department of Education in the middle 90's:

*In general in the Department secretaries tried to support us, they were aware of the problems, wanted to find a solution, but they didn't...*

*It is known that people who work in the Department are not the best qualified to handle such issues, they do not have the appropriate knowledge, and they just occupy the positions. A wrong person in wrong positions...*

The mother of the child with mild multiple disabilities was sent to the Department of Education, while she was searching for an inclusive setting in the secondary education during the school year 2004-2005. When she contacted the Department of Education they indicated another responsible:

*They told me to go to the Department of Education, in the Department they told me to contact the school counselor... the school counselor told me that he will undertake the organization but the administration of the Department will undertake the staff...*

It is remarked from the interviews' extracts that the Department of Education as Pontius Pilate on one hand legislates the right of education for disabled children and school-family collaboration and on the other hand displaces responsibilities either to school units or to school counsellors in structures unprepared to apply law's provisions.

#### *Centers of Mental Health as processors*

Some of the first official centers of diagnosis and reference to school units for disabled children in Greece were the Centers of Mental Health that functioned under the supervision of the Department of Health. Nonetheless, the reference given to the family with the child with Down syndrome was restrictive and determinant for her future education. Her course began with the enrollment and attendance at an institutional center for some years. In the middle 90's, her family wished to enroll the child in a special vocational school. School's reply was the following:

*...you should have enrolled the child in a special public school in order to get a certificate. No one had ever informed me, because when I went to the Center of Mental Health they told me about educable and non educable children and that the best setting for her case was that one and we went there, so we didn't have the certificate and she wasn't accepted.*

Parents seem to trust the diagnostic-consultative structures. In spite of their trust, centers function as processors, acting negatively upon child's educational course and finding of the best possible educational setting.

#### *School counselor as a legal counselor*

The mother of the child with mild multiple disabilities (microcephaly, hyperactivity, mild learning disability, hard of hearing) remembers special education school counselor's intervention during an incident of conflict with the teacher of the regular class regarding the difficulties raised by her child's enrollment in the inclusive setting. It was a legitimate, but disappointing intervention without perspective. The incident took place in the late 90's:

*Teacher's complaints must have been intense, so the school counselor called me at home and said...will you keep him for another year at home? And I told him, you must be joking...he is already seven and a half years old, when will he begin attending school? Probably he didn't know his age and he said, yes, he is already seven and a half years old? Anyway, bring all the papers needed in order to be legitimate and we will see what we can do.*

At first the school counselor shows some signs of collaboration and interest. He calls family but suggests the solution of keeping the child home or the presentment of diagnostic papers that will allow child's enrollment in a school setting. It was a legitimate act suiting to a lawyer but had no educational perspective.

#### *Special schools' administrations as specialists of medical model*

The family of the child with multiple disabilities (deafness and leaning disability) remembers the first attempt to enroll the child in special public schools and the denials of specialized schools. The way that a special school's administration perceived the education of children with multiple disabilities is also revealing. Children were perceived as patients during the 90's:

*School's administration... asked us many times to take our children to the hospital, to enroll them in a hospital's school in order to be near to the doctors, because our children have psycho-social problems, there's nothing left to say...*

During the 90's while special schools seem to be the most appropriate settings for the education of disabled children, they act as specialists of medical model perceiving the cases

of children with additional disabilities as patients and not students.

*Special schools' teachers as prophets*

The family with the child with multiple disabilities (deafness and autism) describes the educational staff's ignorance and the special pre-school education setting's rejection. They remember an incident from the 90's:

*Ok, it was the most tragic incident in his course for the parents and for the child, they told us: take the child home; he can not be educated...*

Accepting disability is a multi-complex procedure that presupposes conflict with disability (Zoniou-Sideri, 1998). One could never imagine that the educational staff of a special school would act in a stereotyped and prejudiced way that leads to the social construction of disability. The educators of the specific school foresee the limits of development and educational involvement of a child as prophets that predict the exclusion and marginalization of disabled students.

*Regular school's administration: Lost in briefing*

While seeking information about an inclusive class in a junior high school, the mother of the child with mild multiple disabilities contacts the educational administration of her district during the school year 2004-2005. She received the following reply:

*The administration doesn't know anything, not even the fact that 's been approved (the inclusive class), when I called to see what's going to happen, will it be staffed, will it begin this year or next year, they told me we don't know that the application has been approved.*

Educational administration seems completely weak to respond to the institution of inclusive education in the secondary education, declares uninformed and completely unprepared to collaborate with parents even at the level of informing.

*Regular education teachers as defenders of normality*

In an incident of conflict with the teacher of regular class, the mother of the child with mild multiple disabilities (microcephaly, hyperactivity, mild learning disability, hard of hearing) remembers the intense rejective reaction of the teacher and her personal impasse concerning her child's inclusion to the regular school at the beginning of 2000:

*She said that he is inadaptable and I feel sorry but next year I won't take this class even if they beg me. I left with my eyes filled with tears, although she knew I was a teacher as well, and that we could collaborate, and that we could discuss and find solutions, she didn't do it...*

In another general school setting the same mother describes a teacher's attitude concerning disabled students during the school year 2000-2001. She reports:

*Another teacher...told me that since these children came to our school, we are almost out of the window. She said it in a disdainful way, I was really hurt, I wasn't quick in reply or I would have told her, you probably have normal children, because what would you do if you had a child like mine? From whom would you ask for help? Would you keep it home?*

The teachers of regular schools feel threatened by the invasion of disabled children in regular education. This is the result of the gap between the legislation of inclusive education and the lack of preparation of the structures (teachers, school units, etc.). Their reaction, manifested as a way of defending *normal* students' interests, seems like a defensive mechanism against the unknown (disabled child), the personal fear (state of disability) and the inability of educational intervention.

*Regular schools' inclusive teacher: an abashed compromise*

The mother of the child with mild multiple disabilities (microcephaly, hyperactivity, mild learning disability, hard of hearing) remembers the attitude of the inclusive class teacher. The incident happened during the school year 2000-2001:

*That moment the teacher told me, I remember well, we can't sustain that the child is responsible for everything in the school, allowing me indirectly to understand that something's wrong with the teacher and once he told me directly, I can't intervene when she doesn't ask for my help.*

Inclusive class teacher makes the surpass of perceiving school as responsible for the problems of the disabled student, although he thinks that he is unable to intervene to the established functioning of regular education teachers with an abashed compromise that does not wish to conflict, but preserve the existent situation.

### Conclusions

From the analysis of the interviews arise some common opinions and experiences of parents participating in the study. These experiences are presented as mere conclusions, because the nature and the form of the present study do not intend to generalize and give final conclusions.

A growing number of incidents concerning personal tragedy are remarked from the discourse analysis approach. Personal tragedy is a determinant experience for all the cases of the sample. The fact that the highest frequency of discourses concerning personal tragedy is presented in the families with children with multiple disabilities is remarkable.

The majority of discourses of personal tragedy concern the collaboration with the special scientists. Families emphasize the lack of collaboration with specialists, the lack of supportive structures and the communicational difficulties with special professionals of education, a fact that overemphasizes their individual responsibility for the educational course of their disabled children. A high frequency of discourses of personal tragedy appears also in the extracts referring to families' attempts to enroll their disabled children in schools and their individual fight to persuade the educational staff to keep their children in the schools.

It seems that the educational system steadily attempts to differentiate its position concerning the education of a disabled student based on medical terms, for example the enrollment of a child in the school depends on the severity and the kind of disability (it is easier to enroll a child with mild multiple disabilities than a child with Down syndrome or multiple disabilities).

According to parents the way of approaching education is influenced by the medical model of disability, which conflicts with parents' opinion about their children's course of educational involvement. This fact leads parents to approach educational structures using the social model, displacing responsibilities from the severity and the kind of their child's disability to the weaknesses and irreconcilabilities of the educational system.

From the discourse it is noted that the structures involved in the education of disabled students lengthwise the educational hierarchy, beginning with the Department of Education to the educators, perceive the education of disabled people based on the individual model approach of disability displacing responsibilities of education to parents. Disabled children's families experience personal tragedy at multiple levels. Either by means of displacing responsibilities (Department of Education attitude) or by means of fragmental interventions (Center of Mental Health attitude) and formalistic attachment to bureaucratic mechanisms (school counselor, regular education administration, inclusive class teacher's attitude) or by means of lack of acceptance of disability and its conception as a disease (special schools' administration and regular-special education teachers' attitude).

The present study attempted to analyze parents' experiences concerning disabled children's educational course and focused on school-family collaboration. The publication of their opinions aims at the reinforcement of their role in the educational process within the context of an equal and active participation, hence weakening the feeling of personal responsibility and the experience of personal tragedy.

We hope that the present study will not belie the expectations of participating families.

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