

**THE EDUCATION OF MULTIPLE DISABLED CHILDREN AND ADULTS  
IN GREECE:  
THE VOICES AND EXPERIENCES OF PARENTS AND PARENT  
ASSOCIATIONS**

by

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## ***ABSTRACT***

The aim of this research is to take a first step towards shedding some light in the education of MD students in Greece by focusing on the experiences of parents as they accompany their children through their journey and also to reinforce the role of parents in the educational procedure as a valuable source of information. In line with hermeneutic epistemology principles, the study focuses both on the individual and collective experiences and efforts of parents of MD children. In the first phase of the study semi structured interviews conducted with parents provided a more personal account of parent experiences. In the second phase, the same topic was approached through a survey addressed to the representatives of all parents associations for children and adults with multiple and severe disabilities in Greece, which provided the collective perspective and the efforts of the disability movement in promoting the rights of multiple disabled children and adults. During the course of the study it became evident that the parents had a lot more to say that went beyond education and this was manifested both through the interviews with the parents but also through the answers in the questionnaires provided by the members of the PAs. Hence even though the study started with a strict educational focus during its progression more issues emerged concerning the societal exclusion/inclusion for MD children and adults and their families.

The data was analysed using thematic content analysis and statistical analysis for social research. The first phase revealed that parents perceived systemic, pedagogical, financial and cultural barriers in education, and it was evident that the education of MD children and adults is viewed as a personal case and responsibility of the families. Furthermore, parents described the steps and approaches that they used to cope with challenges and to secure an educational placement for their child. The findings from the second phase indicate that the parent associations have ideologically adopted a more social perspective concerning the rights and barriers of MD children and young people in education and struggle towards the educational and social inclusion of their children. However, often they are forced to assume the role of filling the gaps of the non-existent public social provision, thus focusing most of their actions towards the construction of separated settings to accommodate disabled children, and the construction of independent or semi-independent structures.

The inclusion of MD children and adults into the Greek educational system, not merely as presence but as equal participators, requires the total change and reform of the social, and by extension the educational system. By examining the educational reality of MD children and adults, the study yielded the conclusion that maybe we need to return and remember the fundamental principles of education and inclusion. It is crucial to take under consideration that there still is a group of students, who are placed on the margin of policies, of the educational and social life, and often of our thoughts and consideration.

**Key words:** multiple disabilities, education, parental involvement and participation, disability movement, social model of disability

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## **List of abbreviations and glossary**

NCPD	National Confederation of People with Disabilities
CEDAS	Centres for Diagnosis, Assessment and Support
CEDDAS	Centres of Differentiated Diagnosis, Assessment and Support
MD	Multiple Disabled
FPGA for SMDP	Federation of Parents and Guardians Associations for Severely and Multiple Disabled People
PAs	Parent Associations
SEN	Special Education Needs

# CHAPTER ONE: INTRODUCTION

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## **1.1 Introduction**

This thesis explores the parental perceptions and experiences concerning the education of their multiple disabled children in Greece through both an individual and collective perspective, with emphasis on the opportunities provided and the obstacles presented for both the family and the child/adult during their educational course. The aim is to investigate the quality of education provided to multiple disabled children and adults through the experiences of their parents, the value of education as perceived by the parents, and to reinforce the role of parents in the educational procedure. Moreover, this study attempts to highlight the link between rights in education and quality of education provided to MD children and adults and the wider issues of educational policy and human rights.

This chapter will provide the aim of the study, an overview of statistical data concerning the population of MD students in Greece and a presentation of key terms associated with the context of this study. The concluding section summarises the main points raised and provides a brief outline of the subsequent chapters along with the main research questions.

## 1.2 Aim of the study

In the introduction of this thesis please allow me to share a personal story, an incident from several years ago. In a local mall in Athens a mother was taking a walk with her daughter, I remember thinking that they must be in a fight because the daughter was speaking loudly and yelling. Before I had a chance to turn around and take a look my mother stopped me with a question: *'Why isn't she at school? Is it because of her severe disability'*? To be honest, at that moment, even though many different thoughts crossed my mind, my first move was to try and locate where she was, this girl with severe disability. It might come across as prying but believe me that was not the case. The reality was that I had never actually seen a child with severe disabilities in my life, not during the student years, not in my practice in schools during my undergraduate studies in early childhood education, not in the street, not in my neighborhood. Needless to say that I didn't have an informed answer to the question my mother posed, I simply provided the obvious and well rehearsed one: *'of course there is a school for every student, every student should be included'*. My answer proved my ignorance because later on I realized that mother and daughter take the same walk every morning in the mall. I had forgotten all about that incident until I came to Birmingham, United Kingdom for my postgraduate studies in special and inclusive education. And the first thing that impressed me, and still impresses me, was the number of disabled people that I saw on the street, in shops, in restaurants, in the university. It was a whole different reality for me. It was then that I remembered this past story, and the thoughts that crossed my mind then took form again. Everyone has a right in education, or is there a limit? There are schools for every student, but which are they and is access really permitted to all? Education can benefit everyone, but how? I still didn't have the answers.

When I decided to focus my studies on the education of multiple disabled children and adults and admit that I had no previous personal experience on the subject, a suggestion from my supervisor to visit a school for severely and multiple disabled students, where I could assist on a voluntary basis, proved to be a valuable experience but at the same time the source of more questions. I was faced with another personal ideological conflict, on the one hand I had embraced the notion of inclusion for all and on the other hand the educational reality in Greece and probably my own personal bias and stereotypes questioned whether in fact inclusion was possible for MD children. My first attempt to shed some light on the education of MD children was through my dissertation and with the aim to seek information from special educators. The limitation of that study was that, as in my case, most of the educationalists had no experience of including an MD student in their classrooms and the findings of that study were mainly based on attitudes and views. In this thesis main informants are parents of multiple disabled children and adults, in an attempt to follow their educational course through a source closely connected to them. The reasons of why the voices of MD people were not included in the study will be elaborated further on (Chapter 2. Methodology), but it was not a decision taken lightly. By reflecting on the beginning and the completion of this thesis, the part of what drove me personally to pursue this topic now seems less significant in comparison to the way that the issues that emerged from this study have enlightened my own understanding on the subject while at the same time leading me to pose even more questions. Most importantly I came to know MD students and their parents personally, fought with my own bias and stereotypes and formed a better understanding of how individual and societal barriers interconnect and influence the life course of a person.

As it will be elaborated in the policy and literature review (Chapter 2) the education of MD children and adults, within the Greek context, has not been researched systematically. This thesis aims to take a first step towards shedding some light in this particular population of students by examining the experiences of parents, individually and collectively, as they accompany their children through their journey and also to reinforce the role of parents in the educational procedure as a valuable source of information. The study focuses on the issue of school exclusion of MD children and adults, as well as the qualitative characteristics of education, including the educational settings, the curriculum, the available support system, the attitudes of the school and wider social environment as these are presented through the experiences of parents. It considers that the lack of access in education or the low quality of education not only places the MD person out of the educational process but that it is also connected with the danger of maintaining low expectations on the part of the disabled students and exclusion in multiple levels of their current and future social life (Laldler et al, 2007).

As it will be thoroughly presented in the following chapters during the course of the study it became evident that parents had a lot more to say that went beyond education and this was manifested both through the interviews with the parents but also through the answers in the questionnaires provided by members of the PAs for severely and multiple disabled people. Therefore even though the study started with a strict educational focus during its progression more issues emerged concerning the societal exclusion/inclusion for MD children and adults and their families.

### **1.3 The population of multiple disabled students in Greece**

In 2004 and 2005 two major surveys were conducted by the Pedagogical Institute and the Ministry of Education in Greece that examined the population of disabled students placed within the various school units and in the various levels of the educational system (Pedagogical Institute, 2004; Greek Ministry of Education, 2005). The data provided by these surveys are the only sources presenting the population of multiple disabled students in Greece.

The Pedagogical Institute in 2004 conducted a national survey attempting to ‘map’ special education in Greece (Pedagogical Institute, 2004). The data aimed to present the general image of disabled pupils and pupils with special educational needs within the Greek schools. The researchers provided detailed statistical data in relation to the types of disability, gender, age, number of students, school settings, and a list of contact details of services, local authorities and departments. Nevertheless the research failed to provide data on the qualitative characteristics of the education provided to children and young adults in these special educational settings. Another limitation of the survey was that it was not possible to produce information concerning the diagnostic centres responsible for accessing the students, due to limited or false responses received by the researchers.

The survey provided statistical data concerning MD students but without including a specific definition for this group of students. The population of MD students attending special school units, based on the data analysis of the survey in 2004, reached 2,7% (n=431) of the total population of disabled students (n=15850). With regard to the distribution of MD students within the geographical departments of Greece, Attica



collected the largest population (n=144), followed by the Central Macedonia (n=76) and Epirus (n=47). A total of 123 multiple disabled students were placed in boarding schools. Boys presented higher frequencies within the group of multiple disabled students in relation to girls (boys n=9846, girls n= 6004). Concerning the ages of students with multiple disabilities in special education units, the group between 9 and 12 years old, 14 year olds and those above 24 years of age were the most numerous, while the remaining categories appeared in much lower rates. The interesting fact is that after the age of 14 the numbers gradually decreased until 24 years of age and above where we notice a sudden increase in school attendance.

The second report concerning disabled students in Greece was published in 2005 by the Ministry of Education and it examined the issue of disabled students attending special education settings. According to the quantitative data provided, 705 MD pupils were registered within the educational system. The vast majority of these students (n=273) were enrolled in special elementary schools, with fewer MD students (n=137) being enrolled in inclusive elementary classrooms and few students in Special Pre-School Classrooms (n=70). We can again notice the high concentration of disabled students in primary education.

The official statistical data concerning the population of multiple disabled students in Greece provided a general first presentation concerning the number of these pupils, their educational level and school setting placement, age, gender and other characteristics. The following section provides the definition of multiple disability as it will be used within the context of the study and the definitions of other key terms.

## **1.4 Terminology and the search for definitions**

Three key terms will be used in the context of this study: multiple disability, parents, and parents' associations. The definitions of these key terms will be discussed below. In addition, and due to the language differences and the acknowledgment that certain terms may have different meanings in different contexts, a brief presentation of the terms special and inclusive education will be presented. At this point it should be noted that throughout this study quotations from primary sources in Greek (articles, books, laws) are included and the use of these terms exactly as they appear in the original passages ensures that each meaning is conveyed accurately. Also, quotations drawn from Greek literature are translated in a way that ensures that the original meaning of the author is protected and at the same time the basic principles of the English language, syntax and grammar are incorporated.

### **1.4.1 Multiple Disabilities**

#### **1.4.1.1 Terminology**

The term: 'multiple disabilities', or 'multiple disability' as it is also commonly used in singular in Greek, includes a meaning that it is highly complicated to define. This lack of clarity has its roots in the fact that multiple disabilities appear in great variety and unevenness and may also be perceived differently according to the cultural and political background of each country. The term 'multiple disabilities' rarely appears alone and usually the use of adjectives, namely severe, profound or complex, is employed, and most often the term is used in plural. Other terms used to describe multiple disability by professionals are multiply-handicapped, multi-handicapped, wheelchair child, educationally sub-normal (ESNS), handicapped, severe learning

difficulties, developmentally threatened, profound and multiply handicapped (Mednick, 2004). In the English literature professionals use the acronym 'PMLD' which most commonly stands for '*profound and multiple learning difficulties*', '*profound and multiple learning disabilities*' or '*profound and moderate learning difficulties*'. However, children with multiple disabilities in the international literature are considered, in the majority of cases, as a sub-group, maybe the most vulnerable one of the pupils with intellectual disabilities.

In Greece, before the introduction of the first law concerning special education, other derogatory terms were used to describe children with multiple disabilities, including spastic, idiot, cripple (Sideri, 1998). The use of these terms diminished significantly as the years went by and as awareness in society increased, still we cannot state with certainty that this shift applies to all the Greek population. Law 1143/1981 introduced the terms '*the ones with physical disorders (spastics, etc.)*' (p. 787), and '*the ones who are or have been inmates of special institutions (asylums, centres for child care, etc.) and for that reason are presenting emotional inhibitions and social deficits*' (p.787). Children with multiple disabilities according to the Law 603/1982 were considered '*those students who present more than one defect*' and were later replaced by the term '*people with complex cognitive, emotional and social difficulties and those who present autism and other developmental disorders*' (Law 2817/2000). The use of the term '*multiple disabilities*' in Greece was introduced for the first time in 2006 and continues to be used within the most recent legislation documents (Law 3699/2008).

Throughout this study the terms ‘multiple disabled children’, ‘multiple disability’ and ‘multiple disabilities’ will be adopted, as these are the terms most commonly used in the Greek context.

#### **1.4.1.2 Definitions**

In this study an effort is being made to move away from the clinical image of multiple disability, and consequently proceed under the premise of defining it in medical terms (syndromes, health characteristics), towards focusing on the social barriers, lack of opportunities and provision which lead to the construction of multiple disabilities. The following review and presentation of definitions aims to present how the social interaction of disability in the micro level of everyday life represents the macro level of the wider social political planning.

The search for definitions has proven to be complicated as variations exist in terms of age, severity and the ‘*qualitative combination*’ of these disabilities (Deropoulou, 2000), meaning that the effect that multiple disabilities may have on a person is not cumulative, disabilities interact. This aspect of multiple disability is often disregarded within the educational settings, especially when we find multiple disabled students attending schools that are designed to only partly meet their needs. Multiple disabilities according to the IDEA are concomitant impairments (such as intellectual disability-blindness, intellectual disability-physical disability, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in a special education program solely for one of the disabilities. Furthermore, the meaning

of the term multiple disability may vary between different countries and cultures and as a result there can be no common working definition (Aird, 2001).

Children and adults with multiple disabilities are those who present more than one disabilities, (Orellove & Sobsey: 1996) which are considered primary (Deropoulou, 2000) or concomitant. Warren, (1984) refers to the term ‘multiple handicap’ as the combination of any of a variety of conditions which would in themselves constitute areas of concern. Mc Innes, Treffrey (1982) and Best (1992) refer to these children and adults as multi-sensory impaired and they focus on the special and complex needs or the distorted information received due to sensory loss. In addition, Gulliford and Upton (1992) identify deaf blind children as multiple disabled based on the fact that multi-sensory disability may lead to additional disabilities and therefore complex needs. Other researchers are in agreement that children with multiple disabilities are considered children who have profound intellectual disability along with one or more disabilities such as sensory, physical or other medical conditions (Evans and Ware, 1987; Ware: 1990; Lacey, 1998; Cartwright & Wind-Cowie, 2005). Tadema (2005) focuses on the need for an accurate insight to the abilities of each child, and Jones (2005) states that there is a need *‘to appreciate the coexistence of strengths as well as the limitations’* of each child (p.378). Jones (2005) also highlights the fact that even though the most recent definitions (Aird, 2001; Lacey & Ouvry, 1998) continue to accept profound intensity, multiplicity and degrees of disability, they move the concept of disability from being personal and individual towards becoming a social phenomenon (Jones, 2005). Dawkins (2006) attempted to provide a definition by focusing on the needs of MD people and formed the following categories: education,

communication, movement, health, sensory, behavioural. By adopting this definition he describes MD pupils based on their needs in the above mentioned areas and provides hints to educationalists on the areas that they should focus on, without pausing on the clinical image of the student. Also, the characteristics of multiple disabled children and adults may be a result of the provision provided to them. Downing & Eichinger (2002) agree that:

*‘It is best to avoid any kind of labels whenever possible but to address each child as a unique learner with specific strengths as well as limitations’ (pp.1-2).*

The National Confederation of People with Disabilities in Greece (NCPD 2005) provides three definitions for people with ‘severe disabilities and multiple needs of dependence’: (a) people who have a severe disability (cognitive or physical) which is accompanied by other disabilities (e.g. visual or hearing disability) and for whom the coexistence of multiple disabilities confines the possibilities for autonomy and communication and his/her life depends on others (family, society, state); (b) people with severe disabilities who are denied access to training, education and support adjusted to their needs; and (c) people with very severe intellectual disability, autism, neuropsychiatric disorders, neurological syndromes or cell growth diseases (NCPD, 2005).

Still, the definition of the term remains general and broad. It should also be reminded that an important aspect is exactly the combined impact of each disability and how this combination may affect the child’s or adult person’s life. For the purpose of this thesis multiple disabled children and adults that constitute the focus of this study are

people who experience in their lives more than one severe disability and the combination of these disabilities has excluded them from the education and social system while they are likely to need ongoing training in caring for oneself, communicating, learning, and working.

### **1.4.2 Parents-family**

Family is the first and most powerful system in which a person may be included and have the feeling of belonging (McGoldrick & Gerson, 1999). It is a significant social institution and *performs the primary function of socializing the child* (Schiamberg, 1985). According to Ackerman (1985) parents are the ones who are called to ensure that their children are safe and healthy, to ensure that their children will be financially secure, that they will have the capability to support themselves as productive adults and to ensure that their children will enjoy the cultural benefits of the society they live in.

It is difficult to describe family as a typical unit as we may find very different types of families. The nuclear family which consists of two spouses and their children; the extended family which consists of the nuclear family and the relatives of the two spouses; the one-parent family which has only one parent due to death, divorce or a single parent; the reinvented family in which one of the spouses or both spouses come from a previous marriage and often the child or the children are not the biological children of the spouses (Symeonidou & Magadalinos, 2007). Furthermore, it was previously socially accepted that parents consist of a male and a female figure, however, in modern society we increasingly find families where both parents are of the same gender (Brodzinsky & Pertman, 2012).

Tsimpidaki (2007) provides a brief history of the evolution of family within the Greek society. In Greece family was considered to be a ‘patriarchic-extended rural family’ and this type was common during the late 19<sup>th</sup> century and the beginning of the 20<sup>th</sup>, by which time the first internal migration commenced, moving away from the rural areas and heading towards the urban centres. In this type of family the roles were strictly established and the obligations of each member were precise and aimed at preserving the family unity and preventing clashes. The father was the ‘leader’ of the family, the one who would take all the important decisions and provide financially for the family whereas the mother was the one responsible for the care of the house and the children. This traditional type of Greek family nowadays is transforming as a result of contemporary social changes in the western world. The Modern Greek family now moves away from the traditional model (rural-agricultural) into the modern type (urban-industrial). The structure, values, function of the family is transformed. The autarchic role of the father and the passive submission of the mother are being rejected, however the values about keeping the family together and having specific responsibilities and obligations within the family remain important values even in the younger generations (Tsimpidaki, 2007). Another common phenomenon within the Greek family is that children stay in the same house with their parents for a significantly longer period of time and remain dependent, financially, physically and emotionally, for even much longer (Georgas, 2012). In the Greek language the term parent (γονέας) means literally the one who gives birth (γεννά). Etymologically the term family (οικογένεια) in the Greek language is the combination of the terms house (οίκος) and generation (γενιά), but it is not uncommon to use the term familia (φαμίλια) from the English term *family*. The meaning of the terms ‘family’ and ‘parent’ change over time, under different circumstances and in different cultures. For the purpose of



this study the term ‘parent(s)’ will be defined as the person(s) or guardian(s) who are caregivers of/raising a multiple disabled child or adult, without taking under consideration whether their connection to the child is biological or not and without placing any attention on the gender, age or ethnicity of the ‘parent figure’. It should be noted that throughout the text the term child might appear in relation to parents where ‘child’ refers to offspring and it is not indicative of age.

### **1.4.3 Parent associations**

According to the article 53 of law N. 1655/85 parental associations can be established in every school unit. For the formation of an association at least 21 parents are needed. This group of parents will compose the statute of the association and elect the temporary administration board. This will be followed by the submission of a request, through a lawyer, to their court of residence and wait for approval. The association is allowed to accept members following the official approval.

This study requested the participation of all parental associations for children with severe disabilities who are members of the Pan-Hellenic Parents and Guardians Federation of Associations for Severely and Multiple Disabled People (mainly intellectual disabilities, autism, psychoses, physical disabilities and multiple disabilities) (PAGFA for SMDP).

### **1.4.4 Special Education**

The first definition of Special Education in Greece is provided by Invrioti (1939) who used the term ‘*Therapeutical Education*’ to introduce the:

*'Discipline which provides education, teaching and care to all the children whose physical and mental development are being obstructed by personal and social factors' (p. 7)*

It is interesting that in this definition there is a clear mention on the social factors as a barrier to the development of a child (Zoniou-Sideri, 2000), an attribution that the first law concerning special education does not provide:

*'the provision of special education and special vocational training for people who deviate from the normal, the implementation of measures for social care and the inclusion of these people depending on their abilities in the social and vocational life through the implementation of special educational programs and in combination to other medical and social measures' (Law 1143/1981, chapter A, article 1).*

This latter definition was in force until 2008 when the Law 3699 introduced a new term, that of *Special Education and Training*, and a new definition. This definition is used in the context of this study:

*'Special Education and Training is the sum of the provided educational services for students with disabilities and identified special educational needs or for students with special educational needs. The state is committed to regulate and to continuously update the compulsory nature of special education and training as an integral part of compulsory, free public education and to ensure the provision of free public education and special education to disabled persons of all ages and in all educational levels. Also the state is committed to ensure for all people with disabilities and identified specific educational needs: equal opportunities for full participation and contribution to society, independent living, economic self-reliance and autonomy, with full guarantee of their rights to education and social and professional integration. The state and all departments and officers of the State shall recognize disability as a complex social and political phenomenon and in every case to prevent the downgrading of the rights of disabled people in the participation or contribution to society' (Law 3699/2008, article 1, paragraph, 1:3499).*

#### **1.4.5 Inclusive Education**

The term Inclusive Education is used to highlight the need for reform of all the existing educational structures in order to include all children in the educational procedure. Ainscow (1997), Lindsay (1997), Florian (1997) and Wedell (1995) agree

that in order to change the existing structures first a shift should be established from the model of social care to the model of equal opportunities and rights, the arsis of discriminations and the acceptance of otherness. It is necessary to re-examine the values and aims of education and therefore proceed towards deep-rooted educational reform which will include the planning of new curricula and the training of educationalists (Sideri, 2000).

Inclusive education is incorporated in the universal agenda of international organisations such as the United Nations (2006) and UNESCO (1994), and is defined as a global obligation. The inclusion of all students in general education is the main objective of educational policy on a European and international level. While efforts are made in order to move towards an educational policy underpinned by the principles of inclusive education we still remain unable to express this away from the logic of special needs and exclusion (Zoniou-Sideri, 2000). A basic reason hindering the efforts towards inclusion remains the practice of attempting to include disabled students in general education which results in those students being in fact assimilated by the system and not included. Armstrong (2004) and Slee (2004) agree that there is a need to find a new pedagogical approach in general schools which will aim to battle exclusion and discrimination experienced by disabled people, and which will serve the values of a democratic school in the frame of 'equity for all'. Inclusion aims to deal with issues of equality and social equity in the frame of human rights. It is a socio-political issue, directly connected to the educational frame (Barton, 2000). Educational systems are part of the societies that have designed them and therefore they have the ability to influence and differentiate these social structures, as this is a two way procedure (Armstrong, 2004).

## **1.6 Outline of the thesis**

Following this introduction there will be an exploration of literature relating to the key aspects of models of disability, the human rights approach, issues of educational policy, the education of MD students, the demands of the disability movement and parental associations for disabled children and adults, independent living issues and the connection of poverty with multiple disability (Chapter two). This is followed by the outline of the thesis research design which also includes the philosophical foundation upon which the research is based, the methods used in each phase of the project and issues concerning access and ethical considerations (Chapter three). The next chapter, based on interviews conducted with parents of MD children and adults, constitutes the first phase of the study and aims to shed light on the quality of education, the opportunities provided to MD children and adults and the obstacles that they face during their educational course, as illustrated from the experiences of the parents (Chapter four). The second phase of the research is addressed to parental associations for children with severe and multiple disabilities. The objective is to investigate how PAs collectively promote the rights in education for multiple disabled children and adults and how parents participate in the decision making procedure in order to promote the rights of MD children and adults (Chapter five). This is followed by a discussion of the main themes arising from the analysis of the findings, with implications for policy and practice and suggestions for further research (Chapter six). The conclusions of the thesis are presented in the final chapter (Chapter seven).

Overall the thesis aims to answer three main research questions:

- In which ways does the Greek educational system shape opportunities for learning and social inclusion for MD students, examined through the views and experiences of parents of MD children and adults?
- What is the role and influence of parents of MD children and adults in the educational process and in the promotion of the rights of multiple disabled people in the school and social life?
- Can education sit in isolation from other concerns and areas of exclusion/inclusion for MD children and adults?

# CHAPTER ONE: POLICY AND LITERATURE REVIEW

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## 2.1 Introduction

This chapter sets out to examine the literature on the area of multiple disability, education, parental participation in education and issues of exclusion/inclusion and find out what is already known about these subjects in relation to the main research questions. The aim was to gather a volume of literature, provide a thorough summary, synthesis and critical analysis of the relevant research and non research literature on the topic under study. In particular, this chapter looks at the research evidence relating to the topic, including the most up to date, and identifies where there are gaps in existing knowledge and to provide justification for further research.

The type of references used included systematic reviews, meta-analysis, previous researches, books, journal articles, government, legislative and policy documents, parental associations' announcements, European and international conventions and declarations of human rights that have influenced the Greek policies and practices. The search was conducted using various combinations of key words, phrases and terms. For example: students with multiple disabilities, the education of PMLD students, multiple disability, parents of disabled children, disability movement, social model of disability, inclusion of students with severe disabilities, independent living, and more. The search concentrated in publications written in the English or the Greek language.

The search of the literature was carried out using academic databases (University of Birmingham library search engine, University of Athens library search engine) and a

range of online full text journals also through the sage journal, Google scholar, government websites, parental associations websites, proquest search library.

After the appropriate literature was gathered a first read of the articles was conducted, during the preview stage, based on the summaries or the abstracts provided and the wide range of articles were screened for eligibility. The articles that were not included in the final review were the ones that did not relate directly to disability or had a strict medical/health rehabilitation focus, still they were kept in a separate folder in case they could be of use later in the study. The remaining core of articles were classified based on their content. The final literature review was organised and presented by dividing the references into themes. References in the Greek language were also included in the review because from these sources it was possible to better investigate the topic and note the gaps in literature concerning the situation in Greece.

As highlighted in Chapter one, the education of MD children and adults in Greece is an area of research that requires further investigation. In addition, the role of parents during the educational course of their children, their participation in the decisions concerning the design and implementation of educational programs and the selection of appropriate educational settings remain unexplored within the Greek literature and especially regarding MD children and adults.

This chapter sets out to provide the theoretical framework and the philosophical foundations of the study: the social model of disability and the human rights approach. In addition, it examines the literature concerning the existing educational policies in Greece with emphasis on multiple disabled children and adults, parental participation and role in the education of their children. This is followed by a wide description of multiple disabled children and the different perspectives and theories

referring to their education. The final section of the chapter focuses on the disability movement and one of their central aims of promoting the right of independent living for all disabled people, with emphasis on multiple disabled people. The main objective is to explore and present what is already known in order to guide and support the findings of the study and identify where there are gaps in the existing knowledge in relation to the specific research questions. The final part of the chapter summarises the main themes from the literature review, places attention on where there are gaps and draws together the conclusions emerging from this review.

## **2.2 Theoretical Framework**

The choice of a particular perspective or model of disability can affect attitudes, policies and provision, as well as shape opportunities or create obstacles for disabled children and adults. Social inclusion and exclusion in education and in social life for a MD child or young adult is an existing reality. All the above issues are interconnected and will be assembled to create the theoretical framework of the thesis through the perspective of the social model of disability and the human rights approach.

### **2.2.1 Models of disability- The debate between the individual/medical and social approach of disability and their implications on disability issues**

Models of disability provide a framework for understanding the way in which disabled people experience disability and disabled people are viewed by society. These theoretical models provide a reference for society in the way that laws, provision, educational and social structures are developed. The definition of disability has mainly being formed based on two perspectives, the medical and the social. In a



sense if we follow the course and the progress of disability studies we can follow the way that the meaning of disability has evolved. The main objective here is to critically examine how the different disability models have affected our understanding and approach of MD people and how this is implemented both in theory but also in practice through the legislation, the structure and function of the Greek educational system, the opportunities provided or challenges faced towards inclusion and equity.

### *The individual/medical model of disability*

Disability, from the perspective of the medical model, is perceived as a ‘disease’, a ‘condition’, which has a negative impact on the normal physical and psychological functioning and is defined as the inability to fulfill social and individual needs and obligations (Barton, 2012). Thereby, disability is considered as a disabled person's individual problem and responsibility, in either mental or physical level, i.e. it focuses on the functional limitations of the individual and seeks treatment, in this way it attaches a therapeutic perspective to disability (Barnes & Mercer, 2003; Thompon, 2006). The medical model is understood within the context of pathology, which defines disability as a condition of deficiency and as biologically defined (Ainsow, 1999), also known as the ‘*personal tragedy model*’ of disability (Drake, 1999:10). Emphasis is placed on the pathology and the diagnostic image of disability (Barnes, Mercer & Shakespear, 1999), so the person with disability is approached based on the type and degree of disability. The fundamental aim of the medical model is for disabled people to adjust to the mainstream educational and social system and help them achieve *normalisation* (Wolfensberger, 1972). If they achieve normalisation using their own powers, by overcoming or removing their impairment, then they will

have equal access in society and they will enjoy a similar lifestyle as the majority of people (Walmsley, 1994).

The medical model created fertile ground for the development of guilt emotions to the disabled people and their families, thus weakening the sense of collective responsibility, collective struggles and demands. The theory of 'personal tragedy' has contributed to the individualisation of the problems of these families (Oliver, 1996). Parents perceive as personal tragedy the birth of a disabled child and this has resulted in the family feeling trapped in an experience of 'personal tragedy' and thus faces each challenge, in the process of educational and social progress of the child, as a personal responsibility (Zoniou-Sideri & Deropoulou-Derou, 2008). So we meet families of disabled children who 'become disabled' themselves, although people without disabilities, carrying the identity of a disabled family, limited and excluded from the right to participate in the socio - political and educational institutions (Zoniou-Sideri & Deropoulou-Derou, 2008). Charlton (1998) also maintains that the majority of disabled people and their families have been so oppressed by society that they have internalised this oppression through which they have come to believe that they are less capable than others.

### *The social model of disability*

In response to the critique of the medical model of disability, a social model of disability arose aiming to highlight the fact that the experience of disability is generated by interactions with a natural and social world designed for the non-disabled (Swain, Filkenstein, French and Oliver, 1993) and that disability is the result

of society's failure to provide adequate and appropriate services to all citizens. If society succeeds in meeting the different needs of people, then disabled people would be less disabled by society (Thomas & Woods, 2003).

The social model has been strongly argued since the early 1970s. The main source of contestation against the medical model comes from the disability movement, specifically from the Union of Physically Impaired Against Segregation (UPIAS) based on the need to include economic and political excluded groups in the post bio-engineering society; the declarations of global movements of human rights; and the contemporary academic movements in the field of sociology which tend to examine disability as a social phenomenon and not biological. Thus, disability is not perceived as a private and individual problem but it is socially constructed (Shakespeare & Watson, 1997). While impairment is defined in an individual and medical way, disability is a social creation and people are disabled not by the disability itself, but by the way in which their social environment deals with this disability (Barton & Oliver, 1997). The social model has been interconnected with changes in the production process. The transition from agricultural activity to industrial labor has excluded a great percentage of the disabled population from the paid employment under the assumption that they are not capable of being part of the competitive working environment which demands and serves the growth of the economy (Barnes et al, 1999). Abberley (1987) places disabled people amongst the wider category of people who experience exclusion due to a specific historical period (for example women).

According to Oliver (1990) the social and economical exclusion of people with

disabilities is a result of the contemporary capitalistic structure of society, which tends to limit out groups of people that cannot contribute to production, meaning that the rise of capitalism also gave rise to the premise that a distinction needed to be drawn between those considered 'able-bodied', and by implication able to work, and those who were considered disabled.

The social model of disability emphasizes the social dimension of disability and aims towards the suppression of social barriers and of discriminations against individuals. Overall, it expresses the political choice of equality.

The scientific concern also changes orientation, from the need to change the individual characteristics of disabled people towards the need for change of the social institutions and attitudes to include disabled people. The social model shifts the issue of impairment away from the person and places it in the collective responsibility of the modern society, offering a liberating power and voice to disabled people (Tregaskis, 2002). On a daily basis, disabled people face social and physical barriers such as attitudinal prejudice related to their disability, inaccessibility of buildings and other infrastructure, as well as inaccessibility of information and communication tools. Disabled persons can fully participate in the society if the behavioral and physical barriers are removed and it is the role of society to remove these barriers (Christie & Mensah-Coker, 1999). Oliver (1996) also stresses the need to change the language used when referring to disability issues and provides examples to show how underpinning premises are associated with differentiations in the existing terminology. Therefore, the term *medicalization* should be replaced with the term *self-*

*help, prejudice with discrimination, care with rights, policy with politics*, and so on (p.34). The different use of terms implies a shift from traditional attitudes and perspectives concerning disability from a medical scope towards a more social understanding of disability. The distinction between ‘impairment’ and ‘disability’ is the key in order to understand that disability by definition is not a problem. Disability is a socially constructed convention and not a personal characteristic. The term ‘impairment’ is limited to the description of biologically related limitations which cannot be overlooked but at the same time should not constitute the cause of exclusion.

*Beyond the social model of disability? The social model under critique.*

Even though the founders of the social model of disability have stated that it is not a dogma or a new orthodoxy (Oliver, 1996), its unchanging and rigid form has triggered critiques, mainly from the perspective of the feminist theories, concerning its practicality and limitations and the need to take a more holistic view in its construction (Pinder, 1997).

French (1993) argues that the obstacles of impairment cannot entirely be eliminated by societal change and we should keep in mind that different impairments may have different individual and social implications. Both the body and the social barriers cause disablement (Jay, 1981). The positive value of the social model as a means of enablement against exclusion and discrimination is also celebrated by Crow (1996) who states that: *‘I don’t think that it’s an exaggeration to say that the social model has saved lives’* (p. 207). At the same time she points out the importance of including

the personal experiences of disabled people in order to strengthen the influence of the social model even more. The social model liberated disabled people from the traditional 'medical model' view of disability and defined disability as a form of social oppression. Nevertheless this model includes, according to Shakespeare and Watson (1997), some weaknesses, as it does not encompass the personal experiences of pain and the limitations of impairment. The social model in their view is radical, needs to be revised and ought to transform depending on the changes of various socio-economical relations and culture.

Another strong defender of the social model, Morris (2001) comes to the conclusion in her article *'Impairment and disability: Constructing an ethics of care that promotes human rights'* that the social model should allow room for the sharing of personal experiences of the body and of impairment. She goes on to explain that the social model gave the power to disabled people to fight collectively for equal opportunities, to claim their rights and foremost their *'right to exist'* (p. 12) and she articulates the concern that by starting to express the negative aspects of living with an impairment and illness non-disabled people *'will turn around and say: there you are then, we always knew that your lives weren't worth living'* (p.10). Even so, no one should be denied the right to express the experiences of their bodies and the consequences they hold in terms of provision and the different levels of intervention needed. Disabled people must share their own understanding and experience of impairment otherwise someone else will do it for them and this power will be once again taken away from them. The same suggestion is proposed by French and Swain (2006):

*'The diversity of experience militates against the simplification of complex issues and towards a politics of hope that is both individually empowering and collectively emancipatory' (p.394).*

According to their analysis if disabled people start sharing their stories, it will be liberating for them and at the same time it might also *'transform history'* (p.385).

The feminist approach suggests an expansion of the notion of disability by using additional criteria such as gender, age, nationality, sexuality, the physical obstacles that impairment can cause to a person and other suppressive conditions that co-exist in the life of a disabled person (Tregaskis, 2002). Also, emphasis is placed on the fact that disability studies should focus on the particular historical period and follow the contemporary social and political facts.

#### *Alternative models of disability*

Shakespeare and Watson (2001) propose an alternative model based on the ontology of disability. Their conception is triggered by the premise that all bodies are impaired in some way and limitations may occur to everyone from trivial to severe levels. *An embodied ontology* then implies that impairment is a part of human nature and, therefore, there is no difference between disabled and non-disabled. A proportion of people never experience additional oppression from society because society has managed to deal with their problems, but still a minority of people remain excluded and disempowered due to the failure of society to meet their needs and provide solutions.

*'Understanding the processes of exclusion and discrimination is where the core focus of an empowering disability studies should lie' (Shakespeare & Watson, 2001:25).*

Brett (2002), with '*alliance model*', attempts to build a model of disability based on the case of multiple disabled children. From his perspective both the medical and the social model have failed to include the views and experiences of MD children and adults and their parents, and these experiences are considered vital towards understanding disability. Parents are the proxies of their children, of their experiences, choices and preferences and a model of disability should include them. The alliance model is focused on the lived experiences of the parents of MD children and adults. Parents often feel disempowered, oppressed, under physical and emotional stress, and for that reason a model by which parents will be able to relate to professionals will help them to regain power and autonomy.

The above review of disability models attempted to highlight two main points. First, that there is a high level of complexity around the meaning and essence of disability, and secondly, that as the existing knowledge, the historical and political scenery change, so does the way we view and understand disability. This meaning of disability whether examined through the medical or the social model, may be transformed through culture and through the characteristics of each society in different countries. The various models of disabilities do not follow on one another, they do not follow a historic continuity, and in many occasions two different approaches and views on disability may co-exist in a society. The adaptation of one specific model of disability is not enough to enlighten every aspect of exclusion that disabled people experience and for that reason it is essential to be aware and take into account all the different perspectives on disability.



### **2.2.2 The human rights approach**

Human rights were never in history treated as universal or were protected within societies by default. Directly connected with the attitudes, cultures and socioeconomic conditions of each time period and each country, the notion and value of human rights changes, transforms and adapts. Nations have formed treaties and legal conventions to ensure that human rights are acknowledged, promoted and secured for all people. From the International Bill of Human Rights leading to the Universal Declaration of Human Rights (1948), the International Covenant on Civil and Political Rights (1966), the International Covenant on Economic, Social and Cultural Rights (1966), and the individual constitutions of each country, nations are trying to create effective ways to establish and monitor how human rights are incorporated and secured in different countries. A series of general principles and standards of human rights, the definition of specific rights, and the obligations of countries have been set and ratified by different states which, therefore, means that those countries are legally bound to act in line with the above decisions. The above conventions provided the power to the people to demand equality and equity from the society in which they live and grow (Albert & Hurst, 2006).

In contradiction with this progress, within the frame of human rights' establishment, the protection of disabled people rights remains unaddressed. Even now that the paradigm of human rights is changing and people are now the ones demanding their rights and not simply receiving them, now that the discussion is focused on disabled people, this shift does not seem to apply and disabled people remain the passive receivers of care and protection. Consequently a need was expressed by the Disability

The United Nations Convention on the Rights of Persons with Disability (2006) and its optional protocol comes to close this particular gap and takes an official step towards the recognition that disabled people have equal rights and that these should not be overlooked.

*‘Throughout history, persons with disabilities have been viewed as individuals who require societal protection and evoke sympathy rather than respect. This convention is a major step toward changing the perception of disability and ensures that societies recognize that all people must be provided with the opportunities to live life to their fullest potential, whatever that may be’ (Convention on the Rights of Persons with Disability: Q&A, 2006).*

The purpose of the Convention is to promote, protect and ensure the human rights of: accessibility, personal mobility, health, education, employment, habilitation and rehabilitation, participation in political life, and equality and non-discrimination for all disabled people and children. The basic aim is not to provide additional protection or special treatment for disabled people but to declare the irrefutable fact that people with disabilities should no longer be considered objects of pity and sympathy but viewed as citizens with the same rights and needs as everyone. Therefore, the Convention comes to complete the previous declarations of human rights of the wider population by arguing and supporting that the societal barriers and prejudices preventing disabled people from enjoying equal rights must be lifted.

The countries that have ratified the Convention need to proceed to all the necessary adaptations and changes to ensure the equal access of disabled people, and the implementation of the Convention’s obligations will be monitored regularly to ensure the promotion of all disabled people rights without discrimination. Greece has not yet

committed to follow the principles and obligations set in terms of legislation, the adoption of new policies, and the accessibility of all disabled people in services, goods and facilities. However, even in the frame of human rights discussions we are still in the middle of a debate on how some groups of the population, namely women, children, refugees and disabled people will be able to enjoy these same rights on equal terms. It is alarming that special conventions need to be formed to make sure that all countries will make special adjustments to include disabled people, considering them vulnerable social groups and separating them from notions of equity and equal participation. In addition, all the conventions, legislations and policies may be the basis for change but they will remain vague philosophical and rhetoric notions unless we move towards their actual implementation. In this direction attention should be given in the change of culture and attitudes towards disabled people, for they should no longer be treated as separate and special, in need of special treatment. Therefore, the human rights approach as elaborated through the bills and conventions can either be perceived as a way to battle injustice and exploitation as experienced by disabled people (Gustavsson, 1999) or it is actually a way to correct or cover the existing inequalities and the fact that this distinction amongst people should have been prevented from the very beginning.

Furthermore groups of the disabled population remain excluded and are still denied their human rights (Armstrong & Barton, 1999), including MD people, and they are regarded as weak and in need of the support of stronger people to survive due to the severity of their needs and their level of dependence on others. In this concept multiple disabled people move away from being perceived as equal and strong citizens of a country living a full and meaningful life. The human rights approach in

line with the social model of disability attempts to change the existing discriminating conditions experienced by disabled people within society. While the international influences and the national policy measures are set to promote inclusion, the gap between this effort for inclusion of disabled students and the actual experience of exclusion for many disabled students appears to be growing (Oliver, 2009).

## **2.3 Multiple disability in the Greek Context.**

### **2.3.1 Policy background to the study-International level**

The education of disabled students has been one of the most crucial issues discussed within the educational research field over the last decades, both in Greece and globally. The central trend and the main aim of European and international educational and social policy concerning the education of disabled children and adults follows the scientific paradigm of inclusive education, and this is translated in the right of all to education regardless of their gender, nationality, religion, national or ethnic background, disability, economic background or health condition.

The Salamanca Conference in 1994 marked a new era for the rights of all children to education, with greater emphasis on the rights of children with special educational needs (SEN). In this world conference the right to education for all children was re-stated and guidelines applicable to all countries were specified.

*‘Every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptant level of learning’*  
(Salamanca conference, 1994: viii).

Greece was one of the countries to ratify this declaration and for the past two decades efforts have been made towards this new educational direction of inclusion. The

Salamanca conference was used as a starting point for many changes in the legislation and educational policy in Greece.

A more recent conference concerning the Rights of Persons with Disability was the United Nations Convention in 2006. The convention which came to force in 2008 provided statistical facts concerning the population of disabled people, with the most important being that today more than 650 million people live with a disability<sup>1</sup> and this number is increasing through population growth, medical advances and the ageing process. The right to inclusive education is enshrined in article 24 of the Convention where once again the right to education of disabled persons is recognised. Disabled students are not to be excluded from the general education system on the basis of their disability and are entitled to free and compulsory primary and secondary education. Also, all concerned parties must ensure that disabled people will have equal access to tertiary education, vocational training, adult education and lifelong learning. It is also outlined that state parties must take appropriate measures in order to facilitate students' full and equal participation in education, including accommodation, individualised support measures, appropriate language and means of communication (United Nations, 2006). So far, 25 countries have ratified the Convention, while more than 120 have signed it. Greece is amongst the countries which signed the convention on the 30<sup>th</sup> of March 2007, providing an intention to ratify in the future and by that agreeing to adapt the domestic legislation to the international standards laid out in the treaty (United Nations, 2006). The ratification of the convention principles holds a binding obligation for the countries to proceed to all necessary reforms in order to ensure equal opportunities and quality education for

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<sup>1</sup>around 10 per cent of the world's population

all students. Greece continues to postpone this ratification even though it could provide a strong force for change, could promote the provision of a better educational environment for all disabled children, could help break down barriers and challenge existing stereotypes.

### **2.3.2 Policy background to the study-National level**

The inclusion of children with Special Educational Needs in mainstream schools was introduced with law 2817/2000 concerning special education, and federal it clearly stated that all children are entitled to free public education. Although inclusion has been central in the Greek educational debate for the last twenty years, nevertheless, schools of Special Education still function in Greece for a number of reasons. Special schools in Greece are divided into seven broad categories according to the records of the Ministry of Education, Lifelong Learning and Religious Affairs: *‘Autism, Autism/Mental Retardation, Hearing Impairment, Physical Impairment, Visual Impairment and Not specified/ wide range of special needs’* (Greek Ministry of Education, Lifelong Learning and Religious Affairs: 2005). Within these categories it is not clearly recognized or stated where MD students should be, or are, expected to be placed. Based on available records and relevant legislation the appropriate educational setting for MD students remains vague as does their progress within the educational system.

In the frame of the ‘Developmental Strategy for Education’ for the period 2007-2013 which included the strategic planning for education in Greece, based on the four principles of development-competitiveness- education- employment, special reference is made based on the directions of the European Union to disabled people and other

vulnerable social groups. It is stated that, among other priorities, a fundamental goal is to *'continue the effort of reducing all educational inequalities and exclusion'* (Greek Ministry of Education, 2007: 73), in recognition that *'all European education systems, others more and others less, are characterised by the educational inequalities which reproduce and are interconnected with the general socioeconomic inequalities'* (Greek Ministry of Education, 2007:73).

From the above it becomes clear that despite the general effort for a qualitative upgrade of the Greek educational system, and despite the fact that emphasis is placed upon *'the facilitation of access for vulnerable social groups in all educational levels'* (Greek Ministry of Education, 2007: 60), the progress in Greece remains low in comparison to the average progress marked in the European Union. Therefore, there is an urgent need to *'step up the efforts for upgrading those fields of education where there have been concerns of weaknesses and problems'* (Ministry of Education, 2007:63).

The need for further reinforcement of access in all the educational levels for disabled children is also highlighted in the 'National Report of Strategy for the Social Protection and Social Inclusion for the years 2008-2010' and with the voting of the law on compulsory Special Education (Law: N3699/2008). Despite the fact that social exclusion is a rather multileveled and complicated subject, exclusion from education is a basic component. The majority of disabled students in Greece continue to be educated in special educational settings (Zoniou-Sideri, 2004). According to Ministry of Education data, based on a research study conducted in 2005, from a total of 19.038 disabled students and students with special educational needs, over 80% of the

population is limited to primary education (pre-school education, elementary school) including inclusive classrooms in mainstream school settings (Ministry of Education, 2005).

### **2.3.3 A school without walls**

The Ministry of Education introduced in 2010 the idea of the ‘New School’ or ‘School without walls’ (Ministry of Education, 2010). Under this title a series of new principles and aims have been outlined for the better functioning of the educational system. The main principles describe a school that is ‘open to society’, connected with the local communities and where parents, educators, students, and local administrators hold equal and significant roles concerning the planning and the function of the educational system. It is argued that a school that is ‘green’, a school that will cultivate the environmental consciousness of the student and a school that is ‘digital’ (by introducing new technologies) will ensure that all students and educators will experience a better educational outcome through the creation of a united environment. Above all, it outlines a school that provides free high quality, public education to all students. In this new system the school will prepare the new generation to cultivate the principles of humanity, to obtain knowledge, to participate effectively in the economical life with opportunities of social elevation, to become responsible citizens and to participate actively in the social and political life. The student becomes *‘a little intellectual’*, *‘a little scientist’*, *‘a little researcher’*, *‘a citizen of Greece’*, *‘a citizen of the world’* and learns how to learn (Ministry of Education, 2010).

However, in the twenty seven pages where this model is described the Ministry of Education fails to include the measures, legislations and reforms needed for the actual



implementation of the model. At the same time, and in the middle of a crucial economic crisis, we see higher numbers of students per classroom, fewer placements of educators in schools, fewer efforts towards the inclusion of all students, and fewer available resources. At the same time within the description of a 'school for all' model, the issue of inclusion of disabled students is mentioned only in two points concerning the differentiation of pedagogical practices, individual differences, different social and cultural identities. Furthermore, this report proposed the creation of a record of disabled students without providing specific details concerning what these records will include or how they will be used. It appears that, while Greece was eager to follow international guidelines in terms of inclusive education, it has been very slow in actually taking the necessary steps to making them a reality.

*'All Greeks have the right to free public education in all the educational levels of the national schools. The state supports the pupils who distinguish and those who need help or special protection, according to their abilities' (Government Newspaper, 2001:1626).*

Educational policy is directly connected to the socio-economic and political forces, conditions and relations of each time period and in each country (Barton & Armstrong, 2001). The education policy concerning the education of disabled students should be a part of the wider social and educational policies (Oliver, 1998) and not be considered as a separate/special section. The opposition against the provision of separated education for disabled students commenced around 1960 from disability and social movements demanding equal human and political rights for all disabled people (Dunn, 1968). Around the same time the traditional individual and medical approach of disability was being contested. The decades of 1970 and 1980 brought more changes, while in the U.S.A and many European countries the idea of inclusion

and compulsory education from a very young age for all disabled children was being promoted and regulated by legislation and a paradigm shift in the use of language and social attitudes can be observed (Lampropoulou & Panteliadou, 2005).

Educational policy can be determined and influenced depending on the purposes it has been attributed to serve. Barton and Armstrong (2001) support that students are being pre-evaluated as non-productive when they will enter the work force but at the same time their education will need additional funds from the governments and, therefore, there is a need to find ways to exclude them or separate them from the existing system. If we accept this theory then the quality of education provided for MD students is at great risk. If education aims to support the economy and not to promote social equality and inclusion then it will continue to serve only a small minority of students who will later contribute to the further development and sustainability of the economy (Fragkoudaki, 1985) and will continue to disregard or trivially attend to the needs of the student population not fitting in the promotion of this target.

In Greece disabled students were being educated in charity institutions as they were the only settings ‘caring’ for disabled children and young people (Lampropoulou & Panteliadou, 2005). It is only after 1980 that we begin to notice movements within the Greek context in line with changes undergone in other European countries and internationally. As a first step we can note that from the beginning of the ‘80s the responsibility of dealing with matters concerning the education of disabled students is transferred from the Ministry of Health and Provision to the jurisdiction of the Ministry of Education and Religion (Zoniou-Sideri, 1998), which now has been renamed to Ministry of Education, Long life Education and Religious Affairs. Law

1143/1981 '*Concerning Special Education, Special Vocational Training, Employment and Social Care for people who deviate from the normal and other clauses*' introduces the idea of special education in Greece but the focus is largely on the medical care and much less on the education and vocational training of disabled people.

Law 603/1982 provided more details concerning the structure and function of special education units in Greece. In 1985 the law 1566 is the first legislation attempt to include special education as part of the general education and the term '*special needs*' is introduced and intends to replace the previous term of '*people who deviate from the normal*' which implied an immediate exclusion of disabled people, although, it maintains the former practice of categorising students according to their specific disabilities. From these characteristics we come to the conclusion that this law actually introduces only superficial changes in the educational system. Nevertheless, the foundations for the growth of special education are officially established and there is evidence of a high rise of the number of '*pupils with special needs*' being enrolled in special schools or in the new founded special classrooms within mainstream schools and thus prolonging the practices of exclusion of disabled students (Vlachou & Zoniou-Sideri, 2000).

In the years 1990-2006 Greece is sponsored by the European Community with important funds aimed for the benefit of disabled pupils. The financial support that the European Union offered to Greece is based in the A, B and C Community frame of Support. In the National Action Plan (2001) for the confrontation of Social Exclusion, people with disabilities are considered a group of high priority.

With the law 2817/2000 the constitutional frame of special education is being set based on a more contemporary attitude towards disability, but again it fails to make special primary education compulsory and available free to all. The most characteristic points in this law are the foundation of CEDAS (Centres of Diagnosis, Assessment and Support) and the renaming of ‘special classrooms’ to ‘inclusive classrooms’. It is important to note at this point that the decision of whether a student will be placed in a Special Education School Unit or not is still based on the evaluation of the difficulties of the student and not according to the premise of how organised the specific educational unit is in order to meet the needs of the student. Once again the law organises a whole special education system which runs a parallel course along the general one (Sideri, 2000), without moving further to implement changes in the structure and the function of the general educational system.

As a conclusion, and even though the influence of the European Union is important, the Greek educational policy cannot completely follow this new educational direction of inclusion. To be more precise in the article 1/paragraph 12 of law 2817 it is mentioned that:

*‘The education of people with special educational needs in the mainstream schools or in the inclusive classrooms is highly difficult, because of the type or the severity of their problems, the education for these children is provided (...) in special schools, centers for rehabilitation, institutions for minors’.*

This small fragment of legislation has an underlying meaning. The public mainstream school still holds the right to deny the access to a certain population of children when it is considered that there are ‘problems’. In Greece the statistical data concerning the

number of children with disabilities are limited. There are approximately 180.000-200.000 pupils with disabilities aged between 4-24 years old. From this wide population only about 19.500 children and youngsters are placed within the educational system and in the majority they are enrolled in primary education: in special classrooms, inclusive classrooms or mainstream schools (Skordilis, 2006). From the database of the Hellenic Scientific Association for Special Education an *'unidentified percentage of children with disabilities'* is placed in under private law special educational facilities, facilities that are funded and supported by organizations and parental associations for disabled people; under private law institutions with the monitoring of the Ministry of Health and Provision or; within their homes.

It becomes clear that the education of disabled students, and especially MD students, is not legally binding, which may lead to school drop outs and the oncoming social exclusion. Also, it can only be accessed through special educational settings, and mainly through private and charity initiatives. Sideri (2000:36) points out that *'since 1985, few are the pupils with disabilities that have been included in the existing educational system'*. Especially when the matter comes to the education of MD children and adults, the basic reasons why these pupils are being led towards school exclusion are: the complexity of the disability, the obvious disability, the high cost that is demanded in order to complete their education, but even more the failure of the state to take responsibility. While Greece is officially complying and promoting the social and inclusive model of disability, in reality and in the case of MD children and adults it seems that an exception exists.

In 2008 the most recent version of the law about the structure and the aims of special education and training is voted (Law 3699/2008). One of the first changes to be noticed is the renaming of the term *Special Education* to the term *Special Education and Training*. In law 3699 it is firmly stated that '*special education and training is an integral part of a united and available free to all public educational system*'. The new law presents a complete system of educational structures which are responsible for providing education for disabled students but again the main critique is that through the specific practices suggested in this law we take a step back from the inclusion of all children in a united general educational system. The specific educational frame for each student will be determined based on the type and the level of the difficulties faced by the student. New categories of students are formed: *students with talents, students with complex intellectual, emotional and social difficulties or challenging behavior* and now the percentage of students that may be placed in one of these categories is once again expanded. Inclusion is mentioned as an extra adjustment, the general educational system remains intact and at the same time allows room for excuses in order to move more students away from the general educational system, those students characterised as having special needs. Again in article 6, paragraph 4 of the law it is noted that '*the education of children who are extremely difficult to be educated in the general school units, will be provided within special education units*'.

#### **2.4 The education of multiple disabled students: barriers and opportunities-Theories and practices in an international level**

The population of multiple disabled students is heterogeneous, as it was demonstrated in the introduction chapter, therefore, the education provided for them must be appropriate and prepared to meet their specific needs, as it is the case for their non-disabled peers. Overall quality education should include: early childhood education

programs; small classrooms; adjusted environments; equipment and the collaboration of an interdisciplinary team. All of the above should be supported from the very early years with the assistance of appropriate equipment and at a later stage with the use of more advanced technology. In this section the main interest is to investigate what has been written and researched concerning the education of MD students. In most papers and documents about multiple disabled students reference is made to their physical needs, complex health and mental health issues, sensory needs and behavioral challenges. In this thesis the main concern is to focus on the learning, communication and social interactions of MD students. The fundamental principle while approaching this topic will be that:

*‘Children with multiple disabilities are entitled to be enlightened, empowered and enabled, as are all children. The onus is upon us and society to bring this about’ (Mednick, 2004: 3).*

The right of all students to have access in education and their capability to learn and progress, no matter the degree of abilities or disabilities, has led to optimistic changes concerning the education of children with multiple disabilities (Ware, 1989).

*‘Like all of us people with multiple disabilities will continue to learn throughout their lives if offered the appropriate opportunities. Such opportunities must take account of the fact that most people are likely to be learning skills that generally appear at a very early stage of development’ (PMLD network, 2005:4).*

All children have the capability to learn and can benefit from the acquisition of new skills and knowledge, especially concerning MD students it is a way to move beyond

the idea that they only need to be taken care of towards the reality that they should be equally valued.

A great deal of controversy derives from the debate concerning special versus general or inclusive education in the sense of which is the most appropriate educational setting for MD pupils. MD children and adults are the ones most likely to be excluded due to the growing emphasis on school achievements and exam results. Though governments are trying to promote the idea of inclusion for MD pupils in the mainstream classrooms, the foundations are not solid and the dilemma concerning the inclusion or not of the students is greater than that of any other educational need matter (Aird, 2001)., therefore MD students are most commonly placed in special schools. The extent to which special settings are appropriate is rarely examined, even though the reason of this placement is based on the belief that mainstream settings are '*off limits*' because MD students operate at early developmental stages and the educational program of general education will be too advanced for them (Simmons and Bayliss, 2007).

Jenkinson (1997) also supports that it against the benefit of MD students to be fully included into regular classrooms, not only because the traditional teaching lessons are of minimum use for multiple disabled children and young people but also because their learning needs are very different than those of the general population. Students with severe disabilities may need to be trained in everyday situations and acquire skills that other children have established within their personal and family environment even before attending school (Jenkinson, 1997).



Aird (2001) introduces the idea that inclusion was based on economical interests and, therefore, supports that it was considered relatively less cost demanding to educate all children in one common school than maintaining expensive special schools. Governments in an attempt to proceed with this plan as quickly as possible have failed to prepare mainstream education to accept MD students and again continue to ‘mask’ or silence their real needs in a time when their needs should be paramount. Therefore, we have proceeded in implementing this idea of inclusion without former planning and changes in the existing educational system, as it is the case of Greece. There is a basic belief in the desirability of inclusion but no real thought or planning of how it will be actually realized (Croll & Moses, 2000: 10-11). Particularly in the case of MD pupils in Greece the national curriculum and the whole structure of education has failed to adapt and meet their needs, disregarding their rights to equal participation in the educational system. It is what Cole (1999) describes as a ‘middle solution’, in that governments are making efforts in including mild and ‘trainable’ special needs students in the mainstream classrooms whereas children with severe and multiple disabilities are being excluded from almost every educational setting.

Simmons and Bayliss (2007) contradicted the faith in ‘special schools’ based on their research on special schools’ educationalists and support staff. They came to the conclusion that the quality of education provided in those settings remains low due to the lack of awareness, education and training of all involved in the educational procedure concerning multiple disability issues, and the lack of appropriate resources and educational material. MD students show slow progress and the educational gains may appear small, yet they are highly significant. Educationalists and support staff when they are not in a position to notice, monitor and evaluate these small steps of progress, they are led to construct negative attitudes and hold low expectations of

their multiple disabled students, thus providing less opportunities for learning and personal development (Simon & Bayliss, 2007).

Ware (1990) places attention on the need of creating more responsive environments for MD pupils in the classrooms. In a responsive environment the students feel that they actively participate and that their actions are not ignored but valued by everyone involved, therefore are provided with the opportunity to influence their environment. According to Ware (1990) this constitutes the foundation for communication and for social and cognitive development. In non-responsive environments the opportunities to participate in such interactions are few and teachers tend to control these interactions using commands. As the disabled students' communication efforts are not recognized eventually they stop trying. Interactions and efforts for communication lead to the awareness of who we are and enhance personal development, self-respect and value. It is crucial to establish a communication basis between the child and the social environment. For MD children and adults the ways of communication vary and can be difficult to detect, understand and use. Nevertheless teachers, parents and peers need to cultivate any attempt the child makes to communicate, and they need to facilitate this effort in every possible opportunity. The aim is for the MD students to at least be encouraged to communicate their basic wants in the classroom: yes, no, more, less (Mednick, 2009).

*'Many multi-disabled children live in a world of their own, which is egocentric, self stimulating and motivating. If our world is confusing, unstimulating and unexciting, then they will shut down and enter their own world that offers more' (Mednick, 2009:32).*

The promotion of inclusive education for MD children is supported mainly in relation to the development of socialization skills (Kennedy, Cushing and Cohen, 1997). If planned systematically the social interactions between pupils with severe disabilities

and their typically developed peers can be enhanced and have positive effects on the whole student group. Kennedy et al (1997) demonstrated through their research how each time a child with severe disabilities was included in mainstream classrooms, with the support and cooperation of the educationalists, peer assistance, positive expectations and the appropriate differentiation of the curriculum, there was an evident increase in the development of social relationships and friendship networks between children. Typically developed children are rarely provided with the opportunity to meet and interact with multiple disabled students due to the historic isolation of MD pupils who remain isolated and in occasions unknown to their peers (Shelvin, 2003). Though a systematically guided program which included video recording, Shelvin (2003) and his colleagues prepared pupils from mainstream settings to come in contact with their MD peers and vice versa, as a result non-disabled pupils gained confidence in engaging in social interactions with multiple disabled peers and the creation of positive expectations formed the basis for establishing productive relationships.

Another implication that should be considered is the fact that MD students may be absent from school for long periods of time due to intense medical problems leading to long term hospitalisation (Borgioli and Kennedy, 2003). These periods of absence should be taken into account and new programs should be designed in order to support the students and to compensate for the lost school hours. The Greek legislation does not include a clause protecting students in these situations, consequently students are usually required to remain inactive and in the same educational level for many years.

The need for further research concerning the education of MD students is also highlighted by Arthur Kelly et al (2008) especially concerning the ecology surrounding them. The nature of education delivered to this group of students will help us improve our understanding both of the individual needs of the MD children and young people but also the role of peers and educationalists, in order to maximize the participation in education and the quality of benefits for MD pupils.

## **2.5 The education of multiple disabled students: Legislation and practices on a National level**

In Greece following the voting of law 2817/2000, and its recent revision, the education of MD students changed orientation in relation to earlier times when educational issues were silenced or vaguely mentioned. This legislation document is underpinned by the philosophy of effectively including all disabled students, as well as severe and multiple disabled students in the educational system. By inclusion here it is meant that MD children have equal rights to education and it is the state's responsibility to create appropriate educational structures, schools or classrooms in order to accommodate and provide quality education. This shift raises many issues concerning the natural surroundings (classroom and school accessibility, equipment), the form and quality of the existing educational methods, the national curriculum, the values and ethos of the social environment, the debate of whether inclusive education in fact provides the appropriate learning environment for a MD child or not. In Greece most of the MD children and young people are denied the right of access in schools and few are those who are included in the existing educational system. A small minority of these children are able to reach a high level of educational and social life, if the personal abilities of the child are discovered and if they have access to special training,

technical help and systems of support. Between these two extremes there are some children who if given the appropriate support and equipment will be able to receive education and establish a level of autonomy (National confederation of disabled people, 2004).

According to the most recent law of 3699/2008 students with severe and multiple disabilities and special educational needs may attend a general classroom with the parallel support of a special education teacher based on the nature and the degree of severity of special educational needs, or in appropriately staffed and equipped inclusive classrooms which function within the general or vocational education schools. In the inclusive classrooms two different educational programs are proposed - either the use of common and specialized educational programs for students with mild special educational needs or individualised programs for students with more severe special educational needs. This individualized program can be totally different from the one followed in the general classroom. In addition, students *who do not have the skills of self-care* may be educated in independent special education and training units or in general school units or in inclusive classrooms with the assistance of special support staff, again depending on the students nature of disability and degree of special educational needs severity. Students who are diagnosed with special educational needs that are difficult to meet in the general education school units or in inclusive classrooms, will attend independent special education and training units (special school, special classroom, school units in hospitals, rehabilitation centers, institutions for the education of minors, mental health units, and so on). Those students with the most severe, brief or long term, health problems whose

transportation to school and regular attendance is highly difficult will be home-schooled.

The educational program of students with special educational needs and disabilities is designed by the interdisciplinary team of the region's CEDDAS, composed and implemented by the responsible special education teacher in cooperation with the educationalist of the general classroom and the special education and training school consultant. Also, the parents and guardians of the students and the special education assistants may participate in the educational program planning after invitation from the region's CEDDAS.

From reading the law it becomes clear that it has been composed in a way that leaves gaps in both understanding and interpretation. It is clearly stated that the diagnosis and the recommendation of each responsible CEDDAS plays a defining role in the placement of disabled students and that the parents may participate only after invitation. There are two ways to interpret the law: either as an official document ensuring inclusion for all children in the Greek educational system, or as an official document which legitimates the governments and at the same time leaves the responsibility to the appropriate CEDDAS and educationalists to decide who amongst the students will be able to benefit from education, who has the right to be included in the system and what will they learn (Apple, 2003) *'depending on the nature of disability' and 'degree of severity'*. The sections referring to MD students are vague and fail to answer accurately the questions arising for parents and students: In practice where are the children with multiple disabilities placed? How does the legislation and

the structure of the educational system ensures the access and inclusion of disabled students in qualitative educational structures?

## **2.5 Parents of disabled children in their dual role: care givers/educators and advocates of their children's rights in education**

### **2.5.1 Parents as care givers:**

*'One category of children that is frequently confronted with (severe) problems and, as a consequence, pose considerable demands on parents are those with profound multiple disabilities' (Geeter et al, 2002: 444).*

It has been shown that they are different and multiple realities and experiences amongst parents caring for a MD child and these parents share differences and similarities (Brett 2004). Finding out that a child has special needs is very difficult for families and they need time to understand what this means and adjust (Kalyanpur & Harry, 2004).

Hornby (1995) has developed a model of the process, parents with disabled children go through, while coming to terms with their reality and this process is described through different stages of emotional reactions. Parents move from a state of shock, after the initial diagnosis, to a state of disbelief. This stage is followed by anger and the need to put blame on someone. When anger wears off, parents enter a state of sadness, isolation and detachment before reaching the state of reorganization, at which point they accept the reality of their situation and begin to plan the future and act to meet their children's needs (Hornby, 1995). Unsurprisingly, because of the great diversity among families with disabled children, no single reaction or sequence

of reactions can be found in all parents (Seligman & Darling, 1997) however the model of emotional reaction stages could add to our understanding concerning the parents' struggle while they try to cope with the everyday needs of the family. According to Kalyanpur and Harry (2004) hopelessness, disempowerment and confusion is another common experience amongst the parents with disabled children and in their research, few families with disabled children had positive experiences to share.

Both mothers and fathers of a disabled child experience higher levels of parenting stress than parents of children who have no disability (Esdaile & Greenwood, 2003), while parents caring for a child with severe multiple disabilities (Brown et al, 2006) or developmental disabilities (Smith et al, 2001) experience additional stress. Parenting stress is attributed, by parents, to their concern and uncertainty for their child's future, employment opportunities, the child's safety and the worry of who will assume the support of their child when the parents are older (Lehman & Roberto, 1996; Goupil, 2002). Parents are stressed, and there is a lack of services to help them cope with the above stressors (Resch et al, 2010).

Even though the research literature has widely been focused on the negative effects, stress factors and family instability of having a disabled child in the family, many parents '*respond to the emotional and caretaking challenges they face when their child has a serious disability with positive coping and resiliency*' (Trute et al, 2007:1). Both negative and positive appraisals appear to coexist and may determine the overall adjustment of the family in the long term (Trute et al, 2007). As Gupta (2004)



maintains, if we move away from the stressors and negative aspects of living with a disabled child and focus on the positive perceptions and views of parents, we can see that in fact this is the perspective that leads to a better quality of life within the families. The adoption of a more positive perspective from parents with disabled children can be used as an effective coping strategy in order to maximize the efforts to provide opportunities for their child, help the family be united and furthermore parents with positive perceptions can help other parents with disabled children during their process of coping. Positive feelings occur when parents disengage from the negative attribute of living with a disabled child, accept their reality and focus on the successes and the abilities of their child and their own (Gupta, 2004).

Many parents agree that there are many happy moments, moments of joy and positive feelings about having a disabled child in the family and parents are proud when their child makes achievements, even if they seem small and unimportant to others (Olson et al, 2003). *'Despite the sadness and grief we experienced on learning of our child's disability, our love for our child remains undiminished even when confronted with behavior we find abhorrent'* (Greogory, 2000: 7-8). The unconditional love that parents hold for their children is a factor that we need to understand and accept as true, if we wish to move away from viewing families with disabled children as problematic and dysfunctional (Carpenter, 2000).

### **2.5.2 Parents as educators and advocates of their children's rights in education**

We should take under consideration that the parents of disabled children hold a double role in the lives of their children, they themselves more than often become educators and at the same time advocates and defenders of their children's needs and rights in education (Ftiaka, 2008). The parental role in education has been reinforced in terms of empowerment and decision making in theory through legislative mandates, but in practice the implementation of the legislation is limited to the minimum requirements (Hess et al, 2006). Parents according to legislation hold the right to be involved in their children's school placement, be a part of decisions and be informed concerning their children progress (Russell, 2003). They don't seek pity and control, they wish to be valued and faced as equals (Carpenter, 2000) but at the same time they need to be supported in order to play an active role in their children's education, and use their knowledge to influence and challenge the current conditions that exclude their children from multiple aspects of social life (Russell, 2003). Regardless of the introduction of recent legislation promoting the participation of parents in their children's education, the experiences of parents are not used in practice and an effective partnership cannot be realized while educationalists remain the main decision makers at school and while home is considered an outside separate area (Moses & Croll, 1987). Parents need to make decisions for their children and they don't always feel confident in doing so, the pressure only increases when the parents feel alone and unsupported in the process (Sloper, 1999).

Parents should be recognised as an essential subsystem of their child's life and of the educational system, they hold great power and are very well informed of the legislation and provision available for their children (Hadjiyiannakou et al, 2007). The view that parents are an essential subsystem of their child's life can be linked to Bronfenbrenner's (1997) ecological model of how the child belongs at the same time in different subsystems, and how these interact with each other and with the child,

influencing the child's development: from the microsystem (family, school, neighborhood) to the mesosystem (connections and relations between school and family) and to the macro system (the prevailing ideology and culture that informs the educational, social and political systems and determines the beliefs and values of the society) (Bronfenbrenner, 1997). The perspective that the roles of school and family should be discreet and independent should be revised, and the parental role in the educational process as an essential source of support and information for the policy makers, educators and other practitioners, should be recognised and celebrated. School and family coexist in the life of a child for many years and both influence the child's development and progress equally. This common responsibility between parents and teachers to provide care, education and socialization to children, dictates the adoption of a mutual approach and the cooperation between these two systems, especially in the current changing social conditions (Kastanidou, 2004).

Parents of disabled children are increasingly considered as experts. They have the knowledge and an abundance of know how based on their experience about the child's usual way of interacting, behavior styles, functional abilities, current mood and situation as well as the whole context (Wilder & Granlund, 2003). Parents possess a wealth of information about their child and his/hers behavior in typical environments. Information that is often not requested by the professionals, even though this information exchange could benefit both parts (Paul & Simeonsson, 1995). While parents know their children from birth and in their usual surroundings, at the same time teachers and other professionals hold a different expertise, a different perspective of the children that could help parents better understand their children's

disabilities (Russell, 2003) and provide them with the appropriate support and guidance.

Still many factors obstruct the effort of establishing equal partnerships between parents and professionals. On the one side parents, by the time their child reaches school age, have already been in a long state of isolation and have accumulated years of negative experiences and behaviors by others, therefore they are cautious and cannot readily appreciate the guidance, views and help that the professionals wish to offer (Hadjyiannakou et al, 2007). On the other side professionals need to abandon the deficit model in their interactions with parents and be open to the parents' opinions, concerns and suggestions (Hadjyiannakou et al, 2007). Blamires, Robertson and Blamires (1997) inform us that recently a new pseudo social science has emerged amongst certain groups of experts called '*parentology*' defined as the categorization process of parents as implemented by educators, other specialists and professionals. This categorization does not promote any kind of cooperation, and the use of labels, like '*the emotionally disturbed parent*', '*the hostile parent*', '*the insecure parent*' and so on, precludes and destroys any chance of good relations and communication (Blamires et al, 1997). For equal partnerships to be established it is imperative to make parents assertive in their relationship with the professionals and provide them with the support needed to expand their skills in order to make optimal use of their expertise (Ftiaka, 2008). Professionals also need to be supported, recognised for their efforts, further trained and educated in order to be confident in welcoming and managing this partnership (Hadjyiannakou et al, 2007), through open dialogue in cooperation with the parents (Blamires et al, 1997).

Therefore, this whole process involves dedication from both parts, and the acceptance that power will be equally shared and not rested in the hands of the experts thus intimidating and alienating parents from the educational procedures:

*'Power sharing is the extent to which partnership is possible or desirable between parents and professionals in the special needs area. The issue is about agreeing principles (the underlying rationale to involve parents in their child development and education) clarifying parameters (acknowledgements by all parties of the realities and limitations upon co-operation for example time available by teachers) and establishing ground rules (mutual respect for each other's roles and responsibilities and acknowledgement of the complementarity of role are cardinal features' (Wolfendale, 1989: 116).*

Despite the broad dissemination of the inclusive movement and the theoretical acceptance of equal opportunities, the research and education community states a series of concerns about the definition of inclusion in education, particularly full inclusion, and its practical implementation. Ftiaka (2008) maintains that inclusion is not a private, isolated matter remaining on the efforts of the family, but it should entail a collective effort of the whole educational and social system to change attitudes and perspectives and that reform should include educators, parents, students and the society in general (Ftiaka, 2008). Democracy should be based on polyphony and pluralism, different voices are the ones to compose the dialogue and promote inclusion and all members should be equally valued and heard (Deropoulou, 2004). The participation of the parents could be crucial for the design and implementation of educational policies, since they are the ones immediately concerned with the subject, they are the ones that bear the cost and care of their children, hold a more spherical and longitudinal image of their children, they are emotionally bonded with them, and most importantly they, and their children, are the main consumers of the education or care provision that the system provides (Ftiaka, 2008). Solid foundations should be

built to allow and value the equal involvement and participation of parents in all forms of educational planning, provision and procedures. In Greece the level of parental participation in schools is currently limited to the participation of parents in school associations, visits to the school to be informed of their child's progress, viewing their children's school plays, the financial support of the school, participation in school events and in some cases in supporting the teacher in every day classroom activities (Dodotsakis, 2000).

## **2.6 The role and participation of parents with disabled children in the education of their children in Greece-Current policy and legislation.**

Families of MD children hold an important role in their children's lives, both in terms of care and nurture but also because this specific group of children has explicit needs concerning issues of representation and advocacy. Lately, the importance of evaluating the views and experiences of the parents concerning the educational and social inclusion of their children has emerged (Brett, 2002). Education does not begin and finish at school. Parents are better aware of their children's abilities and difficulties and should be involved and assist teachers in their efforts of planning an appropriate educational programme. Parents should be involved in any decision made for their child in matters concerning their education, policies and social inclusion. But this great source of information and experiences remains unexplored by the experts (Case, 2000).

In Greece it appears that the cooperation between parents and schools and the right of the parents to participate in the decision making concerning their children educational

is officially recognised and specified in the legislation (Zoniou- Sideri & Deropoulou, 2008).

Previously, in law 1566/1985 we note the first attempt to initiate issues of cooperation with the parents. In the article 32/paragraph 6 the law includes the organisation and role of parental associations: they are provided with the opportunity to cooperate and participate in all matters concerning education along with the Ministry of Education. According to the same law the Centres of Mental Health and the Centres of Medical and Education Affairs are responsible for providing diagnosis, proposing school placements and educational programs for all students with special needs, along with the responsibility to provide guidance and advice to the parents (Law 1566/1985, Article 33, Paragraph 1).

Later, with the voting of the legislation paper of 2817/2000, the previous suggestion for active cooperation between parents and the Ministry of Education is maintained and in addition a new service, that of the Pedagogical Institute, Department of Special Education, is introduced in order to offer consulting and supportive services to the parents of disabled children (Article 1, Paragraph 20). In the same legislation document a new organisation is introduced that of CEDDAS (Centres of Differentiated Diagnosis, Assessment and Support for children with special needs) and their role is to assume the responsibilities placed formerly in the Centres of Mental Health and the Centres of Medical and Education Affairs (Article 2, Paragraph 3).

In the more recent decree of the law concerning special education published in 2007 there is a lengthy reference to the cooperation between special educationists and parents:

*‘Special educationalists cooperate with the parents and provide to them every form of facilitation in their cooperation with the educational staff of the school. They schedule and organise informative meetings of parents with the educationalists, the educational staff or other involved carriers, in matters of common interest’ (Law 449/2007, paragraph 7, p. 9389).*

In addition, educationalists working in special schools have to guide all parents in matters of special education and support them even within their homes (Law 449/2007, p. 9390). Educationalists working in inclusive classrooms also have to cooperate with the parents and have to be aware that:

*‘Under any circumstance no student can be excluded from the inclusive classroom if the parents wish for their child to be enrolled in one, even in the case that there is no diagnosis from the official services’ (law 449/2007, p.9390).*

To conclude, emphasis is being placed on the cooperation between families and school psychologists, social workers, speech therapists, experts in vocational orientation, experts in mobility for blind students and experts in sign language for deaf students (Law 449/2007). In the most recent report from the Ministry of Education the aim is to create a school that is ‘open’, and in this school parents, educationalists and students work together and they all participate in the stages of planning and decision-making in equal terms (Ministry of Education: 2010)

Indeed there is no obvious gap in the legislation in issues relating to the cooperation between parents, schools, educationalists and the Ministry of Education and the necessity of a system of cooperation is clearly stated. Nevertheless, from reviewing



the above mentioned articles of the law we come across a wide range of statements and not specific guidelines as to where we set the limits, how the educationalists will counsel and support the families without prior appropriate training and when this cooperation will take place (Zoniou-Sideri & Deropoulou, 2008).

## **2.7 The disability movement**

Social movements are consisted of groups of individuals or associations expressing their opposition against existing social conditions and aiming to promote or resist social changes (Turner & Killian, 1987). According to the definition provided by Blumer (1939):

*‘Social movements can be viewed as collective enterprises to establish a new order of life. They have their inception in the condition of unrest, and derive their motive power on one hand from dissatisfaction with the current form of life, and on the other hand, from wishes and hopes for a new scheme or system of living’ (p.199).*

Symeonidou (2009) describes how the first social movements were organised by groups of disadvantaged citizens, in terms of financial conditions, access and participation in state control, in order to ensure better common financial interests. Around the period of 1960, while the United Kingdom experienced great financial progress, the wealth and benefits distribution for disabled people remained unequal (Oliver, 1997). At that time a new group action is organised which later became known as ‘The disability rights movement’. Therefore, the structural inequalities of society lead to the need of a collective social movement for the promotion of disabled people’s rights as equal citizens.

Disability movements around the world are widely concerned with economic and political issues, issues concerning the care and provision of services and social security (Beckett, 2006) and the fight against the structural barriers created by a society designed to serve the average citizen and preventing disabled people from enjoying their rights in education, employment, accessibility and leisure (Barnes et al, 1999). In addition, the disability movement battles for the promotion of changes in the attitudes and values and towards the establishment of a democratic, equal and just society where disabled people will have the right to raise their voices and demand what is rightfully theirs from their governments (Oliver, 1990). The disability movements today, still not completely free from economical demands, move forward to demand quality of life, equal access and participation in the social life (Lentin, 1999). It is a social movement aiming to bring significant changes in today's society (Giddens, 2001) by stating their oppositions against the current conditions through collective force and self-organization (Peters et al, 2009).

The Disability movement is an organisation of disabled people for disabled people, fighting against the oppressive social reality (Cambell & Oliver, 1996). The first supporters of the disability movement considered this aspect vital in the organisation of the movement, i.e. that disabled people needed to advocate for themselves in contradiction to the common practices of before 1960 where the group actions were formed by non-disabled people while disabled people remained passive recipients and dependent on their fellow citizens' actions. This notion postulates that disabled people are the only experts on their needs, and therefore they must take the initiative, individually and collectively, in designing and promoting better solutions and must unite together around *on one single factor, that society discriminated against them*

(Finkelstein, 1975). In the article presented by Finkelstein and Morrison (1993) on the role of culture in the empowerment of disabled people, they stress the existing danger of forming an elite leadership of disabled people negotiating with those who hold power, *'the active few, while the mass of disable people remain in their traditional passive relationship to others'* (p. 4), and continue to stress the fact that within the disability movement there must be a place for the participation of all disabled people and space for the equal promotion and demands of all disabled people. In addition, Cambell (1996) refers to incidents of *'simulations oppressions'* when disabled people were being discriminated within the disability movement based on the race, gender, sexual orientation or severity of disabilities, by disabled people who dominate the movement, and people with intellectual disabilities were the ones experiencing the exclusion of the movements' activities in the greater extend, multiple disabled people experience similar incidents of discrimination.

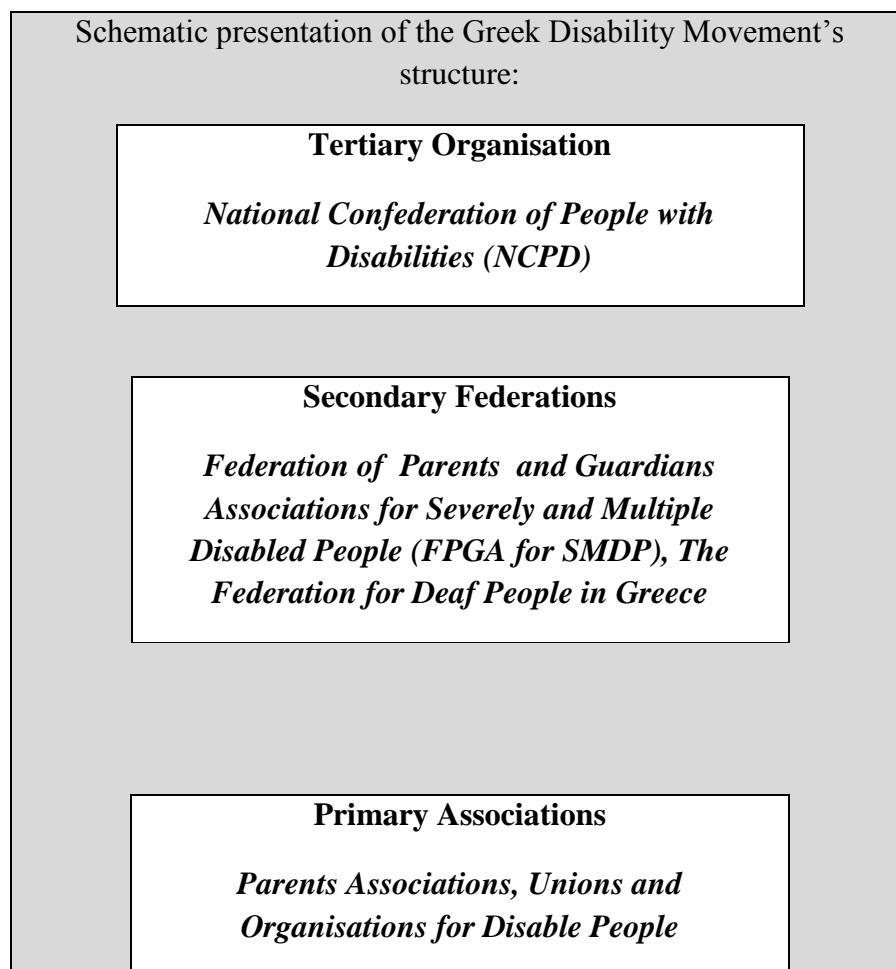
Therefore around the decade 1960-1970 the disability movement is growing with disabled people advocating for themselves, and at the same time the discussion around inclusion commences and the parental associations are making a more strong and demanding appearance. It is the same time when the medical model, approaching disability as a personal tragedy, is contested by researchers, scientists and other experts of the field along with the representatives of the disability movement, and the social dimensions of disability are being explored (Lampropoulou & Panteliadou, 2005).

During this period of international turmoil Greece remains passive until the first associations for disabled people and parental associations for disabled people are being organised. The structure of the disability movement in Greece is divided into three levels. The National Confederation for People with Disabilities (NCPD) is the main representative of the disability movement and the social associate of the State in issues concerning disabilities (Law 2430/1996). According to law 3699/2008 about special education the NCPD has earned the right to vote in all the councils concerning education, it is the tertiary socio-syndicalist organisation of the disability movement in Greece and since its foundation in 1989 until today, it battles for the promotion of politics contributing to the full participation of all disabled people in the social, political and cultural life of the country. From the official statute of NCPD we can detect the specific aims of the organisation. On a national level the Confederation fights for the protection and the promotion of human and social rights for disabled people, the wearying of social prejudice and the eradication of discriminations experienced by disabled people, aiming at the equation of opportunities provided to disabled people in all the aspects of their lives and ensuring decent conditions of living and full inclusion in society. On a European level the Federation recognises the importance of forming common decisions on a European Union level, the effect of these decisions on the lives of disabled people, the need to actively participate in creating a common European policy framework for disability focused on the equality of opportunities and the combat of discriminations and not wanting disabled people as passive receivers of care and charity. Therefore, the Federation participates in an extended network with the National Councils of Disabled People from other countries-members of the EU. From the NCPD principles and aims we can understand what exactly Campell and Oliver (1996) mean when explaining that the

theory of social movements moves from the social disability model focus to include a human rights approach and how the disability movement too can form alliances with other societal movements in order to highlight the phenomena of oppression and exploitation experiences by certain population groups (Oliver and Zarb, 1997).

Under the umbrella of National Confederation for Disabled People PD are the secondary organisations of the Panhellenic Federation of Parents and Guardians Associations for Severely and Multiple Disabled People (FPGA for SMDP) and the Federation for Deaf People. In addition, primary associations of all individual parental associations, societies and organisations for disabled people are included within the disability movement (please consult figure 1 for a schematic presentation of the disability movement in Greece).

**Figure 1 Schematic presentation of the Greek Disability Movement:**



## 2.8 The demand for independent living and the connection with multiple disability

One of the main objectives of the disability rights movement has been the issue of independent living for disabled people in order for them to live as more active citizens in society. The disability movement sets amongst its priorities the establishment of the right of every disabled individual to be able to live independently regardless of diagnoses (cross-disability demand). This issue of de-medicalisation and de-institutionalisation of disability opens a challenging debate, especially for multiple disabled individuals. When referring to independent living programs or structures five main elements are involved: *community based, consumer involvement, services provision, increase of self-determination and minimization of unnecessary dependency*, especially for multiple disabled people the main aim of independent living programs is to facilitate their dependent state of living conditions to a *comparatively independent living situations* (Frieden, 1980). Even though the idea of independent living is underpinned by the existing socio-economic inequalities and injustice it is an issue that should concern everyone and not only people with ascribed disabilities:

*‘For if morality or justice is not sufficient as a motivational force, perhaps personal survival will be. All of us must contend with our continuing inevitable vulnerability. Not to do so can only make us further unprepared for the exigencies of life’ (Zola, 1979: 456).*

The primary principle supporting the rights of independent living is that every human life has value and that this life is worth living. Under this undeniable premise society

needs to change in order to provide the conditions and opportunities for inclusion for all people to be able to enjoy a fulfilling life worth living and embrace diversity, even though current examples from medicine, legislation and research prove that *some lives are deemed more valuable than others* (Campbell, 2003a). An example of such alarming phenomena, where some lives are considered less valuable than others, is the promotion of the legalisation of abortion in the case of children who if born will grow up with multiple and severe disabilities and become *an emotional and financial 'burden' on both the family and the state* and euthanasia, where there is an agreement *that the quality of life is unacceptable* (Barnes, 2003: 8, 9).

Grunewald (2005) supports that all disabled people, even those with severe and multiple needs, have the right to be provided with the means and abilities to escape institutionalism and the opportunity to live alone, with others or with their families in ordinary houses within the community and that the success of this effort lays entirely on the flexibility of the political system. By providing examples of successful implementation of policies of community based systems in Norway and Sweden Grunewald (2005) created a model of independent living structures. The proposed system is not complicated or innovating, it is rather based on the effective development of daily living skills, social skills, communication skills and the self-confidence of each person. The flats provided for disabled people, including people with intellectual disabilities and MD people, are consisted on average of four persons, both men and women. The tenants are provided with personal budgets in order to organise their expenses, pay rent, hire personal assistants, food and so on and are also provided with daily activities in order to further develop their skills and education. As a result the fear both of disabled persons and their parents concerning a future in

loneliness and isolation is reduced, especially when new friendships are established. The organisation of this type of inclusive accommodation is decided with the cooperation of parents and experts from different disciplines and in agreement with the disabled people wants and needs. The key point in this publication is that it is one of the rare occasions in literature when the notions of independent living and inclusion are openly combined and used in direct reference to severe and multiple disabilities:

*‘Those persons who have the most severe disabilities improve the most, when they move from institutions to group homes. They can communicate better, they understand more and they interact with the environment to an extent no one could predict’* (Grunewald, 2005:3).

Oliver (1999), in line with other supporters of the disability movement, identifies the capitalistic society as the main enemy promoting the exclusion of disabled people and their isolation from institutions, day care centres, group homes or boarding houses. He continues to explain that while all structures of confined residential care are being constructed using state or charity funds at the same time disabled people are denied the right of choice of where and how to live returning them to previous notions of disability based on personal tragedy models where the disabled people are viewed as a burden and in need of the welfare state and the pity of their carers in order to survive. The governments are legitimatised regarding the denial of human rights by providing shelters for the disabled and concealed under similar actions while disabled people continue to remain incarcerated in isolated settings and are considered too different and too costly to be included equally in the community (Campbell, 2003b). Lang



(2001) in his essay concerning the development and critiques of the social model of disability describes how Oliver began his inquiry by questioning whether the medicalised, and tragic conception of disability, had been replicated across other cultures and societies, and also between historical periods and how he concluded that the individualist idea of disability was indeed unique to capitalist societies.

Funds' inefficiency is commonly presented as an excuse from governments to justify the lack of independent living structures and their resistance to change and reduce the existing isolated institutions (King, 2000), as is the case in Greece where the available resources assigned towards the aim of creating and supporting independent living structures and schools are less every year. The governments residue in declarations of equal human rights while even the existing independent living structures and educational centres are at risk of shutting down. As revealed by various parental associations and associations of disabled people ([www.ameagreek.gr](http://www.ameagreek.gr), last accessed on 5 August 2013) thirty two child protection agencies are facing the risk of failing to provide health care and educational programs for MD children and adults for the year 2013. These 32 child protection agencies served 15,051 MD children and young people during the year 2012. These agencies employ each year 1,306 people, who in many cases remain unpaid from up to eight months. In addition 21 out of the 32 agencies used to receive state funding, but now they have only received the first installment (out of four) for the year 2012 and hope that within the next days they will receive the second delayed dose. It should also be noted that the budgets of the agencies have been reduced by 50% compared to the year 2010 and that today 8 out of the 32 agencies rely solely on private donations and sponsorships, while the situation is expected to deteriorate further with the new tax bills of 2013 (AmeaGreek.gr, 2013).

As a consequence of political priorities, the attitudes towards disability and the priorities set by each country constitute a culture of dependency. And while all people in a society are, at some level, inter-dependent, for disabled people this dependency is translated as helplessness or burden falling on the shoulders of those who work, of the tax payers, those who provide for them and at the same time they are denied of the opportunities and resources to prove how independent they can actually be by living a life controlled by themselves. Robertson (2001a) also discusses the issue of dependency and autonomy and how it has become a primary goal in life and a core social value, when interdependence is central for everyone, and he continues to propose a new form of education and a new curriculum designed in order to promote issues of self-care, care of others and love instead of a curriculum based on hard edged cognitive aims, evaluating success based on performance indicators and exam results. If the curriculums and the learning methods remain controlled by a traditional model then it will continue to include those intended for economical and social participation and those who are considered able to work, while others will remain excluded under the premise that they have not developed their autonomy.

In conclusion, the philosophy of independent living considers that every human life is valuable, regardless of disability complexities or severity, that everyone needs to be allowed to choose how to live and be able to control his/hers life, that everyone should be included and encouraged to participate fully in the community and that all disabled people will have equal access to mainstream schools, jobs, transport, leisure, and so on (Barnes, 2007). Governments need to be prepared to empower and provide

funding for the movements and organisations working towards this direction and provide sufficient resources for disabled people who want to live an independent life along with the appropriate education and training (Barnes, 2007).

## **2.9 Summary**

The policy and literature review has highlighted areas concerning the education of MD students, their rights in education and the policy context in a national and international level. It also emphasised on the gaps and grey areas of the Greek legislation about the education of MD students and the parental involvement in education. The significance of parental participation in the education of their children and the actions of the disability movement were theoretically supported. The chapter concluded by presenting the demand for independent living as one of the main objectives and priorities for MD people. The evidence provided from the literature and policy review is not sufficient to answer the main research question but it provided the theoretical framework and the philosophical foundation of the study, the social model of disability approach and the human rights approach.

# CHAPTER THREE: METHODOLOGY

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## **3.1 Introduction**

The previous chapters have provided the context of this study by presenting an outline of the theoretical framework and a review of the literature, policies and previous studies relating to multiple disabled people with an emphasis on education.

This chapter will present how this study is designed to make an original contribution to knowledge in the field of severe and multiple disabilities with the intention to address the gaps detected through the literature review and to consider the research decisions that have been made.

A theory of knowledge, an underlying epistemology, is present in all research activity. These elements have a great impact on the research activity and influence it, in terms of validity, methodology and scope. Therefore in every field and science a research philosophy is connected to the development of knowledge. Robson provides a clear view of this approach using three basic elements, he states that the research should be carried out systematically, skeptically and ethically (Robson, 2002: 18). And before discussing the issue of the underpinning philosophy and design of the research a personal concern should be expressed. This concern is based on a cultural issue and must be controlled throughout the implementation of the study and the analysis of data. The education and provision of children with multiple disabilities is often examined from the scope of a humanitarian or ethical approach. Notions and ideas

such as education for all children no matter how noble and encouraging they are, still have to come against other societal and economic issues, and there is a suspicion that because of these issues any suggestion for change or progress seems often to remain inactive. In the case of the Greek educational system, and for certain categories of disabled children, change and progress is imperative in terms of education provision and the promotion of their rights and autonomy. This progress may be initiated and driven by the idea of education for all children but at the same time has found positive ground and circumstances to be built on. In the case of children with multiple disabilities many issues seem to be blocking change and progress. For that reason the research plan, as it is going to be presented in the following section, intends to discover what exactly are the difficulties, fears, or missteps in the education procedure that prevent change from occurring and may exclude children with multiple disabilities from education and whether the function of the educational system provides opportunities and enables children with multiple disabilities. All of the above points will be drawn from the testimonies of parents and their perspectives both from a private/individual and a collective perspective.

The literature review highlighted the need for further research in the area of the education of children with multiple disabilities and the importance of including parents as informants and equal participators in the educational procedure. Specifically in Greece the information available to researchers, parents and teachers concerning the nature and the needs of children with multiple disabilities; their rights and opportunities; educational course and school placements is limited.

### **3.2 Methodological paradigm: Hermeneutic phenomenology**

The methodology research of a project is based on the adoption of a way to approach the social world, a methodological paradigm which will guide thinking and implementation. The philosophical foundation of this specific methodology follows the principals of the hermeneutic approach and attempts to reveal the real situation by the people who are actually experiencing it. The hermeneutic phenomenology, as elaborated by Heidegger (1962), focuses on illuminating the aspect of the lived experiences with the aim to understand and make sense of the real situation under investigation; it entails interpretation and therefore cannot be immune from the researcher's personal beliefs and values. For the purpose of this particular study and while the education of children with multiple disabilities constitutes a grey area of research in Greece, little is known and little is discussed, it is considered a most suitable approach to investigate the parents narrations of their lived experience in order to make sense and follow the course of their children's education through their eyes.

According to the positivist view there is one and only one reality which is understood and admitted by everyone, and in that case the role of the researcher is to discover that reality (Robson, 2002). The purpose of positivism is simply to follow what we can observe and measure with our senses and at this point comes close to the notion of empiricism (Clark, 1994). The realistic approach on the other hand is focused on the conditions of the real world with all the complexity and variables that exist in it and examines the views of the people that live and function in this reality. Educational research seeks to find the world that is beyond our immediate conception, deals with social phenomena, people and policies. The real world is not stable but is constantly

changing through time, space and particular cases. On these grounds the positivist approach has to be rejected whereas the realistic approach is adopted as more appropriate for the nature of this study (Bell, 2005). Realism accepts that there is a reality, independent regardless of our perception of it, and it is the researcher who is called to reveal it (Scott, 2005). It is the approach which suggests that a world exists beyond our immediate knowledge, but still the human mind can capture it. In a pragmatist level the educational policy and provision for children with multiple disabilities is progressing. Legislation which protects the rights in education for children with multiple disabilities exists (Chapter 2, Literature and policy Review), and moreover statistical data demonstrate that these children are enrolled in special schools throughout the country. On the other hand there is no qualitative examination of this reality. We need the experiences of people living in this situation in order to discover what is actually happening.

The interpretive/ hermeneutic approach claims that knowledge is socially constructed by the people who participate actively in the research process. Researchers should make efforts to conceptualise the world through the perspectives of the participants but at the same time bear in mind that the research is a product of the values, beliefs, perspectives on the part of the researcher; subjectivity is an integral part of the hermeneutic approach (Avramides & Kalyva, 2006) and thus has been considered as weak in comparison to the positivist approach. However, who can actually take subjectivity out of any aspect of research? The researcher always has a set of values, hypotheses and beliefs and it is impossible to totally eliminate these aspects from the analysis of the data. The interpretive/ hermeneutic theory has also been criticised for not being suitable for achieving generalisations. Scofield (1993) contradicts this

allegation, explaining that generalisation cannot be achieved through the interpretive theory since it is not amongst the main aims of this approach. The production of generalisations and theories in education research is extremely difficult. In social research, data and theories change every day and that is justified by the fact that people, educational policies, attitudes and circumstances change and, even more, all these elements differ in time and place (Berliner, 2002). The hermeneutic approach can help us follow these changes, present and examine them given that hermeneutics is based on the principle that there are different realities and different truths and the researcher who participates in this procedure is called to comprehend the data collected and provide the optimal interpretation.

Another goal of this research was to draw on the social model of disability perspective throughout the research design, implementation and data analysis. The purpose of this decision, without disregarding the concern raised by other researchers that this exclusive adaptation of the social model in all disability studies hides dangers and tends to form a new orthodoxy or that it overemphasises on the collective nature of disability (Stone & Priestly, 1996) and disregards the individual, was based on exploring the education of children with multiple disability in Greece away from the scope of deficit models and more from the scope of existing societal and physical barriers. It was also intended to be used as a guiding tool which will support the researcher in identifying aspects of the real situation that have not been examined in such a manner before (Barnes, 2003). A social model perspective should entail the empowerment of multiple disabled students and thus an emancipatory methodological paradigm would ideally be more appropriate. Due to the fact that the majority of children with multiple disabilities communicate in non-conventional ways the attempt



to use them as a source of information in a research conducted by only one researcher would present many challenges. Emancipatory research, a research practice that was developed based on the social model of disability and the need to move the research scope beyond the medical definition of disability (Oliver, 1992) is of significant importance and not an unachievable goal; it nevertheless requires different strategies and planning and cannot be easily implemented by only one researcher. Therefore, as the immediate next source of information concerning the education of children with multiple disabilities is the family and therefore the parents/guardians of children with multiple disabilities will be the main informants in this research. Parents are not asked to play the role of proxies, talking on behalf of their children, but the aim is for them to share their experience concerning the matter in question from their own point of view. The parental perspective and action will be examined independently within the family context as well as collectively within the parents' unions/associations context. Even though the emancipatory research cannot be implemented per se, effort is being made to use the basic principles which have led to its formation, in particular: to move the research beyond the pathology of the individual towards the definition of disability according to the social model; to compose interview guide questions and questionnaires without constructing an image of the disabled children as 'others'; to raise the voice of the parents as integral part of the educational procedure and present their personal experiences; to use the findings of the research in order to inform future changes and to adopt various methods of data collection and analysis (Stone & Priesley, 1996).

### **3.3 Research aim and questions**

According to Evans (2002), practicing research means expanding our own knowledge and at the same time creating a foundation for the participants of education who will be called to make use of it. This knowledge ought to be translated into theory and aiming to influence social policy, assist educationalists and other participants of the educational procedure. Research without a specific aim and cause means nothing in terms of progress. The usefulness of each project should be placed as one of the first priorities.

The education of children with multiple disabilities in Greece is an area that has not been methodically researched even though the number of said population is gradually increasing. In the 2004 survey about the population of disabled students conducted by the Pedagogical Institute, 431 multiply disabled students attended special and inclusive settings and according to the records of the Ministry of Education (2005) this number increases in 2005 with 705 students with multiple disabilities being enrolled in state schools. Statistical data of quantitative nature (Ministry of Education, 2005; Pedagogical Institute, 2004), even though dated, are available to the public. However, an in depth research with specific focus on the quality of education provided for children with multiple disabilities in Greece has not been conducted.

In addition, the issue of parents' participation and their views concerning the inclusion of their children in the Greek education system is a subject also rarely researched. While the inclusive movement and the theoretical acceptance of equal opportunities are increasingly promoted, the research and education community still poses a series of objections and concerns regarding the meaning, the practical implementation and the empirical evidence of inclusion, especially when the debate

focuses on full inclusion of all students. Even though parents of disabled children should be an integral part of this process, still the parental voice remains unheard.

The role of the parents has multiple dimensions and complex responsibilities, amongst which is to provide care and education. Parents follow closely every step of the educational course of their children thus constituting a valid source of information on the matter. The value of participation of parents in the decision-making and providing suggestions for improvements has been, therefore, well documented in this study and they will be the main source of information. The choice of this topic was based both on my personal research and academic interests but at the same time as it is a commissioned piece of research it reflects the interests and concerns of the Greek Scholarship Foundation who provided the funding. In terms of my personal involvement and interest on the subject this study is a step further in the area of the education for children with multiple disabilities, as in my dissertation for the Master's Degree in Special Education at the University of Birmingham, the aim of the project was to investigate the views of educationalists working in special education concerning the quality of education provided for students with multiple disabilities.

At this point I would like to add a brief explanation of why the voices of the multiple disabled people themselves were not included in the study, even though it had been considered at the beginning of the study. In the research of Heslop and Abbott (2008) about the issues faced by young people with learning difficulties, and who in some cases experienced also additional intellectual, physical or sensory disabilities, there is a very interesting description of how the research was conducted to include the voices of disabled young people themselves. Firstly the researchers had created DVDs and

accessible written material in order to better explain the process of the study to the participants. Then, when a young person expressed the interest to participate a member of the research team would travel to provide more details about the study, to discuss the best possible means of communication and make certain that each participant would receive the support they needed during the course of the interview and to ensure that informed consent was provided. Finally the member of the team in cooperation with the participant scheduled the dates for the actual interview. Some of the participants had limited verbal communication and used alternative means of communication or gestures during the interviews and the researchers facilitated the interviews by adding pictures and activities for the young people to indicate their preferences, what they liked or disliked (Abbott & Heslop, 2009). As the main aim of the thesis was to investigate the educational course of multiple disabled children and adults it was expected that most if not all of the participants would use many different ways to communicate and that alone would have been a great challenge. While the idea to include the voices of the MD people themselves was at first very intriguing the problems of only one researcher to complete such a task was deemed very difficult.

This project aims to explore the parental perceptions and experiences concerning the function of mainstream and special education settings and the quality of the education provided to students with multiple disabilities in Greece with emphasis on the opportunities provided to children and the barriers presented for both the family and the child during this educational course. Additionally main objectives of the research are to reinforce the role of parents in the educational procedure as a valuable source of information, form suggestions for improvement and to provide ground and space for dialogue in order to explore, understand and disseminate all the issues

connected with the education of students with multiple disabilities in Greece. The research questions emerging from the present study are presented at this point:

**Main Research Questions:**

- In which ways does the Greek educational system shape opportunities for learning and social inclusion for MD students, examined through the views and experiences of parents of MD children and young people?
- What is the role and influence of parents of MD children and young people in the educational process?
- Can education sit in isolation from other concerns and areas of exclusion/inclusion for MD children and young people?

**Specific Research Questions:**

1. According to parental experience where are MD students being placed within the educational system (educational settings, educational levels)?
2. Which are the obstacles faced and the solutions provided during the educational course of their MD children?
3. In the parents' opinion which educational settings promote the education of MD students and in which areas are they focusing (program, structure)?
4. How can parents participate in the decision making procedure in order to promote the rights of MD children and young people?

5. How does the existing legislation and policy support MD children and young people and their families?
6. Is the idea of inclusion possible for MD children and young people according to the parents' views and experiences?
7. Which changes are considered critical and are being introduced by parents in order to effectively include MD children within the Greek educational system?
8. How is the term multiple disability defined and perceived by members of the disability movement?

### **3.4 Sampling process and participants in the study**

Sampling is always a fundamental part of the research methodology design. Three are the main concerns during the sampling procedure according to Drew (1980) and these concerns need to take into account whether the selected sample is appropriate for the research questions, if it is representative, and how many interviewees should be included. In this project the aim was to include parents of children with multiple disabilities with the purpose of interviewing them as individual units and parents of children with multiple disabilities as members of parental associations.

#### **3.4.1 Parents of children with multiple disabilities as individual units**

In order to locate the parents it was necessary first to locate the children with multiple disabilities within the educational system. In Greece there are in total 2.759 public special school units that were created in order to provide education for students with special needs, more specifically for: 'students with vision problems, students with

hearing problems, students with mental retardation, students with physical problems, multiple disabilities, neurological and orthopedic problems' (Ministry of Education, 2005). Within this range of schools available for research, there was a need to identify the ones that would be more appropriate for examining the specific research questions and in the specific research context. Tracking down the schools that included children with multiple disabilities was the most challenging part of the whole study.

By consulting the official records of the Greek Ministry of Education (2005) we found out that 705 pupils with multiple disabilities have been registered within the educational system and that the vast majority of these students ( $n=273$ ) are enrolled in special elementary schools. Regarding the distribution of children with multiple disabilities within the geographical departments, Attica collects the largest concentration ( $n=144$ ). According to the above data we concluded that the sample will include children with multiple disabilities within the region of Attica who attend elementary special schools. Furthermore, when children have reached the elementary education level we assume that parents already have the experience of the pre-school years and they will also be able to share their expectations for the future educational transitions of their children.

#### **3.4.2 Parents of children with multiple disabilities as members of parents associations and unions**

For this part of the study the main source of information comes from the Pan-Hellenic Federation of Parents and Guardians Association for Severely and Multiple Disabled People (FPGA for SMDP), located in Athens. The Federation Members amount to 187 and include associations from all around the country. The vast majority of

associations is located in Macedonia (n=69) and in Attica (n=56), followed by the Peloponnese (n=14) and Main Greece (n=12) while the remaining geographical areas are represented by much lower numbers. For the purposes of this study all the official associations that constitute FPGA for SMDP will be included. FPGA for SMDP is also a member of the National Confederation for Persons with Disabilities (NCPD), a member of the European organization "Inclusion Europe" and its international counterpart "Inclusion International".

As the largest organization of parents with disabled children in Greece, FPGA for SMDP participates in various relevant policy making bodies, such as the Pedagogical Institute- Department of Special Education providing suggestions and posing demands to NCPD for their promotion to the Government. The law 3699/2008 concerning Special Education states that the disability movement in Greece is represented by NCPD and has the right to vote in the parliament councils in all matters concerning the education of disabled students.

### **3.5 Access**

Blaxter et al (1996) notes that 'research is the art of feasible' and in the process of designing this specific project I realized how complicated it is for a researcher to become overambitious in the attempt of researching a topic. Only after working on a theoretical and practical base with the subject and realistically evaluated time, human resources, value and most importantly issues of access did I manage to place specific limits to the project.



Tracking down and contacting parents of children with multiple disabilities in Greece proved to be a highly challenging and time consuming aspect of this research. The information provided to me through official lists was limited. The solution to this problem was provided through previous cooperation and acquaintances in the field of special education. The key link leading to contacts was the former president of FPGA for SMDP and with his support, contacts and guidance the sampling process became possible. A relationship of trust with the participants was built based on the intervention of this person as he was kind enough to liaise me with the principals of special and inclusive schools where children with multiple disabilities were enrolled and from that end I had the opportunity to meet with parents and ask for their participation in the study. The same source of information provided me the list of all parents associations and union for disabled people.

In terms of ensuring access to schools and in order to get in contact with parents a valuable asset proved to be my cooperation with the National and Kapodistrian University of Athens - Department of Early Childhood Education and with the Centre for Research and Evaluation of Inclusive Educational Programs. Whenever a school was reluctant in participating in the research, it proved helpful to mention the connection of the study to the National and Kapodistrian University of Athens and to the University of Birmingham, as was a way to gain positive reactions from the beginning.

### **3.6 Research design**

A mixed methodology in approaching the specific subject was considered most appropriate. The division between qualitative and quantitative methodology, according to Pring (2000) 'the false dualism', tends to disappear whereas the combination of both can provide data collection from various resources, thus the researcher is able to use and analyse multiple aspects of the subject. In general, qualitative analysis is connected with the use of words and quantitative analysis with the use of numbers (Miles and Huberman 1984, cited in Hammersley 1992). Another distinction often used is the connection of quantitative analysis to a realistic approach and that of qualitative analysis to a more idealistic approach (Smith 1984, cited in Hammersley 1992). Nevertheless, Brannen (1992), Bryman (1992) and Hammersley (1992) agree, based on a series of epistemological and practical considerations, that the integration within a study of both quantitative and qualitative approach can provide a rounded point of view of the subject under research.

This mixed-approach has drawbacks as well as advantages and requires constant critical reflection on behalf of the researcher. This study includes case studies on parents of students with multiple disabilities and a survey on parents associations. Surveys are a practical way of acquiring and analysing large amounts of data (Robson, 2002) in a short period of time (Denscombe, 1998), using different kinds of methods such as questionnaires. The use of surveys because it provides the possibility of obtaining large amount of data can attribute breadth to the research but it is more difficult to achieve depth (Denscombe, 1998). In the words of Bell (1997), 'Surveys can provide answers to the questions, What? Where? And How?, but it is not so easy to find out Why?'(p.11). On the other hand, case studies provide the researcher with

the opportunity to examine a situation more closely and in every detail, most importantly, in depth. The use of qualitative and quantitative methods can contribute to the micro-level and the macro-level understanding of the barriers faced by disabled people and of their needs.

A valid question at this point is how the philosophical foundation based on realism and the hermeneutic approach can be incorporated to this study. In the first research phase, the implementation of personal interviews with parents and the qualitative analysis of the data will provide an in-depth understanding of the situation deriving from their own point of view and experiences. In the second phase, the use of questionnaires addressed to parents, who are members of parental associations for children with severe disabilities, and the quantitative analysis of this data will provide a wider picture of the situation. By using elements from these two approaches the study will examine the topic in depth and breadth and answer the questions of ‘what is happening’? and ‘Why and how it is happening’? (McBride & Schostak, 2003).

In relation to the aims of the study and the specific research questions the primary objective is to collect research data concerning the educational course of a child with multiple disabilities in the public special and inclusive settings through the experiences and actions of their parents, in a family context. The second objective is to investigate the same topic through a collective mechanism, that of parents associations for disabled children. By following the educational procedure for children with multiple disabilities through the eyes of their parents provided a much more consistent and in depth analysis of the opportunities and difficulties that students

with multiple disabilities are facing, as well as suggestions to overcome problems and promoted the value of the participation of parents as a source of information.

One great concern while designing the methodology of the research was to explore all possible research tools that could lead to the collection of the information needed and that would be in agreement with the philosophical foundation of the study.

### **3.7 Research Method Phase One and Data Analysis: Interviews**

A main goal of this study is to provide space for the voice of parents of children with multiple disabilities to be heard, to investigate their experience and insights of the educational course of their children within the state special and inclusive schools, hence the use of semi-structured interview was selected as the most appropriate method of data collection for the first phase of the study. When aiming to investigate the way that participants view the world through their perspective, a research method is required that will allow the opportunity for relations of trust and reciprocity to be built (Mertens, 2005). The use of semi-structured interviews can allow us to approach reality as experienced by others (Grawitz, 2006) as long as the interviewer is neutral and non judgmental towards the interviewee and asks questions clearly and succinctly; it provides access to the way that other people view the existing reality (Altrichter et al, 1993).

An interview is a form of social conversation, but with a specific purpose, a specific topic of discussion and structure (Robson, 2000). It is considered a direct and flexible method for data gathering (May, 1997; Stake, 1995) and can provide an in-depth

analysis of the research questions. Interviews are adaptable, the researcher has the opportunity to follow up interesting answers and work through them (Robson, 2000). According to Bell (2005), interviewing can provide information that other instruments of collecting data cannot. Facial expressions, hesitation to answer a question, the tone of voice and other non-verbal cues can reveal important information to the researcher (Bell, 2005). Holstein and Gubrium (1995) consider that in the case of the interview the involvement of personal experience and background knowledge of the interviewer can be useful in order to assist the responders to answer questions, go deeper in what they are trying to express, as well as in analysing their reactions (Holstein & Gubrium, 1995).

Burroughs (1975), Arksey & Knight (1999) describe semi-structured interviews as a method where the researcher has a design, a guide which includes all the information he intends to collect, this design not being strict but providing the opportunity for the researcher to decide which question to use or omit according to the nature and personality of each interviewee in order to obtain the information needed. The use of semi-structured interviews aims to collect qualitative data based on specific thematic axes and can be used in conjunction with other research methods in a study (Cohen et al, 2009).

The use of other types of interview process would not be as helpful for the purposes of this study as the use of unstructured interviews, where the interviewer is not leading the conversation (Arksey & Knight, 1999), allows the participants to narrate their live stories without a specific focus and therefore the information needed may not be collected. The same applies to the use of structured interviews in which there

are precise and pre-determined questions, more of an oral form of questionnaire, (Arksey & Knight, 1999) during which the participants and the researcher do not have the element of flexibility needed to elaborate and investigate in depth the interviewees narrations.

Gillham (2000) states that in the case of the semi-structured interview 'simplicity is deceptive'. Clearly he emphasizes on the fact that interviewing has weak points and needs a careful and detailed preparation, but it is in the hands of the researcher to minimize risks. Cohen et al (2009) agree that the researcher needs to be cautious on how to control personal bias during the interview. One of the dangers of using the interview method is its low reliability when the researchers use it loosely (Burroughs, 1975). The element of subjectivity is a part of the interview, the researcher is as much a part of the interview as is the participant, it is a dual process but when the subjectivity of the researcher dominates the discussion, concerns are raised concerning the reliability of the process and conclusions (Iosifidis, 2003).

According to Best and Kahn (1986) interviews can be a superior data gathering method as long as they are planned and prepared carefully and held by an experienced interviewer. People in many cases feel more secure discussing a specific issue than writing thoughts down on a piece of paper. Anderson (1990) agrees that people are more likely to give answers in an interview than in the case of a questionnaire where they may choose to avoid, skip or fail to understand some questions.

The interview, however, is a very time-consuming research tool and thus the researcher needs to plan ahead, arrange appointments, allow time to explain to the interviewees the purpose and topic of the research and carefully choose the location, a

place without noise and somewhere where the interviewee feels secure and comfortable (Anderson, 1990).

As commented by Walker (1985), for the implementation of interviews the use of a tape recorder is practical for three major reasons: it offers the interviewer the chance to be concentrated during the interview without the anxiety of keeping notes and therefore appear to be giving less attention to the participant; it generates accurate data that can be used at any point of the analysis and can reveal the progress of the discussion, the stages that both the interviewee and the interviewer went through before forming an answer or a question. Above all it provides an authentic and permanent record (Kvale, 1996). Though it is tempting to use a tape recorder during interviews, it is not always accepted by the participants, they might find it intrusive and cumbersome (Walker, 1985) and the researcher needs to be prepared to use note taking during the interview.

The interviewees in this study were parents of disabled children. Parents can be interviewed either as two separate individuals, or as a pair, or only one of them, depending on who is more available to participate (Walford, 2001). All three options can provide different information and include both strengths and limitations. In the first case (separately) the opportunity arises to compare the experiences and views of two different members of the family, but in this case it is taken for granted that all families have both parents living and raising their child together, which often may not be possible, and that they both have available time to arrange meetings. In the second case (as a pair) parents will both be allowed time to state their individual experiences and also assist or contradict each other, but again it will be very difficult to engage both parents at the same time for a meeting or to assume that that in every family both

parents live in the household and that they both are willing to interact. In the third case (only one of the parents) it will be interesting to examine whether it is the mother or the father who is usually available and the reasons for that (closer to the child and his/her education, more time in the house, etc.) but in this case only the mother's or father's contribution will be included. The most practical and considerate approach seems to be to offer the parents the opportunity to decide on their own if they prefer the interview to be conducted separately, as a couple, or if only one parent should participate.

The interview data analysis was based on the principles of content analysis with the use of open and thematic coding and the construction of categories, as it will be elaborated in detail in Chapter four. The objective was to present information expressed in a common knowledge and not the quantification of the results (Kvale, 1996).

### **3.8 Research Method Phase Two and Data Analysis: Questionnaires**

By interviewing parents, the initial aim of obtaining some insight and depth concerning the educational settings and placement of children with multiple disabilities through the experiences and actions of their parents as members of a family, was accomplished. The second objective sets out to investigate the same topic through a collective mechanism, that of parents' associations and unions for disabled children.



The Parents Associations hold a vital role for the decisions made for the educational provision of children with multiple disabilities and are responsible for promoting their rights and opportunities; they have a big part in the representation of disabled children as a means of pressure to the government. In order to research this population the use of questionnaires was preferred. The use of questionnaires provided a quantitative substance to the study and allowed me to include all associations in all the geographical areas of Greece.

The quantitative research based on standardized questionnaires is the most common method of investigating social phenomena and it is used widely in social sciences since it provides the possibility of collecting comparable data. Surveys are flexible and they provide a quick, inexpensive, efficient and accurate means of accessing information about a population and provide a significant amount of data (Gillham, 2007).

The use of questionnaires in surveys although popular, may still be influenced by some common errors. The most frequent are: random sampling error, systematic error, non-response error and response bias, which includes deliberate falsification, unconscious misinterpretation, acquiescence bias, extremity bias and social desirability bias (Zikmun, 2003). What is more, some administrative errors may occur, such as processing errors and sample collection errors (Zikmun, 2003). According to Coolican (2004) there are some principles that should be followed when constructing a questionnaire. The researcher must always bear in mind the specific research questions set by the study and therefore expect from the respondents the minimum of the information required (Coolican, 2004); too much information may

not be needed and it will be highly time-consuming in terms of analysis. The questions in a survey should be posed in a way that can be answered. There is no need to put the participants in a position where in order to produce answers they may be untruthful, inaccurate or reach a point when they refuse to share their thoughts and opinions (Coolican, 2004).

In a questionnaire there are two types of questions: open and closed-ended. The open questions provide greater freedom of expression, the opportunity to the participants to add their personal comments and raise relevant issues to the topic that may not have been included in the questionnaire by the researcher. The two great disadvantages when using this type of question are that coding is time-consuming and more importantly there is a risk of the researcher misinterpreting and therefore misclassifying a response (Mouly, 1978).

Closed-ended questions are quick to answer and easy to code, and there is also no difference between articulate and inarticulate responders. Nevertheless, this type of questions may draw misleading conclusions due to the limited range of options (Mouly, 1978).

In this project open and closed-ended questions are used, in order to exploit the advantages of both types and also limit the disadvantages and risks that might affect the outcomes of the data analysis. The formation of questions is based on the analysis and conclusions of phase one of the research. Closed-ended questions can be presented in various ways; this questionnaire includes: dichotomous (question offering two choices), the Likert scale (statement with which the respondent shows

the amount of agreement/ disagreement) and the rank order (respondent is asked to rate or rank each option as applies). Open questions will mainly be unstructured, the respondents having the opportunity to answer in an unlimited number of ways.

The questionnaire data analysis is based on the quantitative approach with the assistance of the NVivo software statistical program. The quantitative findings will be further supported by the qualitative data gathered through the open questions provided by the questionnaire which will be analysed based on the thematic content analysis as it will be elaborated in detail in Chapter 5.

A more concentrated image of the research design is summarised and presented in the following table (table 1, research design table).

Table 1 Research design table

Phase	Sample size	Research Questions	Method of data collection	Method of data analysis	Justification
One	15  (mothers of MD children and adults)	<p><i>From the parental experiences where are multiple disabled children being placed within the educational system?</i></p> <p><i>In the parents views which are the public educational settings that promote the education of MD children and adults and on which areas they are focusing?</i></p> <p><i>How is the existing legislation and policy supporting MD children and adults in education?</i></p> <p><i>Which changes are considered critical, and the parents introduce, in order to effectively include MD children and adults in the Greek educational system?</i></p>	<p>Semi-structured interviews based on a pre-composed interview guide revised after the pilot interview</p> <p>The interviews were audiotaped, transcribed in written form and translated from Greek to English prior to the analysis.</p>	<p>Thematic content analysis</p> <p>Step one: Open coding with the assistance of N Vivo software program</p> <p>Step two: Thematic coding</p> <p>Step three: findings presentation based on two main categories: barriers and opportunities in education for MD children and adults</p>	<p>Provides an in depth look at individuals, their lived experiences and insights.</p> <p>It is a method flexible, open and immediate allowing adaptations.</p> <p>The subject under investigation is approached through an individual/personal perspective</p> <p>It will provide the basis, a first picture of the existing reality for students with multiple disabilities and their parents, mainly mothers. The construction of questionnaire was informed by this first phase.</p>

Phase	Sample size	Research Questions	Method of data collection	Method of data analysis	Justification
<b>Two</b>	65 (representatives of parent associations for children and adults with severe disabilities)	<p><i>How do parents perceive and define multiple disability?</i></p> <p><i>From the parental experience where are the MD children and adults being placed within the educational system?</i></p> <p><i>How can parents participate in the decision making procedure in order to promote the rights of MD children and adults and in which areas they are focusing?</i></p> <p><i>Is the idea of inclusion possible for MD children and adults according to the parents' perspectives and experience?</i></p>	<p>Questionnaires (open and closed questions)</p> <p>Finalised after piloting the first draft of the questionnaire</p>	<p>Quantitatively with the assistance of SPSS 17 software statistical program for social sciences and the use of supportive qualitative data analysed through thematic content analysis</p>	<p>Allows for the study of a wider part of the population and the expansion in different geographical areas of Greece and provides a more general picture of the situation.</p> <p>Large amount of data are processed.</p> <p>The subject under investigation is approached through a collective and political perspective.</p> <p>The findings of the second phase will inform, add, differentiate from and/or support the interview findings.</p>

### **3.9 Validity and reliability of the research**

Generalizations, validity and the production of theories are considered the hardest part of educational research (Berliner, 2002) and mainly a result of the nature of the research and the fact that social data can transform, as they are strongly connected with society and people where changes in attitudes, beliefs and conditions take place every day. New educational policies are being launched, attitudes and beliefs change, the culture of people and circumstances of the political setting of a country vary. Everything that was considered until one point valid and secure may no longer be so.

In terms of validity, one way to examine its level is through its various forms. Internal validity can be measured by the level of accuracy between the phenomenon that is being researched and the data used to examine it (Cohen et al, 2009). For that reason it is essential for the researcher to decide on appropriate data collection methods and on the nature of the data that are considered useful. In this specific study this is ensured by the involvement of multiple participants and data sources in order to minimize the risk and secure authenticity and credibility. External validity refers to the level of generalizations that can be produced and whether the findings can apply to a wider population or situation (Cohen et al, 2009). This form of validity is more risky and difficult to prove especially in social research where change never ceases to occur. In order for external validity to be ensured one has to consider issues of sampling and triangulation (Stake, 1995).

The specific proposed methodology adopts a combination of appropriate methods and research tools in order to prevent the distortion of the actual image of the situation as

presented by the specific population; to draw validated conclusions; and to limit the methodological dangers of using exclusively only one research tool (Bryman, 1992). This combined methodology seeks to use interviews, questionnaires and document analysis of the existing legislation with the intention of presenting the complications and opportunities within the educational system for children with multiple disabilities drawn from the experiences of parents and highlighting that parents can be a valuable source of information and a valuable mechanism for action and change.

According to Bryman when using triangulation (1992) attention should be placed in the fact that quantitative and qualitative methods have different advantages and disadvantages and aim to discover different patterns, therefore, it is of high importance to combine them carefully and in the best possible way. Also, the researcher should be prepared and critical in case of qualitative and quantitative data presenting different results, and should be able to evaluate the significance of each finding.

Referring to the data gathered specifically from interviews Best and Kahn (1986) emphasise that validity can only be ensured by careful planning and the selection of key questions. To achieve reliability the researcher needs to use various ways in order to check the truthfulness of the responder's answers by posing questions in different ways and in different parts of the interview, repeat the interview after a period of time, or use more than one researcher to conduct the interviews and score the transcripts.

The reliability of a research is very challenging to achieve but it can be successful in its realization by providing clarity regarding the methods used, the process and the results.

### **3.10 Ethical considerations**

As mentioned before the researcher is the main conduit of a project. Personal values, attitudes and beliefs might emerge in any part of it. Consequently, it is essential for the researcher to construct and follow an ethical frame which will be helpful in defining the rights and responsibilities of both parties (those of the researcher and the participants) as well as securing the value and status of data.

In social research most methods of data collection are in fact based on the principles of a social interaction and activity, hence rules should apply. Scott and Usher (1999) define three possible models of ethical research: *covert*, *open democratic* and *open autocratic research* (pp.132-134). Open autocratic research is most suitable according to the nature, aim and philosophy of this study as it provides the most appropriate model for protecting the rights and interests of the researcher and the participants. Participants, according to this model, are totally aware of the aim, value, purpose and use of the study. At the same time the researcher keeps the right to handle this data in a way that it is useful for public knowledge, always protecting the rights and anonymity of the participants to protect them from any harm (Burgess, 1989) and valuing their trust.

This study follows the guidelines provided by the British Educational Research Association (2004), in order to cover all ethical responsibilities towards: the



participants, the sponsors of the research and the community of educational researchers.

All participants regardless of their sex, age, race, religion, political beliefs or lifestyles were treated equally with respect. Initially, all participants either in person or through a brief written report were informed about the interview process, the reasons why their participation was important for the purpose of this particular study and the ways that the research would be used. This was followed by every participant given a consent form to sign which ensured the confidential and anonymous treatment of the data on behalf of the research and the right of the participants to withdraw at any given time during the course of the study. The parents who were interviewed and those who participated in the questionnaire survey had all the contact details of the researcher in case they needed further clarifications or other information concerning the progress of the study. A lot of effort was placed on protecting the privacy of the participants and on respecting their limited time. This study did not use any incentives to encourage participation other than the good will and enthusiasm of the parents to be a part of the research and share information concerning this particular topic. All data gathered is stored securely and every participant is allowed to review the information provided by them at any time.

The main sponsor for this study is the Greek Scholarship Foundation (IKY). Written agreements between the researcher and the foundation were signed at the beginning of their cooperation covering: the main purpose of the thesis, a brief research design presentation and a suggested time table. Every six months the researcher provided IKY with written reports concerning the progress of the study. The final obligation of

the author was to mention the contribution of the foundation in the acknowledgments section.

In order to protect the integrity of the educational research this study includes no falsified or distorting research data or findings and all references to other authors are based on good intention and do not aim to criticise other researchers in any form of defamatory or unprofessional manner (BERA, 2004).

On a more personal level I still hold some concerns regarding the ways that this research will be used after its publication and whether it could negatively affect the participants either in terms of the information that they have provided or in terms of the findings of the study. To entertain this concern I have taken all the necessary precautions to ensure the anonymity of the participants in the highest possible level and at the same time to ensure that the aim of the study, which includes the empowerment of parents and their role in the education of the children as well as the dissemination of the issues surrounding the inclusion of children with multiple disabilities in the Greek education system are central in the planning, implementation and conclusions of the study.

Another personal concern was how I was going to be able, as a non-disabled researcher and without being the parent of a multiple disabled child, to interpret the experiences of parents without having similar experiences of exclusion or oppression. For that reason large quotations from both the interviews and the questionnaires are included in various parts of the thesis to make certain that the voice of parents is being heard.

### **3.11 Summary**

This chapter provided the methodology and research design of the thesis. The study adopts the principles of the hermeneutic approach aiming to examine the existing reality according to the people that are experiencing it, more particularly in what way parents of children with multiple disabilities experience their children's educational course. The research is divided into two phases. The first phase includes interviews with parents of disabled children as members of a family in order to provide an in-depth look at individuals, their insights and lived experiences concerning the education course of their children. The second phase includes the distribution of questionnaires to parents of children with severe and multiple disabilities as members of parental associations, thus including a wider sample of the population of parents with multiple disabled children while at the same providing a more collective and political perspective on the issues discussed.

The specific steps and process of the research implementation and data analysis will be presented in detail in the following chapters.

# CHAPTER FOUR: PHASE ONE

## METHOD AND FINDINGS

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### 4.1 Introduction

This chapter describes the first phase of the study aiming to explore and look in depth into the parental insights and experiences concerning the education of their children in Greece, with emphasis on the opportunities provided to MD children and adults and the challenges faced by both the family and the child/adult during their educational course. The use of semi- structured interviews provides the opportunity to create a detailed account of the parents' acquired experiences regarding their child's schooling. Personal stories were narrated and memories shared by the parents in reference to the educational course of their children, more specifically the interviews aimed to collect the necessary data to answer the following specific research questions:

9. According to the parental experiences where are MD students being placed within the educational system (educational settings, educational levels)?
10. Which are the obstacles faced and the solutions provided during the educational course of MD students?
11. In the parents' opinion which educational settings promote the education of MD students and in which areas are they focusing (program, structure)?
12. How does the existing legislation and policy support MD children and young people and their families?

13. Which changes are considered critical and are being introduced by parents in order to effectively include MD children and young people within the Greek educational system?

## **4.2 Selection of parents**

Tracking down families of MD children and young adults was a time consuming procedure, mainly due to lack of updated records of the student population within schools. Therefore the main starting point and the only source of information was through the official records of the Greek Ministry of Education of 2005, according to which 705 pupils with multiple disabilities have been registered within the educational system, the vast majority ( $n=273$ ) being enrolled in special elementary schools which are, for the larger part ( $n=144$ ), located in the Attica region (Ministry of Education, 2005). The first step therefore was to contact the 144 special elementary schools in the Attica region and through the head teachers come in contact with parents of MD students. The particular region was chosen mainly because it is the area where the majority of educational settings are recorded and secondly due to the nature of the data collection method. Interviews require planning for making appointments, flexibility in the case that these appointments need to be rescheduled while the possibility of a second follow up interview in case that it is needed is also taken into account. Hence in this phase of the study the focus is limited to the Attica region whereas in the second phase of the study the focus is widened to include all the Greek geographical departments.

Communicating with the school head teachers was another difficult task as they were not as informed as one would expect concerning the student population in their

schools. More than often the head teachers answered that there were no children with multiple disabilities in the school, or they would transfer the call to the psychologist of the school or the social worker of the area. After many attempts to secure information about the population of students in the schools through telephone communication it was decided that the best way to achieve this would be to actually visit the schools. A useful approach proved to be the attendance of parents-teachers meetings in the educational settings where permission and access was granted by the educationalists. During these meetings it was possible to talk to the parents face to face, inform them about the aims of the study and the importance of their contribution and arrange appointments with the parents who showed interest and had time to dedicate.

By the end of these meetings 25 interviews were scheduled to be conducted within a period of three months. In the course of time five interviews were cancelled due to parents' personal and unexpected problems. In addition, the data from another set of five interviews were excluded from the study as, during the interviews, it became clear that the parents had misunderstood the issue under investigation. During the course of the interviews it was discovered that their children experienced sensory disabilities and since it was important for the research to include only parents whose children experienced more than one disability and the way that the interaction of those disabilities affected their course in education data from these interviews could not be used. Consequently, fifteen interviews were scheduled to be conducted. Their children, young people and adults were aged between 8 and 28 years old; nine female and six male. The interviews were conducted with fifteen mothers. In two cases the fathers of the children were in the house and joined us at the beginning of the discussion but did not participate during the entire interview.

### 4.3 Pilot interview

A pilot interview was conducted aiming to assist the researcher in finalizing the interview guide, make changes, additions or correct possible mistakes based on the interviewee's comments. A mother of a MD girl working as a primary education teacher agreed to help pilot the interview guide and was not included in the sample of the study.

Several potential weaknesses of the interview guide were identified based on the thoughts of the participant. The mother mainly focused on the questions that she perceived as leading or not easily understood. She underlined the fact that parents may come from different educational backgrounds and that some of the words or phrases used in the interview schedule may appear too complicated or even unknown to some of them. It should be noted here that although all parents are expected to be able to answer the questions, as it involves information derived from their own personal experience, it is the researcher's duty to phrase and express each question in a way that each parent understands. Based on the interviewee's input and suggestions seven questions were rephrased in order to provide more clarity. An example that incorporates both these comments and in the mother's view needed rephrasing was the one concerning the definition of multiple disability:

*'You don't need to ask the parents to define multiple disability, not all parents are comfortable with labels. Just ask them to describe their child in their own words and from their answers you will be able to get all the information you need' (Pilot interview).*

In addition she maintained that the interview limits should be flexible and open in order for parents to feel that they are entitled to talk about issues or personal concerns

that may not be included in the interview guide and that this will help them feel more comfortable and open up. She then added that parents when referring to their own and their children's lives tend to get carried away and narrate every incident that comes to mind. In this case the role of the interviewer is to remind the parents of the main subject of discussion, but without giving the impression that he/she is not interested in everything else that the parents feel the need to share. In the case that the parents get carried away emotionally and share more intimate information and experiences, she also emphasized that they would be asked later on whether they agree that this material be used and incorporated in the study or not.

Another issue raised during the interview as experienced by the mother confirmed that the topic is truly a sensitive subject for the parents to discuss. At times it may bring emotions of joy but the narrations will be expressed from an aspect of pain and frustration. As this issue was presented during the pilot interview the researcher was more prepared and aware of when to push the participant to proceed with the narration or when it was time to take a break. It was also an opportunity to make a note of the questions that could be more emotionally triggering for the parents.

A final point that was looked into was the fact that the pilot interview lasted approximately 2, 5 hours. Taking into consideration that the parents' time is valuable an effort was made to reduce the amount of questions.



#### **4.4 The semi-structured interview process**

After the completion of the pilot interview the interview guide was edited and finalized in order to be used for the better coordination of the discussion and to ensure that all key issues would be addressed. The interview guide was designed based on five thematic areas and consisted of specific questions (for a more detailed presentation of the interview guide please consult Appendix 2). The guide included the following thematic areas:

**Thematic Area 1: Family composition:** This section includes personal questions about the age, profession, educational background of parents, members in the family, as well as questions concerning the age, disability, strengths and needs of their MD children. The answers to the above questions were obtained while the discussion progressed.

**Thematic area 2: Centres of Differentiated Diagnosis, Assessment and Support for Children with Special needs (CEDDAS):** CEDDAS is the basic state organization for the diagnosis, evaluation and support for disabled children and adults and their families. A representative is appointed to each family in order to form a diagnosis, guide the family, propose the appropriate steps towards their children's personal and educational progress and provide continuous assessments and support. It is a state mechanism which was created and established in order to help families, but the concern of this study is how CEDDAS actually function in practice and how critical their role really is.

**Thematic area 3: Educational course, educators and special education staff:** This part is considered the most essential. It is by answering the questions in this section that parents were provided with the opportunity to describe the educational steps of

their children; the steps and actions from the time when they got the first diagnosis, until the final step of gaining some independence for their children. Here the parents talked about all the challenges they have faced, the opportunities provided, the different educational placements, the educationalists and specialised staff. They were asked to comment on their children's progress, both academically and socially, within the educational settings.

**Thematic area 4: Legislation- Education Policy and Provision:** Parents and their children as citizens of a democratic country have rights. Laws are made to protect and help them. It is of great importance whether they are aware of the existing legislations concerning their child's rights in education and within the general frame of social care and whether they consider them to be effective and focused on their needs or not.

**Thematic area 5: Hopes-expectations-concerns:** The noble aim of education is to provide to all students a welcoming and secure environment with equal opportunities where they will be able to progress in terms of gaining their autonomy, increase their confidence, establish meaningful social relationships; to feel equipped and prepared to face the challenges of the future. Parents of disabled children and adults are mostly concerned about the future of their children especially of what will happen after they stop being able to protect and assist them (Case: 2000, Panteliadou et al: 1994, Thomas et al: 1993). It was considered important to discover how parents imagined their children's future and how they connected the quality of their children's lives in the future with the education they receive today.

The next step was to contact the fifteen participants of the research in order to schedule the time and place of the interview according to their spare time and location preferences. The interviews were conducted on different days allowing time and space for the researcher to reflect on the process.

Ten interviews were conducted in the parents' homes and five in the school area. Ten out of the fifteen mothers were occupied within the household and their children; they explained that they did not have the time or the energy to be occupied with anything else. Two mothers were educationalists working at elementary level and the lyceum and one was working as a bank cashier; they explained that their work hours allowed them time to take care of the house and their children in the afternoons. Two mothers were shop owners but in periods of crisis or distress regarding their children they had employees run their shops. The fathers in the family were mostly occupied in the public and the private sector (for a detailed presentation of the families' composition please consult appendix 3).

A primary concern was to create a welcoming and open environment for the parents in order to help them feel free to express their views and share their personal stories as this was determined as a crucial step during the pilot interview. Before focusing on the interview schedule time was provided for the parents to relax by discussing irrelevant to the subject issues, for example the current political climate, and to express all their questions or worries regarding the interview. At the same time parents were given the opportunity to ask questions concerning my studies, work experience and personal aims.

Once again before starting with the interview questions the participants were informed about the anonymity and confidentiality protocol and the way that the information provided by them would be used in this thesis. An overview of the aim and purpose of the study was repeated to the parents and time was allowed for them to ask questions and request any clarifications. Afterwards the parents were asked to sign the relevant document of participation (please consult Appendix 4) which assured them that all the conditions described by me verbally would also be documented on paper.

What was interesting was that several parents could not understand the reason for these formalities. They felt that it was not necessary to sign a document to exhibit their trust to the researcher since the contract of trust was that they had invited me to their house. Upon my insistence and by explaining that these are typical procedures in order to protect them as well as the researcher, all parents signed the document. A hypothesis based on this incident - parents not feeling the need to sign a document or saying that these technicalities take time away from the discussion- is that parents are not used to the role of 'research subject', that is being participants in similar researches and did not have any previous experience of the typical procedure. However, as far as I am concerned, this was a sign of trust and openness on behalf of the parents and provided me with the confidence to continue.

The researcher asked the participants' permission to record the conversation. In cases where the participants seemed reluctant the researcher explained that she was prepared to keep notes if necessary. Thankfully, all parents accepted to be recorded on

tape thus providing an authentic record of the interview. Parents that seemed reluctant towards being recorded explained that they felt embarrassed and nervous so I tried to keep the recorder in a spot that was not so obvious to the parents and soon after the beginning of the interview while narrating their personal stories the parents forgot it existed.

The interview was conducted in a form of a discussion and I tried to keep the interview guide out of sight, in order to not intimidate the participants or lose focus. Only at the end of the interview one last consultation of the interview guide ensured that all issues were addressed.

The issues discussed during the pilot interview emerged during the discussion with the parents. For example, mothers tended to drift from the core of the subject which was the education of their children to discuss issues of religion, discipline of the child, personal regrets and marital status. These narrations did not fall into the pre constructed thematic areas of the research but they were most welcomed as they helped to create a more holistic frame of the families. These parts were not included in the study but added to the researcher's better understanding of the complexity of each family and the need for support that families with MD children and young adults should have. In some cases mothers were so emotional that the interview had to be paused in order to regroup and continue.

Again, as observed during the pilot interview the discussion with parents when referring to their children could last for hours. Prepared for that possibility, and after all the key issues had been discussed I would mention the time, explaining to the

parents that it was not my intention to abuse their personal time. In some cases the parents stated that they wished for the discussion to be continued and that was respected.

At the end of the interview the parents were provided with my contact details and were informed that they could contact me at any time if they had any objections about the information shared or in case they wanted to add, change or remove parts of their narrations. Following the transcription of the interviews the interviewees were again contacted and invited to review the material if they wished so and were once again reminded of their right to withdraw from the research at any time.

Overall the decision to use the research method of semi-structured interviews was appropriate for the purposes of this research. It allowed for the flexibility needed to create an open and meaningful conversation with the parents and provided the opportunity to use probes in order to help the participants to elaborate more on the issues discussed and therefore to make better sense of their perspective.

## **4.5 Data analysis**

In order for the data from the interviews to be analysed the first step was to transcribe all the audio data. These first transcriptions were in the Greek language, the language in which the interviews were conducted. In a second step all the transcripts were translated into English, so that key quotations could be used in the analysis of the interviews. While translating from one language to another there is always a risk of not being able to convey the exact meaning of the expressions that the parents used in their answers. For that reason the translation is word by word, using the exact same

sentences and sequence of words that the parents used. When an expression used in Greek and intended to express a specific meaning or situation had no equivalent in English and in order to relay the same meaning detailed information about the meaning of the word or phrase in question is provided for the reader.

After the completion of the transcripts the amount of data was large. Each interview lasted between about forty five minutes and one hour and a half. The process of data coding was based on the narrative approach (Bryman, 1992) and thematic content analysis. Content analysis allowed the synthesis of a large amount of data to be presented in an organized and clear way (Julien, 2008).

Because of the large amount of data and in order to serve the purposes of this study both the open coding and thematic coding method were used. It was important to first read all interviews several times in order to form a general idea of each parental experience and then to isolate, highlight and extract the appropriate passages of each interview (open coding) that were significant to this project and to the specific research question. In this way the large amount of data was reduced and I was able to construct thematic codes and a first conceptual map. During the first step of coding the N Vivo qualitative data management software program facilitated the process, as it allowed input of all the various passages of the interviews and the creation of initial thematic codes.

The thematic codes used during the first level of data analysis were based on the interview guide themes: Family composition, Centres of Differentiated Diagnosis, Assessment and Support for Children with Special needs, Educational course, educators and special education staff, Legislation- Education Policy and Provision, Hopes-expectations-concerns. These thematic codes helped to group the data at a first level and detect the new themes emerging from the information provided by the

participants, some of which were not in the original pre-constructed themes set by the researcher. Parts of the interviews were compared with one another to decide if the items belonged together but in some cases some quotes could be coded into many different areas which is nevertheless probable during this initial analysis.

Even though my intention was to focus exclusively on issues concerning the existing education provision, available school structures, quality of education and educational program, it became clear from the parents' narration that practices of exclusion in various levels of their lives acted as barriers and prevented their children from accessing education or receiving quality education. Parents narrated personal experiences and it was hard for them to concentrate on specific subjects; in their narrations all these experiences were interconnected and overlapping. In particular, when discussing the educational placements of their children, they immediately connected this issue with the financial hardship of the family at the time and the state provision that raises barriers against access in education. Based on that understanding the new themes used in the analysis were data driven.

The next step included the creation of categories and an attempt to highlight connections between the thematic codes which could create more abstract meanings. By constantly revisiting the material and since an attempt was made to collect rich and detailed descriptions of parents past experiences and highlight these experiences the final categories were created based on the parents' replies and moved away from the initial interview guide categories. The three final main categories were formed based on the **challenges and barriers** in education faced during the educational course of their child, **opportunities** provided and the **recommendations** for future



reform proposed by parents. The category of challenges and barriers was then divided into the following sub-categories: bureaucratic, structural, pedagogical, cultural as well as communication, health care/provision and financial barriers. Parts of the interviews were then placed in the relevant category or sub-category (Weber, 1990).

As mentioned in the introduction chapter the education of MD students and young people and the issue of their exclusion is not limited on areas only directly connected to education and this became more clear through the parents narrations. The issues of health care and provision and the financial barriers faced by the families play an equally important part of the MD children and young people lives and they certainly affect their education in two levels: primarily due to the fact that a family that still struggles to cover the health care and provision needs of their child has limited time and energy to focus on educational matters and secondly families that struggle financially cannot afford to provide additional educational help, extra curricular activities or even secure the transportation of their children, if not provided by the school. Therefore even if these two categories on the first glance may seem irrelevant and detached from the subject under investigation, there is in fact a deep connection between these major issues: education-health care-economy and the parents through their interviews provided these missing links.

Original, and representative of the research findings, quotations have been incorporated in the following section to support the arguments and the interpretations emerging from the interviews with the parents. Parents had given their permission for these quotations to be used in the final thesis and all names and other identifying characteristics have been altered and presented in an anonymous form. The quotations

used here were chosen based on the content of the statements themselves at the level of isolated phrases but at the same time this selection also depended on the context that led the participants to make these statements. By being part of the interview procedure I was aware of the issues discussed before, during and after each statement. This process facilitated the grouping of different quotations in the relevant categories. In addition, the findings were validated by a colleague of mine, working at the Centre for Research and Evaluation of Inclusive Educational Programs, National and Kapodistrian University of Athens, who during the process of data analysis, was kind enough to assist in the transcription of data. Based on the fact that she was aware of the parents narrations I asked for her assistance in order to co code parts of the interviews and to cross-check whether the categories formed and the quotations used represented the voice of parents and that I was not leaping to interpretation of data. Her input was valuable in terms of self-reflection and consideration of the steps leading to the findings presentation.

In order to ensure the anonymity of the participants the quotations used will hereinafter be coded to show the number of the interview conducted, i.e. passage extracted from the first interview will be coded as 'I1'.

## **4.6 Findings presentation: Barriers and Challenges to education as presented by the interviewed parents**

### **4.6.1 Bureaucracy**

Bureaucracy is defined by excessively complicated administrative procedures, and usually refers to government departments, in particular those perceived as being concerned with procedural correctness at the expense of people's needs. From the parents narration it became clear that they had the same understanding of the term.

*'It is frustrating to experience the slow moving ways of the Greek bureaucratic public sector, especially when you are running out of time, when your child's well-being, education, safety, mental health is on the line. We have to act fast so we have to act alone' (I6).*

*'Sometimes I sit down and wonder...who designed these procedures...what they had in mind. If the aim was to create more delays against the public getting what they need then they have succeeded' (I3).*

The first milestone that parents needed to confront was the procedure of diagnosis and school placement. Parents were the first to notice that their child is different and they were seeking for answers. A diagnosis, the need to put a name to the child's differences, was the primary concern.

*'We as parents knew that something was different with our child. But the diagnostic centers 20 years ago were not experienced enough' (I2).*

*'My girl had problems I could see it from the very beginning, she wasn't growing up, couldn't stand, didn't make eye contact. I would talk to her and she would look side way. No expert could figure it out. I was telling to everyone that something was wrong, to the doctors to the diagnosticians. No one told me to take my child somewhere to check her out in other ways' (I7).*

*'Yes we needed this diagnosis, not only for the schools but for ourselves... we believed that along with the diagnosis came solutions, directions, guidance' (I10).*

This diagnosis could be produced by the hospital, the medical and pedagogy centres or the appropriate CEDDAS of the area, but the procedure was proven to be much more bewildering than the parents expected at first. In order for the parents to secure an appropriate school placement for the child they needed two main requirements: an official diagnosis and the recommendation of CEDDAS. If the parents were not aware of this procedure the school was responsible for redirecting the parents towards getting both the diagnosis and recommendation before the child's school enrolment, but the parents in their interviews all noted the problem of lack of information and direction from the state.

*'The state? What state? You ask for things and they won't even make an appointment to discuss it with you, to guide you on time. Where should I address to? Where is the ministry of education with their special and inclusive education? There isn't any' (I4.)*

*'The most difficult educational period was when I didn't know. I couldn't find someone to tell me where to go and ask. There was no one, not a centre, not a state institution to approach me and tell me: 'Meme your child has this. You have to do this'. I searched, I asked, I find my solutions to my problems' (I13).*

*'No one helps us, and we need help and guidance. Someone to point us to the right direction. But no the responsibility of all the decisions and all the moves fall on the parent and the parent alone' (I11).*

Therefore, one of the main challenges during the educational placement of children with multiple disabilities was the failure of the diagnostic and support services to provide answers on time, and the parents were then introduced to the absence of effective structures and organisation by their initial attempts to secure a diagnosis on

time. The delays when anticipating a diagnosis and furthermore the recommendation for an appropriate school setting were long and as a result the child remained inactive and excluded from the education system for long periods of time, delays which resulted in children moving backwards in terms of progress, personal and social development. Parents noted the need for more staff placements in CEDDAS and more centres per region so that the work load would be distributed equally. It took up to a year for parents to receive a valid diagnosis. So the family again was left alone without support, the teacher would maybe continue to accommodate the child in the classroom in any possible way or send the child home until he/she received a valid diagnosis. Valuable time, educational time gone wasted.

*'We enrolled him in an inclusive classroom on the beginning of the school year. From the first days it was obvious that the difficulties were many. They asked from us to provide the CEDDAS recommendation, the appointment that we managed to book was not for another three months. The head teacher asked me to move him in a special school he knew that would accommodate my child. After a long way he was enrolled in that school on January. This meant that for half the school year my son didn't have a school, no place for him, he was in the air' (I15).*

*'Every year twice a year M. has to go through a hearing to monitor typically her progress and allow her to be enrolled in a special school. What do they think that will change every 6 months? My child will miraculously be able to walk properly or her mental retardation will magically vanish? Or provide them with a long speech about her progress? The only thing that they accomplish with these hearings is to humiliate us once again, to make my child anxious and stress. This is not fair; this isn't how things are supposed to be. So they can keep the allowance away from us and the schools locked for my child, I am giving all this up, it is not worth it in the end' (I4).*

New problems appeared even after the parents had secured a diagnosis and the recommendation from CEDDAS, as at this stage the parents needed to face the challenges within the specific schools and classrooms where their child was sent. In the schools the educationalists provided their own views on the matter and on some

occasions after a short period of time redirected the child to yet another school or classroom.

*'She told me (his teacher): you shouldn't leave your child here, we will cause many troubles for him. She also knew the head teacher of nearby public special school in Athens. He was accepted there but from January ■' (114).*

In other cases the school was waiting for a special teacher to be appointed before accepting the student in the classroom and the parents were asked to keep their child at home until that teacher arrived, again adding many delays which endangered the child's progress and inclusion.

*'We were so happy to hear that our child could go to the school next to our house. But then again we didn't know what would follow. The preschool teacher told us that we had to wait for the Ministry of Education to send a special teacher to assist her. We waited, we called everyone that we thought that could help speed things up but it was too complicated, we never understood how this procedure works. After three months they send someone, it was right after the Christmas holiday. Needless to say how difficult it was then for my son to adjust or be accepted to the classroom' (12).*

#### **4.6.2 Structural**

In this section the aim was to investigate the existing educational structures available for MD students through the narratives of their parents and their attempts to find an appropriate educational setting for their children, or in this case as it will be presented, any educational setting that would accommodate their children.

All of the parents as a first option wanted to enroll their children in the general public kindergarten of their neighborhood or an inclusive classroom, if there was one

operating in the area. Gaining access to a general education structure and convincing the educationalists and school councils to accept their child was the first challenge. The second challenge was made clear to the parents when they realized that their children were accepted in a school environment not prepared to meet their different needs.

*'We decided to enroll him in a mainstream school and see how that goes, I remember very well that from the very first week it was obvious that it wasn't the right choice after all. He was tensed, aggressive, negative in general, he was feeling so much pressure and that made everything worse' (I2).*

*'In mainstream education access is not easy and even if you manage to enter the situation is very challenging. In general there is a struggle in order for these children to have equal opportunities. I wanted to try and provide to my child a normal school life' (I1).*

*'No my child could not attend a public mainstream school, not in our circumstances. She couldn't sit in the chairs and desks they had. She couldn't communicate with anyone' (I4).*

Unfortunately, according to the parents experiences, the legislation is open to interpretations and if the teachers and/or the school consultant of the area decided that it was not in the child's best interest to attend a general education classroom or if the teacher refused to proceed with the enrollment based on concerns about the student's personal safety or concerns about the progress of the rest of the classroom then the child could still be excluded.

*'It is a battle to ask for equal opportunities. We may have them on paper but in practice, in this country we are still way back in progress, of course some attempts are being made, but we still have a long way to go' (I5).*

*'He told me (the teacher) that what he was afraid the most was that the rest of the class will fall behind, even if another teacher would be sent to assist him he couldn't see how the lesson could be done' (I9).*

Three of the parents had hired on their own personal expenses special teachers or private teacher assistants to support the general education teacher in the classroom, during lunchtime, playground hours and for the child's self-service needs.

*'When I first visited the public school here in the neighbourhood, and I had a first discussion they were much more positive. And again here I hired a young girl, a teacher who was not yet appointed to a school, to look after her during break time and sometimes escort her home' (I8).*

*'Her educational course was very -very difficult. There were no special schools. I enrolled her in the nearby mainstream public school and I was paying a special teacher every day to be in the classroom and help her to learn some "letters"' (I9).*

Parents came to terms from the first few weeks with the fact that few general education structures would accept their children and fewer of them could provide the educational program that was needed to meet their needs. The second educational option available for students with multiple disabilities was in special education structures. But still problems and difficulties arose within this context as well. Parents were reluctant from the beginning to enroll their children to special education settings and that was clear from the fact that their first thought and expectation was to approach a general school. From then on it was a series of attempts between private and public special schools but there also the available spaces were limited and new anxieties were created.

*'My child at the beginning of his course was enrolled in mainstream education, in the kindergarten. That only lasted a year. The teacher told me that she couldn't keep him any longer. I had to come to terms that I should search for a special school' (I8).*



*'The schools for 'these' children are so limited. We tried to find the best place for our children. The first year we came up against chaos and disorder. Many situations which you had to endure because you had no other choice' (I11).*

*'What is not the worst is considered the best'*, this ancient Greek saying came up in almost all the interviews. The meaning of this phrase is that when you have dealt with the most difficult and challenging situations everything else seems like the better option. In this context two parents (I3, I7) explained how, after many attempts, they found educational structures where their children were happy, safe and accepted. Without minimizing the importance of such feelings it is also important to note the fact that the same parents did not provide any comments concerning the children's and adults' educational progress. The children did show progress in terms of behavioral attitude and this is not considered a small achievement, but it makes us wonder if that is enough when discussing issues of qualitative education against more old and traditional views where the education of disabled children and adults was a synonym of care and safe keeping.

*'So, as I was saying he became a different child, finally he could spend some time with children in his own age. M. is very tall, almost two feet high; I think he was always very big I can't remember him being little. In the previous special school he had to be in the same classroom with children younger and of course smaller than him, he didn't like that. Finally he seemed happy and well adjusted' (I7).*

Parents, when searching for an acceptable educational setting, were interested in finding a pleasant environment, a clean and well-equipped school and above all a welcoming environment. Instead parents realized that the classrooms where their

children were placed were inadequate to their expectations, small spaces with minimum educational material and limited opportunities for learning.

*'I tried all schools. Wherever I didn't like a school I wouldn't send my girl. I wanted for my child something that she deserved a friendly and nice environment...a school clean, with some acceptable pleasant aesthetic. I wanted a beautiful school for her. Why shouldn't I? She is entitled to one, or she supposed to be entitled to one' (I12).*

*'The classroom in the special school that was provided for children like my daughter was an old and tiny warehouse. It was empty because they had taken all the equipment that the school used to store there and moved them to a more secure room. But as it seems it was perfect for our children to be accommodated in' (I6).*

In addition, the parents commented on the fact that the classrooms were not adapted to their children needs. Access was highly difficult and there was no adaptable material or equipment to assist their children in their effort to follow the school program.

*'No my child could not attend a public mainstream school, not in our circumstances. She couldn't sit in the chairs and desks they had' (I10).*

*'She couldn't see the board or any other material in long distance, she needed everything to be maximized for her to even notice it but the school could not provide that for her' (I8).*

*'My son can't leave me, not even for a second. And every day we have to face a new problem. He cannot use the stairs, or a downhill road. I have to be there to guide him, hold him, push him or carry him. A child with needs like my son could not even approach the classroom without someone carrying him inside and then he was restricted there until it was time for me to pick him up' (I12).*

While witnessing this situation three mothers (I6, I13, I15) turned to private schools for assistance but also in the private sector there was a reluctance to assume the responsibility of a multiple disabled student.

*'In the private school they kept telling me that they didn't know if they could be responsible for her well-being, 'what will happen if she falls and hurts herself?'. Their attitude restrained me from enrolling K. there' (I6).*

*'When it was her time to proceed into primary education I approached two private schools, but I was not at all happy from our initial discussions, so my final decision was to enroll her to the public mainstream school here in our neighborhood (I13)'*

Therefore on the one hand the parents had the option of enrolling their children in a public school where there was a lack of resources, staff and appropriate space and on the other hand the private schools, even though the parents had to pay high tuition fees and lack of recourses was not an issue, were hesitant to include them.

Three were the institutions mentioned by almost all the parents: [REDACTED] , [REDACTED] and [REDACTED] . The procedure for getting into these schools was very strict and long due to the limited spaces. The parents went through interviews because the schools wanted to ensure that they would be able to cooperate with them and they also needed to assess the child. The children and adults who managed to secure a place in these institutions showed progress in terms of their personal well being. There they had the opportunity to get involved with different activities and to be with children of their own age. Again the issue of socialization with children without disabilities remains unaddressed.

*'We, as I am sure many parents already have told you, tried to get into [REDACTED] . But the places were few and our children many. The selection of children is very strict. There is a selection of children and parents*

*through a personal interview. If the school decided that it will not be possible to cooperate with the parents in basic issues then the child was not accepted' (14).*

*'After many experiments like the above one we decided it to enroll her to [REDACTED], where she learned how to use the knitting machine, at some level. It seemed that there we had found a place more suitable to her, to her needs. Her mood was better and this change was mentioned and welcomed by all the members in our family' (11).*

*'So, as I was saying he became a different child, finally he could spend some time with children in his own age. M. is very tall, almost two feet high; I think he was always very big I can't remember him being little. In the previous special school he had to be in the same classroom with children younger and of course smaller than him, he didn't like that. Finally he seemed happy and well adjusted' (17).*

When the families realized that they could not expect progress from the school establishments they had to use 'out of school' educational structures and paid services provided to their children in the house or in private institutions. All the children in the interviews were visiting after school hour's private centers for physiotherapy, psychotherapy, speech therapy, occupational therapy; along with a special educator in the house for the evening hours in the cases of mothers who required additional help.

*'We always thought that if from the very beginning we provided everything that our child needed: speech therapy, psychologists, etc. then it would soon get better and won't need so much, but it isn't like this. These procedures and the struggle for progress last a life time' (15).*

*'N. has many activities out of the house but in the house I didn't need any help. Only in case I was going out I used to call a young girl to stay with her, play with her but not on a daily basis' (16).*

*'I tried to keep him busy all day, therapeutic theatre, gym. I am so tired to drive him around all day, but he likes these activities so much that I can't do otherwise' (112).*

*'Inside the house we had many others, a special educator, a psychotherapist, speech therapist. I knew that my child couldn't learn much and whatever he would actually learn it would take a really long*

*time and a great deal of effort, he stayed in that special school until he was 15, trying to spell his name' (I9).*

*'It was a wise thing that I have arranged for him in the afternoon psychotherapy three times a week-privately, outside of the school. At least we witnessed some progress' (I1).*

Parents made very clear through their personal examples that an educational structure that provides opportunities for socialization, motivation, learning and self-development was not available for MD students. Their children's educational course did not have a stable and continuing progress but was constantly interrupted by transfers between different educational structures. This backward movement had a direct effect on the child's progress, confidence and feeling of security.

*'My child went to a special public school for the 'primary education' years. First he attended a [REDACTED] regular kindergarten and there they kept him for a year. But J. couldn't speak at all; he could not communicate at all. He was accepted by his co students but the teacher made it absolutely clear that there was no meaning to keep him in the school. He couldn't understand anything; he was in the classroom but couldn't do anything at all. Then they advised me to take him to [REDACTED] which was the educational setting that was considered most appropriate for a child like my son. We stayed there for two years and then we decided to try other schools again, we went to another school in [REDACTED] and then in [REDACTED] but it was hopeless, we had to return to [REDACTED] where we could find the education he needed' (I15).*

*'While experimenting we lost time...In the school from the age of 6 until the age of 15 years old they were trying to teach him how to write his name' (I12).*

Another point made by the parents was the lack of multidisciplinary public centres available for MD children and adults. A structure that would help children interact with other children. Specific goals and objectives would be decided by the whole team and with the participation of parents and students. This could provide a sense of

stability for MD children and adults and where all specialists would join forces and cooperate in order to achieve specific goals each term, evaluate and reevaluate these goals, the progress of the child, the need for differentiated approaches and teaching methods.

*'What I can also see is that there is a lack of specialized centres. Somewhere where we can go for physiotherapy and all the rest. A team of all the experts and a doctor, who will sit down and discuss and take decisions of each child's progress, where to focus, etc. For example to say that this month we will all work together and focus in a specific aspect of J.'s progress. A whole team: a speech therapist, a physiotherapist, a psychologist and a doctor to sit down and make a personal plan for each child every 6 months. You cannot find any centre like the one I am describing in a state/public level. You can hardly find a private one. For many years J. did his physic and speech therapy in the house. But he want to go out, to be with other children' (I15).*

Parents in search of an appropriate educational setting have witnessed firsthand the policy and legislation reforms. Nevertheless, they state that in the everyday reality few changes towards more effective diagnostic and support services are being implemented, and even less of these reforms concerned their children directly.

*'Yes, maybe the diagnostic centers have changed, but I don't see it. The same attention that we received in 1986, and the same procedures and the same diagnosis I received then, the same I got now from the CEDAS. Some things don't change' (I14).*

*'The legislation keeps changing and now I know that the official direction in education is a school for all, but again for our children nothing new has been introduced. Still there are no educational structure, still they don't fit in 'the school for all'' (I11).*

Parents at the end of the interview where asked if they would have chosen a different course knowing then what they know now concerning the obstacles that they had to face within the educational system and their answers where that in their mind and heart they did everything they could have done at the time. They visited different

educational settings, they tried not to compromise, they had to work alone and fight for their children needs. Moreover all parents explained how amongst all the difficulties (for example their children's health, the financial instability, the time needed to take care of their other children) they feel proud that they also took interest and fought for their children rights in education and that they understood the importance of finding an appropriate educational setting for their children's development and progress.

*'I don't have any regrets about the way I decided his educational course, I won't ever have regrets. I did the best with what I had. I fought for him and even in the mainstream school no one kicked us out, they had no right to do that, I took my child and left' (I2).*

It should be noted at this point that seven of the parents in the interviews admitted that after this long search for an appropriate public educational structure either in the context of general or special educational settings they have decided that they need to address to private institutions, day care centres or workshop for the next academic year. That is if their financials will allow this move and if there are enough places.

*'From the following year M. will be in a private workshop school' (I13).*

*'The cost of tuition fees is something that we are trying not to think but we will try to contact a day care centre to accommodate him' (I4).*

*'I believe that we did everything we could in order to provide her the opportunity to be educated along with the rest of the children in school, but now we realize that we have to give up, concentrate on finding a good workshop with other children with similar needs, maybe it is for the best' (I10).*

*'We had tried in the past to place him in a private care centre but at that time it was full, we will try again this year, they promised us that she will get in' (I2).*

The lack of public and free independent or semi-independent living structures was highlighted by the parents. They demanded solutions so that every MD person without a strong financial background will be entitled to a place in a house where they can live with other people, with continuous educational and training programs, specialist staff and health care.

*'I was talking with another mother during my daughter's physiotherapy and she told me that they were already making moves in order to create an independent living home for the children. I felt sad...it is impossible for my family now to invest in a project like this. But I also want for my daughter to have a place in the future and I cannot understand why there cannot be one free for all the children that need it'(11).*

*'When we are asking for independent living structures what we want is a decent place where our children will be able to share their lives with others, learn, progress, even after we are long gone' (15).*

#### **4.6.3 Pedagogical**

Parents on a second level describe from their point of view the pedagogical issues and complications faced within the above mentioned educational structures. Firstly, the parents commented on the fact that the general education schools were not properly staffed with teaching assistants or special teachers to support the general education teachers in meeting the needs of a diverse classroom, in terms of practical assistance, educational planning, implementation and assessment. Due to this need parents decided to privately hire assistants and special educators to accompany their children during the school day. This decision was made because the parents understood that it was not be possible by only one educationalist to be responsible for all the students'



safety and personal needs and at the same time to be able to organize and implement individual and differentiated programs. Soon they came to realize that even with this support educationalists were not prepared to change their teaching routes and methods or effectively cooperate with their colleagues.

*'We did hire an assistant for our teacher. It seemed like the descent choice, of course it is the states responsibly to provide one, but it was our responsibility to do whatever we can so that our child could receive a proper education. With two teachers in the classroom we had the hope that at least one of them would focus on the educational program. And we were hoping that we would minimize any complaints from the school not being able to accommodate M.'s needs' (I7).*

*'On our part we tried everything. We even paid for a special educator, a girl who had just completed their studies, to join him in the classroom. But what we didn't know was that it was very difficult for the educationalist to cooperate with her, even though it was the pre-school years together they couldn't find a way to work and create an appropriate educational program. As I said it was in the kindergarten, we managed to finish the year there but we were not welcomed to stay the following year (I15).*

*'We were paying someone to help her (the educationalist) and my child was still laying all day in the floor with the same toys and alone. Two persons in that classroom and no one could make her even change her position. Of course she couldn't stay there, of course she would be made fun of by the other children. I am not trying to blame anyone, it is what it is' (I8).*

Another recorded restriction against MD students attending general education expressed by the parents was the rigid focus in cognitive based activities and school plans. Even though the curriculum includes various areas of development and demands from the educationalists to differentiate the program according to the students' needs, at the same time it fails to provide a theoretical background or practical methods for the educationalist to feel confident to change their teaching methods and content. What's more the educationalist showed limited expectations of

their multiple disabled students which had a direct negative effect in the student's determination to try and achieve.

*'He couldn't follow the lessons, not that I blame the teacher, he also was not prepared to deal with my child' (I15).*

*'All the other children were sitting together, discussing, writing their names, counting, painting, but my son was always away. The teacher told me that he didn't want to participate so she preferred not pushing him. But how would he change and get better without pushing. In the house I push him, I push him all the time, it is not easy but I do it because I know it is the only way' (I14).*

*'If you ask me I don't know which is true, she (the educationalist) didn't expect much from her she didn't believe that my daughter could improve, she didn't believe that my daughter was capable of doing anything? I don't know- what I know is that she never provided the motivation for my daughter to get involved in the classroom activities in any way. Maybe she didn't want to pressure her, I don't know' (I13).*

Highly important was the issue of motivation and support for the children according to the parents, as it takes a lot of effort on their behalf to learn something new, their progress is slow and they get easily frustrated they need teachers to push them ahead and urge them to keep trying.

*'The point is that she is not giving up, I am coming in touch with other girls in her physiotherapy centre and they are very frustrated, kids often give up, they are tired of trying and trying and need so much time just to make a small step of progress' (I6).*

As previously elaborated parents, after many efforts to include their children in the general education, mainly during the early years, they then turned to special education. There again the conditions were far from ideal, the educational program was once again focused on literacy, there was a lack of specific educational objectives and little was performed in regard to their children needs for socialization and

inclusion. Special schools following the route of knowledge-centered general education programs, were teaching the children 'letters', as the parents call this form of program. An expression used referring to reading and writing skills.

*'In the special school their priority was for our children to gain knowledge, I knew that there was no real purpose in a goal like that, I knew that no amazing progress will come so I limited my expectations. But the school had no program concerning socialization or other activities so that my daughter would learn to do something' (I8).*

*'I think that maybe we went backwards concerning her progress to be honest. Besides the fact that the school gave away an air and a feeling of melancholy and depression the activities were again focused on 'learning', I had the false anticipation that they would do more 'practical' things there, that they would have appropriate educational material and that they would work on the children's self-care and socialization skills' (I3)*

*'In the school from the age of 6 until the age of 15 years old they were trying to teach him how to write his name' (I14).*

*'I knew that my child couldn't learn much and whatever he would actually learn it would take a really long time and a great deal of effort, he stayed in that special school until he was 15, trying to spell his name' (I12).*

In the same discussion topic the parents continued to disclose that they themselves had high expectations concerning their children's academic progress at the very beginning. They wanted for their children to be able to read and write and it was later that they accepted that that was not the main objective. The possibility of their children never reaching the level of reading and writing beset the parents for a long period of time. Nevertheless, they had to battle their own expectations before reaching to the acceptance of a different situation.

*'We wanted for her to learn 'letters' (reading-writing). We changed so many different schools. Word among parents of other children with severe disabilities led us to a department of a well-known special school*

██████████, it was called ██████████' and there the teachers were supposed to be experts in teaching our children 'letters''(I13) .

*'It was too late until we finally realized that our child was not destined to learn how to read and write, of course not-now everything is more clear but it is also too late, our child needed something different a totally different educational approach, totally different educational aims'(I3).*

The moment that parents realized that the educational needs of their children were different and they were able to find the appropriate educational setting then they were able to observe the progress the children made in terms of behavior, positive feelings and progress in skills.

*'When he turned 15 years old we took him to a different school, a totally different educational structure, there their main aim was to provide different activities to our children like cooking. M. was very excited about everything concerning the kitchen, the smells, the colors, the heat. He became a different person in that school. His negative and aggressive behavior almost disappeared, even towards me. He was often very upset with me because I had to be the mean one, the one that had to set some limits' (I2).*

*'So, as I was saying he became a different child, finally he could spend some time with children in his own age. M. is very tall, almost two feet high; I think he was always very big I can't remember him being little. But in the special school he had to be in the same classroom with children younger and of course smaller than him, he didn't like that. He started to show some progress' (I10).*

Furthermore parents came to the realization that education for their children meant to be able to gain some level of autonomy and independence with the main starting point being the ability to care for themselves through daily simple tasks and the ability to be around other people, to maintain a good body posture, and so on. In order for them to develop these skills a pedagogical program carefully planned and based on repetition, practice and encouragement should be developed. MD students needed an individual and holistic program with specific aims.

*'For children without disabilities being able to perform daily tasks by themselves is usually a given. They will take a bath by themselves, they will eat without any assistance, and they will go out alone. With these children the everyday situation is totally different, they may reach the age of 30-35 even 40 and 50 and still us parents will always have to look after them for as long as we live, you always have a 'tail' following you everywhere. Your child comes with you at all times, no matter the age and you always call it 'child'. Now that I think about it I wish that the school program would find a way to add these aspects in the curriculum and teach them to our children. Not only for my child but for all the children' (I1)*

*'The school needs to work along with us. We learn something with J. at home, they should extend it in the classroom, they should always remind him what to do and how to do it. It is not easy it need planning and commitment, but that is what my child needs to lean. Because we have to face it...Socialisation... self-care...so many problems. And as the years go by and the children age you hope that some of the problems will find their solution but to be honest most of them never do' (I15).*

*'The first years were very challenging. Very difficult years, in the sense that it took a lot of effort and struggle to raise a child who needed you constantly there, around her, behind her, next to her. I wanted her to go to school and learn how to be independent, to be on her own at some level, in the least possible level. Everything K. does during the day has to have in a form of exercise and practice, has to be carefully planned. "K. spread your legs, straighten your arm", all the time because there were some things that only through repetition it was possible to achieve, the brain could not give the right instruction. She was sitting and standing in a wrong posture. I used to take her arm from the shoulder and push her so that she would understand and learn when she was little. And all my free time was for her and with her. But it is not easy, for someone who hasn't experienced similar situations it is difficult to understand me' (I6).*

The parents of MD young adults remember the period in the 80s before the law for special education initiated the creation of special schools and when the education of a MD child had the form of 'care' and 'safekeeping' throughout the school hours.

*'And you know what was the contribution of most schools back in the 80's? It was a simple baby-sitting, nothing more. Yes according to the law it was the beginning of special schools. But the program there? Nothing,*

*they gave to the children colors and waited for the day to finish. There was no educational program of any kind for our children. All together like a mess, all ages, all disabilities, and all abilities' (14).*

Parents couldn't identify any differences between then and today's situation. With the coming of special schools they described a similar, almost chaotic situation with 15 children together in the same classroom and only one teacher, even if the law strictly forbids that. Parents also commented on the renaming of special classrooms to inclusive without any further meaningful changes and differentiations.

*'Chaos yes, all children no matter what their personal needs or strengths were, all together in the same classroom. What they were doing all day there I still don't know' (15).*

*'The education is time consuming and soul-eating especially for us. We had two options either keep the child in the house, or keep them in the schools that the government is offering us. Have you visited these schools? Special they call them, and then inclusive they call them but they seem all the same to me. Nothing gets done. And how could something get done? Just because they have put new signs on the doors, with new names? Someone has to intervene, yes there was a time when I just wished for my child to be able to spend time out of the house but know I want more and I want for my child to progress, whatever this may mean, and for that to happen we need appropriate educational programs and goals and patience' (19).*

The educational objectives, curriculum and individualized programs compile an area where data proved to be insufficient in order to provide a clear image of the situation. The problem here is not centered in the interview questions or the answers of the parents but from their statements it becomes clear that parents were not well informed about the exact curriculum that was followed or the activities that their children were engaged within the school.

*'I am not sure what was the program like, I know that they had time to draw, play in the learning corners, they did some arts and crafts. These were things that I could see because sometimes J. used to bring them home, I am not really sure how many of these were made by him alone' (I15).*

In some cases the parents acknowledged that their priority was to keep the child in school and in achieving this aim they hesitated to challenge the educationalists' competences or question their program and goal setting, instead they felt that they needed to exhibit respect and trust in the educationalists' work.

*'I was glad that he wanted to go to school and to be honest I spent more time trying to make the teacher feel good about her work than ask what exactly they were doing in the classroom. I tried not to interfere too much' (I2).*

*'At the beginning of the year we had a meeting and discussed about the general goals that she had in mind for L. Mostly she wanted to make him feel good about being at school, help him meet other children and other children to meet him, from then on I am not sure how exactly, what they did, the activities and everything. I had to trust her because for the first time I felt calm' (I10)*

Parents who were financially capable offered to their children a variety of extracurricular activities and sports in order to provide to them all the activities that were not included in the school educational program: swimming lessons, dance lessons, theatre lessons and gym activities.

*'She was swimming for many years, ever since she was 5 years old. I used to take her to the swimming pool near our house until she was in the 7<sup>th</sup> grade at least 2 or 3 times week. She also had the opportunity to visit Sweden for a series of games and she loved it there' (I11).*

*'There was also a presentation in the same expedition where this choreographer presented his work and danced with my daughter. Danced...well, they do modern moves. When we went there I couldn't*

*believe my eyes. I told her 'my little girl' I can't believe you did all that with your body' and she is still trying, she is trying in so many levels' (I6).*

*'It was a wise thing that I have arranged for him in the afternoon psychotherapy three times a week... privately, outside of the school. At least we witnessed some progress' (I14).*

One final concern but maybe the highest up on the list was the professional rehabilitation and training of their children. Parents were afraid that their children will not be able to support themselves without the financial support from the parents and they wished that their children would be provided with the appropriate education that could allow them to develop skills in a specific area and maybe earn from these skills.

*'What she will do in the future I don't know, I know for sure that it will be very difficult. In the free market she won't be able to work. Where she will work then? This country is difficult. I would be very happy, if she would manage to go abroad even for a short while. I don't know. There is help abroad. I hope that she can leave for a while, I wish for it. It would do a lot of good to her. I also wish that she would find the opportunity and live abroad if there her life would be easier, I wish she could go' (I6).*

#### **4.6.4 Communication**

The issue of communication is high on the needs of children with multiple disabilities and it is considered a basic instrument for the development of social and cognitive skills for every child, as mentioned by almost all parents. It is well understood that MD children and adults experience difficulties in communication, communication as it is widely perceived, and it has been elaborated within the literature review that the establishment of any form of communication is a sensitive matter which needs to be addressed and dealt with from the very early years of a child's life.



*'When she was away from the house and in school I was very worried mainly because I couldn't imagine how it would be possible for him to express his needs. The teacher had to find a way to understand him because his communication skills are very underdeveloped. He has his own ways. But how could he be a part of what is going on if he couldn't understand and no one could understand him?' (I1).*

*'I believe that from the kindergarten and even before this should have been the key aim. Learn and use different ways to interact, approach other children, talk' (I2).*

In the parents statements it was clear that they placed the responsibility of the communication gap as a problem within the child and there was no mention concerning the efforts made by the school, themselves or the experts to establish a communication code with the MD child or adult.

*'No my child could not attend a public mainstream school, not in our circumstances...she couldn't communicate with anyone' (I10).*

*'But J. couldn't speak at all; he could not communicate at all. He was accepted by his classmates but the teacher made it absolutely clear that there was no meaning to keep him in the school. He couldn't understand anything. He was in the classroom but couldn't do anything at all' (I15).*

*'I know that my child cannot communicate, in the house we have created some codes, signals to communicate but not so much verbally. He uses some signs, points to things and it is easy for me to understand what he wants depending on his mood, but this is with me, I know that this cannot apply to a classroom. He has problems in this area and it is hard for the teachers to approach him and understand him' (I14)*

Parents discussed how the program of the school and the attitudes of all involved did not provide opportunities to overcome communication obstacles or work together with the child or young adult in order to establish alternative forms of communication but at the same time continued to put emphasis on the fact that their children always had difficulties in getting their messages across.

*'I could see that he didn't fit in, he couldn't speak well he couldn't understand well, he didn't communicate. He needed water and would choose all kinds of crazy ways to show it but no one could understand him' (I12).*

*'She was a good person and good with him but she could only do as much. She tried her best. She told me 'madam he doesn't understand, he can't follow up, it is only bad for him, and you should take him from this school' (I6).*

*'I can't think of anything, partly because I was not in the classroom and partly because deep down I knew that it would be very difficult for the teacher to communicate with him, the problems were too many' (I9).*

*'The only thing I can say is that I was not always pleased with how she (the educationalist) dealt with things. She used to tell me that the other children avoid him (my son) and that he also does try to approach them, but I used to wonder: 'Someone has to teach them how to do that, how to communicate', I know it is hard and I am aware that my son has many problems in that area but still I wish they could have done more' (I11).*

Furthermore the educationalists are exonerated by the parents on the basis that they haven't received appropriate and specialised training in meeting the communication needs of MD students. The failure of the teacher education system in providing opportunities for educationalists to experience in practice the demands of an inclusive or a special education classroom was reflected in the educationalists' discomfort and lack of confidence in accommodating their children.

*'Creating codes of communication is the first step. I am certain that teachers knew that, but I am not sure if they also knew how to create them' (I3).*

*'You really believe that all these teachers had prior experiences in educating a child with multiple needs. We are with her in the house all day and still trying to find ways to tell her something or wait for her to answer something back. For a teacher that doesn't know how, was never guided, didn't have the time to practice on how to deal with children like ours I know that it must be much more difficult' (I4).*

*'I could see that she was scared of him, she didn't have the confident to try new things, to come closer to him' (I5)*

The issue of restricted school time also made an appearance during this section. As parents were already aware, it takes time for children with severe disabilities to react to a certain incentive and it needs time for their interlocutor to wait and respond to their reaction and this luxury of time was not always available in schools.

*'She had six more kids in the classroom and she told me 'Even if I want to there isn't enough time in the day to deal with each child in the level that I want to' (I 13).*

In addition there is the issue of parents-educationalists cooperation which remains a lost opportunity during the efforts for the establishment of communication codes.

*'I am not saying that I have all the answers, but now that I think of it maybe I could also have helped her in communicating with my child, I wasn't asked to do so but maybe if I had offered some information about how we do it at home she (the educationalist) could have taken it from there and in the meantime help us also in the house, if she could manage to develop the skills that we had already been working on as a family' (II).*

As a final point, two mothers deciphered the connection between the communication gap in the classroom and the exhibition of aggressive and frustrating feelings from their children to the educationalist and finally the inhibitions of the educationalist to persist towards establishing any form of communication.

*'It is not that the teacher didn't try, I could see her (the educationalist) approaching her (my daughter), trying to hug her, rub her back, touch her but my daughter was very aggressive and angry at points, she has difficulties connecting. At the same time this aggressiveness made the teacher reluctant to proceed and so on...' (I5).*

*'When you are not a part of what is going on you get angry and hostile and when others see you hostile they don't come near you, that is our case, that is what happened' (I7).*

#### **4.6.5 Cultural**

The families of MD children and young adults have experienced exclusion and rejection from schools. Children with severe disabilities were not welcomed or supported by the educationalists or the school leadership. Parents described situations where they had to endure reactions of pity, judgment and fear from the school environment.

*'I will tell you just one of our stories. A day when my blood pressure got so high from anxiety that I could die and I don't suffer from high blood pressure. After the special school I could not find a way, I was going from one school to the other and no one would accept him. In the first school they told us that L. was a child with mild disabilities, in the second they didn't have empty spaces, in the third he was considered a severe situation, in the fourth they told us he had severe ADHD, I didn't know what to do. I was doing everything I could in the house so that I would improve him but outside of the house no one wanted him' (I2)*

*'It is so sad but I could see it in her face, the fear and the pity at the same time. First time we took her to school, before they had the time to even spend a minute with her, give her a chance' (I8).*

*'We did the whole walk of shame, from one classroom to the other, then to the principal's office. Every time I had to tell our story all over again. Do you know how tired I am of telling this story in order to convince people to accept my child and to feel judged by their body posture alone?' (I14)*

*'When I talk about my child it is not uncommon to break in tears, as you witnessed already, but when I visited the school I tried so hard to resist. I*

*don't want anyone to feel sorry for us because we love our child and we are doing everything we can and then even more, we are pushing her, we are training her, we are preparing her and when we visit the schools we ask for what is her right, to be in school we don't want for them to feel sorry' (I10).*

The importance of positive experiences and the need for improved teachers' education was once again an issue raised in the parents' interviews as a way of influencing attitudes, values and beliefs and challenging the existing system of values and ethics within the educational system.

*'Our teachers need to be trained and educated not only through books and exams but also through their minds and souls. Our children are different but they are not weird or sick and we trust the teachers to take them out of the house and treat them with decency and love. If this is something that it is not taught in the university then it should be added' (I13).*

In other cases even when the educationalists would agree to support the students, new upheavals were created by the parents of typically developed students who resisted in the idea of a MD student being included in the same classroom. Parents of non-disabled children expressed fear and aggression. They were afraid of the impact that the presence of a MD student would have on their child's personality and progress and requested their exclusion. As it was also elaborated in the introduction chapter culturally the Greek system has not yet succeeded in implementing the social model of disability either in policies or in the cultural perspectives of the people. Society still presents beliefs and stereotypes that remind us of much older times where the prejudice and superstitions prevailed over the logical and social aspect of disability understanding.

*'They were playing in the yard with the children of the mainstream classrooms during the break time and that cause nothing but trouble. The other mothers used to complain and asked us to take 'our crazy ones' away. It took many efforts until we managed to reach a level of understanding. We the parents had to prove that our children are friendly they are not mean, they are children' (I11).*

*'In the parent-teacher meeting of the first public school a mother approached me and told me: "Your child cannot learn, your child is threatening the lives of our children. Do us a favor and leave our children alone, they are young and they could easily learn to behave the same way as yours''. As if our children carry some disease that other children might catch' (I4).*

The provocative behavior of the classmates against their MD peers and the use of pejorative expressions were also challenging and appeared more escalated in younger ages. The parents were well aware of how erroneous this rejection was but in their majority they preferred to withdraw their children from the negative environment rather than sustain and fight towards the change of attitudes in the school environments.

*'At that time I was more concerned about my son's wellbeing, so my first instinct was to change schools immediately' (I9).*

*'Of course we could have stayed and tried to change things, but for how long? And in the expense of my child I am tired of fighting others. This is not a fight that I should give alone' (I7).*

Parents continued to explain that they did not accuse the classmates but their family and social environments' understanding of disability. Children, especially in younger ages, learn and create their attitudes and personalities through the ethical stimuli that they experience and by imitating the reactions of their parents and others around them. Parents, based on that hypothesis, expressed the need for awareness programs for all parents in disability issues.

*'A child does what he is taught. If you see your father giving money to a disabled beggar you will learn that you have to pity the disabled. If you see your father making fun of that disabled beggar you will learn that you have to mock the disabled. If your father calls you retarded because you spilt a glass of water, then you will know that retarded is a course word. It is all there, all the stereotypes. We all need education' (I11).*

*'What I can see is that things haven't change. We use new words and we are more careful when expressing our feelings concerning disability but some things are deep rooted, a kind of inheritance from one generation to the other, the cruelty has always been a part of our lives. But at the same times we know more things and every one should learn them as well, what is disability, how families with disabled children live every day, what we need from others, how we want to be perceived' (I15).*

Two mothers decided to support their children when these incidents took place based on the fact that negative behavior from others will be at sometimes part of their lives and therefore it was necessary to develop skills in dealing with similar situations.

*'During primary education when children are younger they used to be a little provocative towards her, they were more tough. But again back then it was something that she had to learn how to live with and she was ok. I would talk to her and she was ok' (I6).*

#### 4.6.6 Health Care and provision

There has been mention during various sections of this thesis that in Greece the idea of the medical model of disability is still very strong in the way we understand disability. In this sense even though we should anticipate that the educational and social provision for disabled children is very weak, at the same time we would anticipate that the care and health provision would be designed in detail and implemented effectively. From the interviews with this group of parents one main conclusion is that the care and provision for MD children and adults is practically non-existent. The system has failed to provide for their children equal learning opportunities or a decent welfare provision.

Parents narrated different stressful incidents in the encounter with the state mechanism. Families of children with disabilities mainly deal with two state organizations: IKA and CEDDAS. IKA is the largest Social Security Organisation in Greece. It covers 5,530,000 workers and employees and provides 830,000 pensioners with retirement pension. IKA also covers the medical examinations, medication and is responsible for providing allowance to the people that are entitled to one - this wide group includes disabled people ([www.ika.gr](http://www.ika.gr)).

*'Social care is just a euphemism, care is a euphemism, because when someone cares the main priority is to make the people that need you comfortable, the idea is to make the procedures quicker and simpler not create more trouble when there are more than we can take' (I3).*

*'No one can depend on the state and the welfare, if you want something done do it yourself and go privately' (I1).*



Parents were offered by IKA a welfare allowance of 500-600 Euros per two months, but in order to receive this amount of money the family and the child had to endure a series of bureaucratic and medical examinations every six months. Parents justified the negligence and indifference of the IKA employees based on the supposition that they were earning poor salaries and that no one in their place would be disposed to spend time or effort to help families and children.

*'New parents with a child with multiple disabilities who believe that IKA will cover for all the needs are simply delusional. No one cares. The psychologist or the neurologist in the public hospital couldn't care less. I have tried asking for this kind of public help for years. Yes even in the centers of mental health that were supposed to be responsible for these children. There are very polite some times but they just don't care enough. And why should they? Their salaries reach 500 or in the best case 600 euros per month. It is only natural that they will not sit with my child and preoccupy their minds the whole 6 hours per day with children like my daughter. And even if they want to help, it is not enough. My daughter won't get better we one session per month. It is impossible to book an appointment and sometimes you are like if you manage to book an appointment for after one month' (I14).*

*'And I have an advice for you. Keep doing what you do but go work in the private sector. There you will find the money, loads of money. And you will be able to do your work and help the most fortunate families who will be able to afford you because in the public sector these kinds of jobs don't pay enough. And people well trained don't do their jobs' (I5).*

The queues in the IKA institutions were long and the waiting was exhausting, especially when accompanying a child that was easily frustrated. As a consequence parents chose not to use public services of this kind if they could afford alternative routes, in an attempt to spare themselves of the humiliation and exhaustion of these procedures.

*'If you can afford it then maybe you can find your way around things. If not then you are doomed to wait in lines in the public centers. Go from one public centre to the other and still no result. The public sector has nothing to offer, nothing that we as parents can use. We tried using IKA... chaos' (14).*

CEDDAS on the other end, according to the parents' statements were understaffed and unorganised. CEDDAS are the centres for diagnosis, evaluation and support for disabled people and their families, at the same time they provide services for the awareness of parents, teachers and the society in general on disability issues ([www.kday.gr](http://www.kday.gr)). The means and assessment procedures vary depending on the abilities and needs of each child. Parents again referred to the many school years that their children had to miss due to the delays of a diagnosis. Moreover, whenever parents were offering to share their insights and experiences on the matter, concerning their child and the observations they had made over the years, the experts refused to listen.

*'I, alone, after many attempts took my child to yet another child therapist and he finally agreed with me and we got some answers. He didn't know exactly what; at least he admitted that something was wrong. The official diagnosis came years later and the problems were more than one' (115).*

*'They humiliate us and our children every day and in every way they can. Every year twice a year sometimes M. has to go through a hearing to typically monitor her progress and allow her to be enrolled in a special school. What do they think that will change every 6 months? My child will miraculously be able to walk properly or her mental retardation will magically vanish? Or I should prepare and provide them with a long speech about her progress? The only thing that they accomplish with these hearings is to humiliate us once again, to make my child anxious and stressed. This is not fair; this isn't how things are supposed to be. So they can keep the allowance away from us and the schools locked for my child, I am giving all this up, it is not worth it in the end' (19).*

Complaints concerning the diagnostic centres came from parents both of young adults, before the establishment of the CEDDAS centres, and from new parents. Older parents blamed the lack of experience of the experts back then and the younger parents the slow and long procedures today.

*'Instead of working with us, they are still competing us' (I10)*

*'Maybe things have changed, we just can't see it. We were here when we didn't have CEDAS and we are still here now that we do, and again all we do is wait for a piece of paper' (I8).*

*'The name has changed for sure (from CEDAS to CEDDAS) but other than that what else? Now they have a teacher involved and a social worker and a psychologist, for most of them it is their first year as working people, they cannot have the experience or the expertise needed to access the various needs of our children. We go there to get some answers and because it is our ticket to get special teachers in the schools to support our children' (I2).*

The legislative system even though is intended to support families in reality it fails to provide the framework for practice.

*'Laws, legislation? We found our way alone. It was the wise thing to do. So the government composes laws, do they act on them? For us nothing works. Maybe if you ask younger parents who are now at their beginning, see what they are going through' (I12).*

*'We had many expectations and we helped however we could. But now I am afraid. I am afraid about the future. I am afraid about the many different problems which still wait to make an appearance. (...) My son needs education, needs training, needs sexual education. Again this is something that in the end I will have to deal with alone. I can't leave him like this. I have to try and explain to him everything, find him a girl. Who else will? And if I don't do it then more problems will come and I can't deal with them alone. I will do it. It is so cruel for a mother to go into this procedure for her son. I will do it. What else is there to do? Do you understand? It is a constant fight with everything and everyone' (I7).*

This section will conclude with the parents' declaration of how they came to learn and examine closely all the laws and policies that had any benefit for them or their children. Even though throughout the years they came to realise that the practical implementation was of minimum use to them.

*'We now know more than the experts' (I1).*

*'I am positive than if there was a knowledge competition between us parents and the policy makers we would win. I can recite by heart all the legislation documents concerning the education and the allowances. And it comes in hand to because you will always find someone to tell you: 'The law says...' so we have to be prepared and aware of what exactly the law says' (I10).*

Parents still continue to follow any new government enactments that might be of use to them. An example comes from two mothers who were informed about a government announcement of a new provision entitlement for the families of children with severe disabilities, a financial aid: discount to the cost of utility bills. But, as they came to realise while attempting to claim this discount, it remained in the discretion of each municipality jurisdiction whether to accept the offer of this aid to the citizens or not.

*'The last we heard for the state came to us through the school. There is, they say, a decision from the ministry based upon which, the families of children with disabilities can address to their municipality and if the city council decides so and accepts we can then get a 50% discount or a total exclusion in the fees we have to pay for our municipality I know many municipalities that have made this demand possible. Where we live in the centre of Athens still nothing' (I13).*

*'I am trying to contact the ones responsible for months now. I have been living in the same area for years. It is a huge municipality I recently received a letter stating that my demand cannot be granted because they first have to conduct a board meeting to discuss it. I am repeatedly asking*

*to meet with the mayor, who I have voted for many times in the past, why should I hide it? But even so, no one has accepted to meet with me, so what is it that we are now discussing'? (16).*

#### **4.6.7 Financial**

All of the parents referred to the huge financial burden that they were bound to endure. The main reason why expenses were so high, according to the parents, was due to their children's health problems and multiple needs. MD Children and young adults needed support on various levels and that was immediately translated in specialists' fees, doctors' fees, treatments, extracurricular activities, transportation and so on. The reason why this burden fell on the parents was due to the failure of state care mechanisms to provide meaningful financial support to the parents.

*'So many years we are spending so much money for her, for her education for her wellbeing. Years and years they have financially drained us. If a parent has a huge financial problem when a child like this comes to the world then god help him. We cannot expect anything from the public sector, nothing comes for free and if it does it is not worth it' (113).*

*'I try to keep him busy all day, therapeutic theatre, gym. I am so tired to drive him around all day and pay, but he likes these activities so much that I can't do otherwise' (17).*

Twelve of the parents mentioned IKA as a highly unhealthy and dysfunctional organisation. Parents had experienced long hours of waiting in their attempt to use the public services, especially when accompanied by a child. In order to book an appointment for a visit to a doctor or an expert in conciliation with IKA time and patience were needed and according to the parents both these elements were considered a luxury in the hectic rhythms of their lives. The services provided by

IKA were mainly free of charge except from a small contribution fee. But in practice it was impossible to rely only on IKA to receive the continuous treatment needed by a MD child on time. As a result the parents could not practically use this kind of services because it interfered with their child's health and progress.

*'If you can't afford to help your child alone, you are finished' (I4).*

*'To tell you the truth our generation had to put their hands 'deep in the pocket'. Only with money you could receive a decent care, treatment, diagnosis, education' (I2).*

All parents brought up the allowance of 500-600 Euros per two months, an amount that could barely cover transportation costs.

*'I know that you can pay and get your job done, it is the only way. No state help, nowhere. Oh yes they provide us with an allowance. Every two months from the welfare. It is considered a privileged allowance. You know how much they price us? 500 Euros per two months' (I12).*

Parents, who could afford to, provided private medical and expert services for their child and chose to use individually paid professionals. Parents who could not afford to pay for private services were desperate to be heard, hoping for a change and still waiting in lines.

*'Financially we can't afford the whole procedure, we are doomed to use the public services, it is the only way we have. The parents that have other options are the luckiest ones among us all' (I15).*

*'I have to pay 55 Euros per hour for an expert. I will and I am happy to do it if that will help us, as long as god gives us money to be able to afford it' (I6).*

*'If you don't pay privately and you find yourself running from one public centre to the other and there only once a month you can find an appointment with the physiatrist. And my child did not a physiatrist, she needed psychotherapy. And there in the public centre they would prescribe pills. We didn't want to give her pills we needed her to fight and live without them and improve' (I10).*

*'I will take my son everywhere, to the restaurants, to the theatre, to the cinema, even when I don't feel like it, even when I am not in the mood I would take him. I want him to know the world, not to be afraid to leave the house' (I1).*

Ten of the interviewed mothers explained how they were trying to cut down all 'unnecessary' personal expenses in order to provide for their child.

*'There is nothing. We are the ones that we have to protect our children. We are the ones that have to manage some way to gather another extra 1000 euros per month in order to provide for our disable daughter. And these 1000 are only for her educational, personal and training sessions. We have a whole house to run and another child to look after. And I am asking myself what will happen one day when all our savings are gone. What happens to all the other poor children and parents that don't have any money'? (I11)*

*'And it isn't only the child. We also need help, psychotherapy, because you have to work with yourself as well. And there the public sector has nothing to offer. We used to go to meetings as a family but now we need to cut down expenses and this is the first to go' (I.3)*

One mother during our discussion and in the frame of this topic pointed out the danger of exploitation and manipulation by non-certified structures and institutions promising cure in their effort to offer the best of their child. She specifically referred to a promising program which she took part in France based on classical music therapy. In the end of the program the child didn't show any signs of progress and instead it had a bad impact on the family's stability and economical budget. Another

program in Hungary was mentioned by a mother who explained that they were promised that this program would help the child to get better, gain function of his legs and be able to adjust to the demanding environment of everyday life.

*'When there is no guidance everyone can take advantage of you, especially financially. Like last year we took her and travelled to France, there was supposed to be there an acoustic therapy with classic music. We went there because we are trying everything we can. By the end of it we realized that it was just a profit based business, It harmed us more than helped us. L. was frustrated, the situation in the family got worse, because when we returned the relationship with her sister got worse. She got used to having me all to herself and when we were backing home she didn't want her sister, she was jealous. And it cost us a fortune' (I3).*

*'We flew all the way to Hungary, there is this program there, I don't remember the name of the institute, the promised us everything and the result was that our child became so aggressive and so upset even with us. It was a huge step backwards, we had as a family to gain his trust from the beginning. They pressure him so much to become someone he is not there, how could I believe it I don't know, it was my idea from the beginning' (I9)*

Most parents placed their future hopes in securing a place for their children in an independent or semi-independent living home. The expenses are demanding because the parents need to make donations, support the construction and provide the equipment for these homes long before it is time for their children to move there. Nevertheless six of the parents stated that they were trying to raise the funds to complete these housing structures because they felt that it was their only guarantee of providing for their children the care they need in the future.

*'In the school that we are now I have applied for M. to get a place in the autonomous living house. One house is now complete and already functions and we are waiting for other two to be completed. S. is in the waiting line for the second house, I don't know if I am doing the right*



*thing, maybe it is too soon. Based on his age too soon I mean, S. is turning 28 this June' (I3).*

*We have the obligation to prepare for the future. We have to find S. a house to live on her own (of course with the help of specialists). I am afraid of the future. I can't leave S. as a heritage to my other daughter when I and her father are long gone, it is not fair. I didn't bring my other daughter into this life for her to carry my burdens. I will not accept this to ever happen. I have to find a solution for S. I have to save some money to leave for her, so that we can find her a place to stay. I am 56 now and since I am still able to fight for her I will until I find her a place in a home. I want her to be ok, to be happy. It will be very difficult for me to let her go but at some point I have to, she has to be prepared. I have to find a way to leave her in good hands' (I4).*

#### **4.7 Findings presentation: Opportunities as presented by the interviewed parents**

From the interviews it became clear that any opportunity was emanated and based on personal initiatives on behalf of the parents. They were the ones who had to be responsible for any change and improvement of their children's lives, responsible to discover solutions and to pay individually for their training, education and care.

As 'opportunities', parents identified directly only the educationalists. Parents expressed feelings of gratitude for all those educationalists during their children educational course that were willing to put effort into their children's development and progress.

*'After so many changes when we visited the third school for the year we found Ms. S. she was a different teacher, she went close to J. and started talking to him and immediately after that she addressed to me and asked for my advice. I wasn't used to similar approaches... I felt that this might be our chance to find a place for my son' (I15).*

It is interesting though how parents provided descriptions of the educationalists based mainly on aspects of their personality and less on characteristics based on their work as professionals.

*'She was a good person and good with him' (I2).*

*'She has a teacher that loves all children very much, she gathers all of them around and tries to find the best for them. What they like, what they don't like, she is trying to build friendships and relationship amongst the children. Amazing human being' (I1).*

*'His teacher, she was a good and kind person and that is very important' (I4).*

*'When you say 'thank you' to these people you mean it. 'Thank you'... no one has the obligation to endure, for the money that are being paid by the state, my daughter's fits and nervous break downs. And when I say thank you to these people I mean it because what they are doing is above a simple job. And if you ask me they should be highly paid, they give their souls' (I8).*

*'Such a caring person, she was always polite to us and gentle with our daughter, I thank her for that' (I3).*

Moreover, parents fervently pursued the cooperation with the educationalists and trusted that if given this opportunity the school life of their children would be improved. Parents held important information that upon sharing could facilitate communication and interaction between educationalists and their children. Also, parents needed to be able to discuss the progress of their children with their teachers, be aware of the objectives set in school so that they would be able to work in similar directions in the house.

*'It is a matter of both sides, parents and teachers. We have to be able to work side by side if we both want the best for the children. The teacher knows the child at school, we know the child everywhere else. Imagine if all the information is combined and we sit down and make plans together towards the same aim' (I3).*

*'We don't ask for opportunities only for our child, we also need to be granted the opportunity to be a part of their life in the school. As I told you many times, I came to know things, I can say that I have become an expert of some sort... an expert on my child. If educationalists are willing to cooperate I truly believe that this will have an impact on the education offered to my child' (I10).*

#### **4.7 Findings presentation: Recommendations as presented by the interviewed parents**

Even though parents did not proceed in expressing direct recommendations and propose specific changes in a direct manner, nevertheless when reading between the lines of their narrations a list of proposals is pervasive. Within the interviews there was a wide manifestation of opposition and disagreement with the educational and social provision available to their children and an expression of a holistic reform necessity concerning the legislation on education and its implementation in practice, the care and health provision system and a request for awareness programs and changes in the way we view and understand multiple disability. Moreover, parents demanded the creation of public and free for all independent or semi-independent living structures and the formation of public multidisciplinary centres for the training and therapies of their children. To conclude, parents raised the need for a quality teachers' education in disability issues and periods of practice in inclusive or special education settings prior to their employment.

#### **4.7 Summary of main findings**

The overall picture from the first phase of the research reaffirms the concerns expressed during the introduction of the study and the literature review concerning the education of MD students in Greece. Parents were asked to narrate personal ingrained stories concerning their efforts to secure access in quality education for their children and during this procedure they illustrated, through their experiences, the difficulties and hindrances concerning the education provided for MD students and the quality of this education. The stories provided by the parents revealed similarities in the ways

they experienced the struggle in securing an appropriate educational placement for their children and supported the illustration of the current general image of the educational and other opportunities provided for MD children and adults in vivid but not optimistic colors. To recapitulate the key findings of the data presentation the following synthesis table (Table 2: Findings of the first phase of the study synthesis table) was created:

Challenges
<p><b>Bureaucracy</b></p> <ul style="list-style-type: none"> <li>• Delays of up to one year in the diagnosis procedure due to lack of structure and organization, lack of trained employees. As a result valuable educational and personal time gone wasted.</li> <li>• Delays in the recommendation of appropriate educational settings.</li> <li>• Delays in preparing and equipping the educational settings.</li> <li>• Delays in assigning special educationalists in the schools.</li> <li>• Exhausting assessment and repeated assessments of the children without specific aims, objectives and methods.</li> </ul>
<p><b>Structural</b></p> <ul style="list-style-type: none"> <li>• Exclusion from the mainstream public school structures of their neighborhood</li> </ul>

based on inaccessibility, limited resources, untrained teachers and the concern of the non-disabled students' progress.

- Exclusion from the special public structures based on limited spaces available and children's assessments.
- Exclusion from private school structures based on safety issues.
- Hostile environment in terms of access and utility: small rooms, not properly cleaned or maintained, limited variety of educational materials.
- Responsibility re-directed on parents to privately seek and pay for out of school educational structures and activities for their children.
- Absence of a multidisciplinary public centre.
- Most of MD children and young adults whose parents participated in the interviews are now placed or will soon be placed and educated in private workshops and daily care centres.

### **Pedagogical**

- Educational programs and activities are not differentiated appropriately in order to meet their children's needs and feel equal and included as their classmates.
- Lack of a differentiated curriculum.
- Lack of specific aims and objectives.
- Lack of trained teaching assistants and special education staff assigned by the state. Personal family expenses for hiring private teaching assistants.
- Absence of individual programs, aims for each student, progress reports.
- Initial high expectations on the part of the parents regarding their concern for

their children to acquire plain academic knowledge, learn to write and read.

- Low expectations on the part of educationalists leaving the students without motive and self-esteem.
- Lack of professional training programs for disabled people.

### **Communication**

- The experiences that the parents shared concerning communication issues were based on the model of personal tragedy, it is the child the one who lacks the skills to communicate and the responsibility falls on her/him.
- Educationalists need to be prepared and gain confidence during their studies in meeting the needs of multiple disabled students and using alternative communication systems other than speech and this can be accomplished through practice exercise in inclusive or special classrooms.
- Lack of cooperation between parents and teachers which could create a network of information exchange, support and further progress in the communication area.
- Parents linked the communication gap in the classroom with incidents of aggression and frustration on behalf of their children, leading in the teachers' reluctance to develop communication.

### **Cultural**

- Rejection from the educationalists.

- Aggression and fear from the parents of non-disabled students.
- Provocative and hostile behavior from the non-disabled peers to the MD students.
- Parents were exhausted from fighting hostile attitudes and chose to withdraw their children from the negative environment.
- Parents expressed thoughts of disappointment for the unchanging Greek society and the prevalence of prejudice and stereotypes within the schools.
- Two of the parents took the opportunity to prepare their children for dealing with similar behaviors in the future.

### **Health Care and provision**

- The main conclusion expressed by the parents themselves concerning issues of educational policies and provision was that that health care and provision remains practically non-existent.
- In order for families to receive allowances and state services both the family and the child had to endure a series of bureaucratic and medical examinations every six months.
- Parents did not blame the employees in the state organisations, they considered them overworked and underpaid.
- The queues in the care and provision institutions were long and the waiting exhausting. As a consequence parents chose not to use public services of this kind if they could afford alternative routes, in an attempt to spare themselves of the humiliations and exhaustion of these procedures.
- A gap was highlighted by the parents between the voting of new laws which



aimed to promote the rights of their children and their actual implementation.

- Lack of much needed information: parents themselves had to research and guide themselves through the policies and the provision that they could demand, years of practice and search has made them experts.

### **Opportunities**

- Mainly based on personal initiative and personal financial sponsorships.
- Those educationalists who welcomed their children in the classroom and made an effort to include them, support them and meet their needs, regardless if this attempt was successful or not. Parents expressed grateful and positive feelings for those teachers.
- Close cooperation with the educationalists and information exchange.

### **Recommendations**

- Society needs to be aware of the problems that parents of disabled children and adults face daily and needs to adjust to meet their children's needs.
- A holistic reform of the educational and social care system aiming to include and meet the needs of MD children.
- Schools and all their participants: educationalists, students, parents need to be educated concerning disability issues.

- Educationalists need training and practical experience in order to prepare themselves and be able to include equally MD students in their classrooms with consistency and confidence.
- The state needs to provide accessible and fully equipped educational structures to accommodate MD students.
- There is an urgent need for multidisciplinary public centres for multiple disabled students to attend after school. There a group of experts: special teachers, physiotherapists, work therapists, psychologists, physical exercise teachers, speech therapists and so on will be able to collaborate towards setting specific progress plans for each child, reevaluate the aims frequently and cooperate with the parents.
- There is a need for the creation of public and available to all independent and semi-independent living structures.

**Table 2 Findings of the first phase of the study synthesis table**

In this part of the study the aim was to investigate the experiences and views of parents of MD children and young adults on a personal and individual level. Fifteen parents were invited to share their experiences and their efforts to include their MD children and young adults in the existing educational system. The parents elaborated on the challenges and they proposed possible resolutions of the existing problems, thus forming a lucid and coherent image of the current situation on multiple levels and creating connections between different issues that lead to the exclusion of multiple disabled students from the educational system. The sample included 15 mothers, in two interviews the fathers of the children participated briefly in the discussion, living in the area of Attica-Greece.

In the following stage of this study the same subject is being approached through a different perspective. At this point members of the administrative board of parent associations for people with severe and multiple disabilities from different geographical areas of Greece are invited to share their views concerning the education multiple disabled people in Greece and their own actions towards the promotion of their equal rights in education and social life.

# CHAPTER FIVE PHASE TWO: METHODS AND FINDINGS

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## 5.1 Introduction

This chapter describes the second phase of the study undertaken with the Parents' Associations for severely and multiple disabled people. During the first phase of the study the data collection was based on interviews conducted with parents of MD children and young adults. In the interviews the parents discussed their experiences concerning their children's education in terms of the structural, pedagogical and bureaucracy obstacles, the care and provision and the financial difficulties affecting their children's education, the difficulties in communication between MD students and the school. In addition the parents proposed their own solutions and recommendations towards change and the inclusion of multiple disabled students in the educational system. The analysis of the interviews data aimed to present the way that parents experience the school years and their efforts through an individual perspective and to illustrate how each family alone is trying to cope with the challenges of the Greek education system.

At this point of the research a different scope was adopted. The focus in this part was to investigate how PAs collectively promote the rights in education for multiple disabled children and adults. The Federation of Parents and Guardians Associations, a fundamental supporter of the disability movement in Greece, focuses on the promotion of the rights of severely and multiple disabled people (FPGA for SMDP) therefore it fulfilled two purposes, firstly to examine in more breadth the views of

people who have formed parental groups to promote the rights of disabled people and support their families and secondly to shed some light on the purpose, value and work of PAs for multiple and severely disabled people in Greece. The data collected through the questionnaires assisted in adding to the information provided by the parents through the interviews, in highlighting the similarities or differences in views and perspectives concerning the most suitable educational setting for MD students as well as the obstacles faced and the solutions provided during the educational course of MD students. In addition the PAs representatives were helpful in moving our knowledge further by providing answers regarding to how exactly can parents participate in the decision making procedure in order to promote the rights of MD children and adults, whether the idea of inclusion is possible for MD children and adults according to the PAs representatives' perceptions and how is the term multiple disability defined and perceived by members of the disability movement.

## **5.2 Selection of Parents Association for disabled children.**

FPGA for SMDP provided a list of one hundred and eighty seven (187) registered parents associations for severely and multiple disabled people in Greece. A survey approach was used to provide an overview of the aim, responsibilities, values and practice of the PAs. At this point it should be noted that the questionnaire was addressed to the total population of the 187 Parents Associations in an effort to include all the geographical areas of Greece (for a map of Greek geographical areas please consult Appendix 5). More specifically the sample included parents associations in: Attica (n=56), Crete (n=6), Cyclades (n=1), Dodecanese (n=4), Epirus (n=6), Ionian Islands (n=4), Macedonia (n=69), Main Greece (n=12), North Aegean Islands (n=3), Peloponnese (n=14), Thessaly (n=8) and Thrace (n=4).

## 5.3 Questionnaire

The use of questionnaires was a relatively flexible research tool which allowed data collection from all the parental associations in Greece, comparisons between the associations, investigation of the purpose and aim of their formation, details concerning their demands, actions and struggles with emphasis on their positions concerning the educational provision for children with multiple disabilities.

### 5.3.1 Pilot study

The questionnaire draft schedule was piloted with a father, president of a Parental Association for children with learning and multiple disabilities in Attica, who agreed to help by completing the questionnaire. His contribution was highly valued as he commented on the length, the type and essence of the questions, the phrasing and the vocabulary used and allowed for changes before addressing the questionnaire to the main participants.

The time for the completion of the questionnaire was 15 minutes. His first comment, and the one that he insisted upon the most, was to use only the terms *disabled children* or *children with disabilities* throughout the questionnaire. In this first draft of the questionnaire the terms '*children with special needs*' and '*disabled children*' had been used interchangeably in an attempt to include all the different terms that parents may use. He explained that most parents involved in PAS if they see a reference to their children as having 'special needs' they will be insulted and maybe even refuse to complete the questionnaire. As he further elaborated parents consider the use of the

term '*children with special needs*' a form of euphemism to cover the fact that it is society that disables the children. Therefore, the first change in the draft was to replace the term 'special needs' with the term 'disability', a decision not based on the attempt to be 'politically correct' but as of respect for the parents to whom this questionnaire was addressed to. His long experience in the disability movement provided the inside information needed to complete, add or change questions. Most of his comments were driven from a need to understand the underlying meaning of the questions, for example the use of a question referring to the financial participation of parents in order to support the function of the associations drew his attention, it was then explained to him that the questions were interconnected and presented in a form which would allow the research to collect all the different data needed to draw meaningful conclusions and the aim was not to judge the actions of the associations or to interrogate the participants. This meeting lasted almost three hours by discussing the purpose and the value of each and every question in great depth and proved helpful towards constructing the final form of the questionnaire.

### **5.3.1 Construction of questionnaires**

The pilot interview provided useful information for the finalization of the questionnaire. In order to obtain the necessary information from the participants the questionnaire was divided in four general areas of interest (please consults Appendix 6 for a sample of the questionnaire):

- ✓ General Information (gender, age, profession, nature of their children disability, position in the association: Q1-Q5)

- ✓ Information concerning the specific parental associations for multiple disabled children and young adults participating in the survey (location, year of foundation, number and category of registered members, promotion, subscription, purpose of foundation, specific actions: Q6-Q14)
- ✓ Information concerning all parental associations for multiple disabled children and young adults (sufficiency, communication and cooperation between associations, accomplishments, level of influence: Q15-Q21)
- ✓ Information concerning multiple disabled children and young adults and the associations' support towards promoting their rights in education (appropriate educational setting, the challenges for multiple disabled children and young adults, the level of their rights being met in Greece, actions of the associations promoting the rights of multiple disabled children and young adults in education, definition of multiple disability and reasons for using a specific one: Q22-31)

The questionnaire included thirty one (31) questions, twelve (12) pages in total. To be more precise the final form of the questionnaire included:

- ✓ twenty three (23) closed ended questions, in order to reduce the amount of writing required and the time needed to complete the questionnaire to the minimum level: dichotomous (Q1, 4a, 12a, 15, 16a, 18a, 22a, 27a), multiple choice (Q2, 6, 9, 10, 13, 21, 29), Likert scale (Q11a, 17a, 19, 25, 30) and rank order (Q14, 24) and;
- ✓ eight (8) open questions (Q3, 5, 7, 8, 20, 23, 26, 28) where the respondents have the opportunity to answer in an unlimited number of ways and the researcher to collect more in-depth and detailed information;



- ✓ In addition the Questions 4b, 11b, 12b, 16b, 17b, 18b, 22b and 27b, provide space for the participants to justify their dichotomous, Likert scale and rank order answers.

All the questions included in the questionnaire were interconnected and aimed to extract the information needed to form conclusions on various levels. The final page of the questionnaire provided space for the responders to comment on the questions or add any information they feel that was not presented through their previous answers.

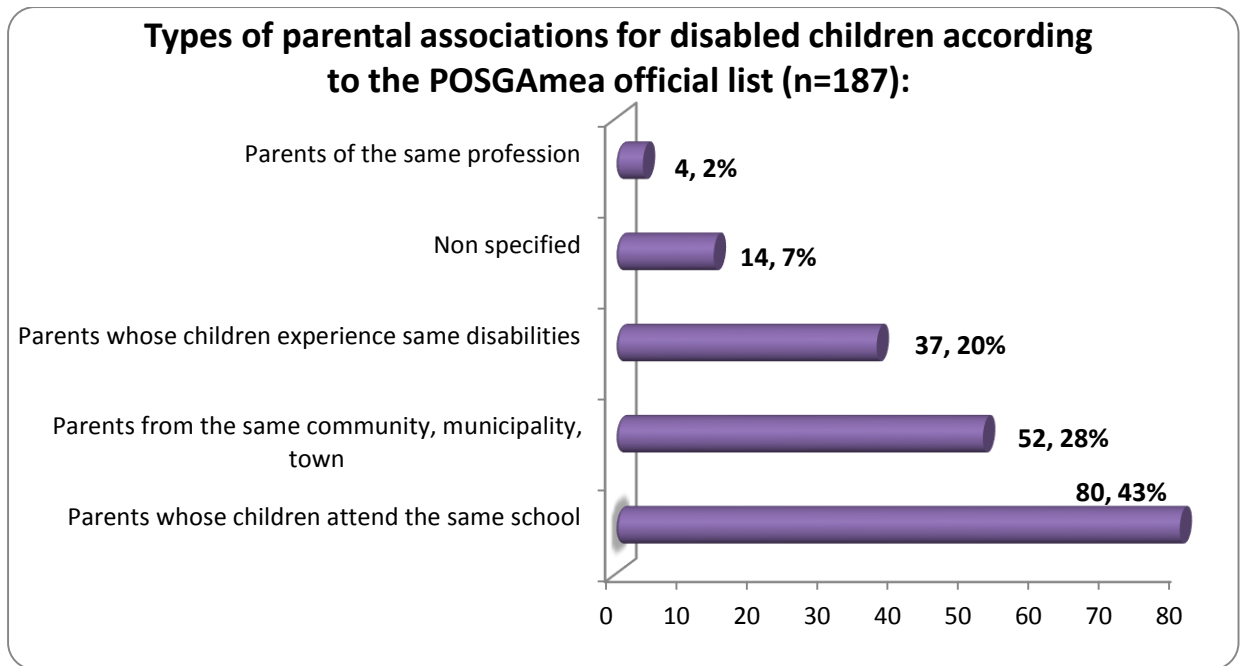
### **5.3.3 Distribution of questionnaires**

The distribution of the questionnaires was initially evaluated as a simple, inexpensive and quick task, however, the actual process proved to be much more challenging. At the beginning of September 2009 the questionnaire schedule was finalised. In addition, a cover letter was composed explaining the purpose of the study, instructions for completion, contact details, with the reassurance that all participants will remain anonymous and that their participation is highly valued (please consult Appendix 6). The questionnaires and the accompanied cover letter were sealed in individual envelopes which included a stamped addressed envelope for the completed questionnaires to be sent back to the researcher. At the end of September 2009 all envelopes were sent out by post to the associations' addresses, provided in the official list, with the request to be completed by a member of the administrative council. This request was based on the fact that the questionnaire included details better known to a member of the elected organizing committee, i.e. questions concerning the year and reasons of foundation, the total number of registered members, the financial

substitution needed, etc. By the beginning of December 2009 only twenty three questionnaires were completed and sent back, a rather low and disappointing response rate. However, there was another option in order to discover the reasons why more questionnaires had not been returned and that was through telephone contact. By calling all the associations it appeared that due to time restraint and busy schedule most of them had neglected to complete and return the questionnaire. In some occasions they had never received the envelope or they had misplaced it. A second round of resending the questionnaires through e-mail, fax or post depending on how it was more convenient for the participants was conducted by the end of December 2009. In addition an important factor affecting the response rate was that a high percentage of the associations (n=40), even though included in the list of FPGA for SMDP, were in fact inactive at the time that the survey was conducted. The positive conclusion was that the format and the context of the questionnaire was not the reason of the initial low response rate. By April 2010 65 completed questionnaires were filled adequately and returned. As an added value it should be noted that many participants (n=41) took the interest of completing even the comments section at the end of the questionnaire, and many participants provided written comments or notes for the researcher next to each question. Both of these actions show that the people who completed the questionnaire were dedicated in what they were requested to do.

## **5.4 The list of parent associations for severely and multiple disabled people – First observations**

Through the official list provided by FPGA for SMDP and the titles of the parental associations for severely and multiple disabled people it was possible to make some first observations concerning their different types and aims based on the information provided to the public by the PAs. The first comment concerns the ways that parents formed into groups and created these associations (Figure 2: Types of parental associations for disabled children). The vast majority of the associations consisted of parents whose children attend the same school, institution or centre (n=80). A second group of associations has been created by parents from the same community, municipality, town or county (n=52). Thirty seven (37) associations have been created in order to promote the rights of children with a specific nature of disability. And as a final point, fourteen (14) associations do not specify in their title the reasons that led to their formation but in some cases they provide their aims: *‘to intervene and provide solutions’*, *‘to promote the right for independent living’*, *‘to promote the right of rehabilitation’*, *‘for people with disabilities in general’*.



**Figure 2 Types of parental associations for disabled children (n=187)**

Concerning the associations formed around specific disability groups (n=37), the majority is addressed to parents of children with learning disabilities (N=6) and autism (n=6). These are followed by five associations that promote the rights of children with chronic illnesses (cystic fibrosis, nodular sclerosis, cancer, diabetes). Other disabilities that are clearly stated in the titles of the associations are for: spastics (n=4), blind (n=4) and deaf (n=3) children, multiple disabled children (n=3), children with Down's syndrome (n=3), children with psychosomatic disabilities (n=2) and children with sensory disabilities. For the construction of these categories the terms of each disability appear as they are used in the titles of each Association, even though some terms are considered inappropriate and derogatory today (for example the use of the term '*spastics*').

To conclude, a brief mention should be made in relation to the names of the associations. While going through the list we come across 22 names of saints and

other religious figures from the Christian Orthodox tradition, namely *Saint Theodore*, *Virgin Mary*, *Saint Andrew*, *The Good Samaritan*, *The Savior*, etc., similar to the first special schools titles created, in their majority, by charity organisations and the church. Also, we find names of feelings and more poetic notions: *Joy*, *Hope*, *Childhood Dreams*, *Fly Away*, *Sunshine* and names which state the need of children with disabilities for relief: *S. O. S*, *Care*, *Open Arms*, *Shelter*, *Protection*, *Solidarity*, *and Welfare*. Lastly, there are also names attempting to promote a stronger disability image: *Winner*, *Flame*, *Fighters*, *Rebirth*, *Victory*, *Sun*, *Horizons*, *Impetus*, *Excellence*, etc.

## **5.5 Data analysis**

The data were processed and analysed with the assistance of the SPSS 17 statistical software package for social sciences. To investigate the correlations between the survey's questions (i.e. the description of the relationship between variables in the survey) techniques of statistical inference (inferential statistics) were used (Gialamas, 2005). For investigating the characteristics of relevance between two variables the Pearson r correlation coefficient was used (Howitt, 2006). The cross tabulation between the survey findings was based on the control x2 independence (Gialamas, 2005; Karagiorgos, 2001, Grais, 2005). The qualitative data collected through the open questions and comments of the participants were analysed based on the content analysis method.

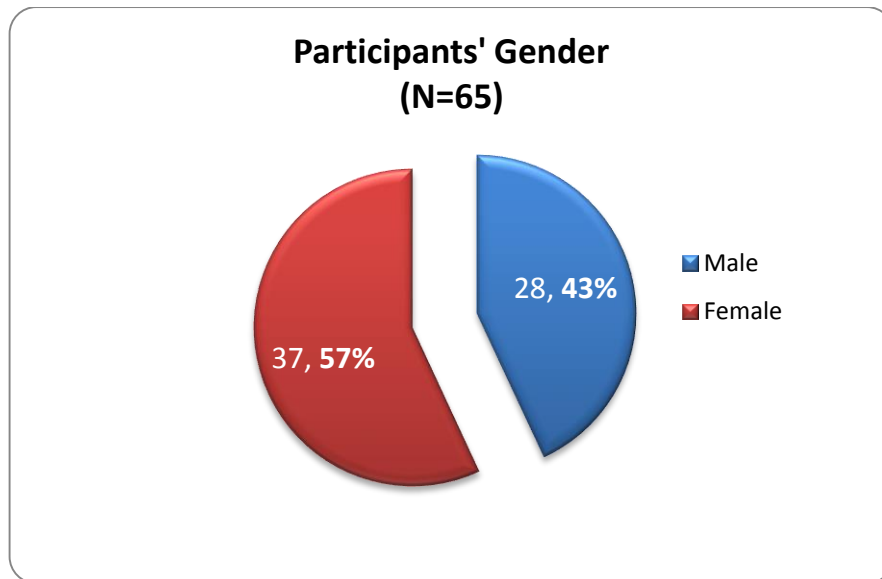
## **5.6 Questionnaire Findings Presentation**

This section aims to present the data collected from the questionnaires addressed to the administrative councils of parental associations for severely and multiple disabled people. The data analysis is based both on the qualitative and quantitative methods of analysis as the qualitative information comes to complete and explicate the quantitative information. Quotations from the questionnaires have been included in various parts of the analysis as they best illustrate the meaning that the participants wished to convey and it allows the voices of the participants to be heard in the exact way that they have formed and expressed their opinions, objectives, values, attitudes and experiences. In order to ensure the anonymity of the participants the quotations used will hereinafter be coded to show the number of the questionnaire analysed, i.e. passage extracted from the first questionnaire will be coded as 'q1'.

### **5.6.1. Participants' General information and characteristics:**

#### **5.6.1.1 Gender**

The survey included 37 male and 28 female respondents (Figure 3: Participants' Gender), which demonstrates an equal distribution amongst genders.



**Figure 3: Participants' Gender (n=65)**

#### **5.6.1.2 Age groups**

The survey included respondents from various age groups (Figure 4: Participants' Age). The majority of the respondents were between the age of 50 and 59 years old (26, 40%) followed by the age of 60-69 (14, 22%) and 40-49 years old (13, 20%). 5 respondents were 30-39 years old and 6 respondents 70-79 years old.

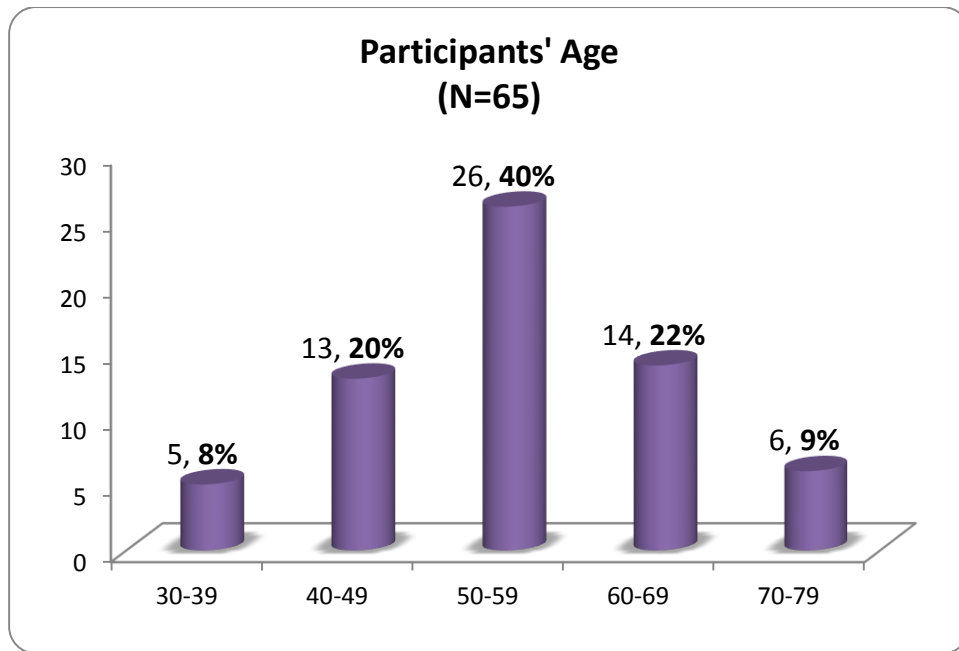


Figure 4 Participants' Age (n=65)

#### 5.6.1.3 Profession

The participants in their majority are employed in the private or public sector (36, 58%) (Figure 5: Participants' Profession). A significant percentage showing that parents' participation in the associations is not their sole activity, they need to balance their time between the demands of organising the association in addition to full time employment and their working responsibilities. Another percentage of the participants are pensioners (11, 18%) or currently unemployed (15, 24%).



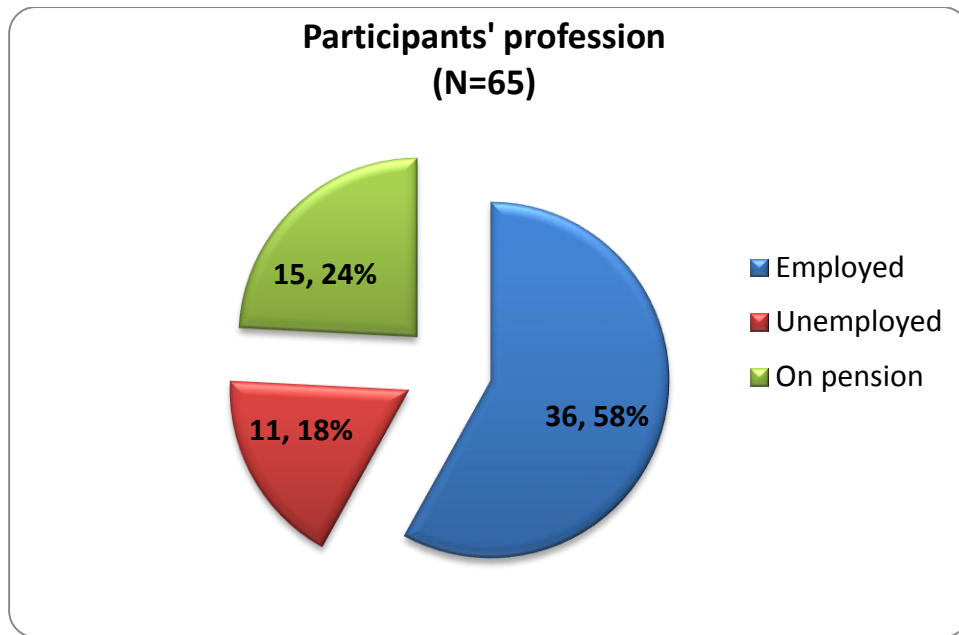
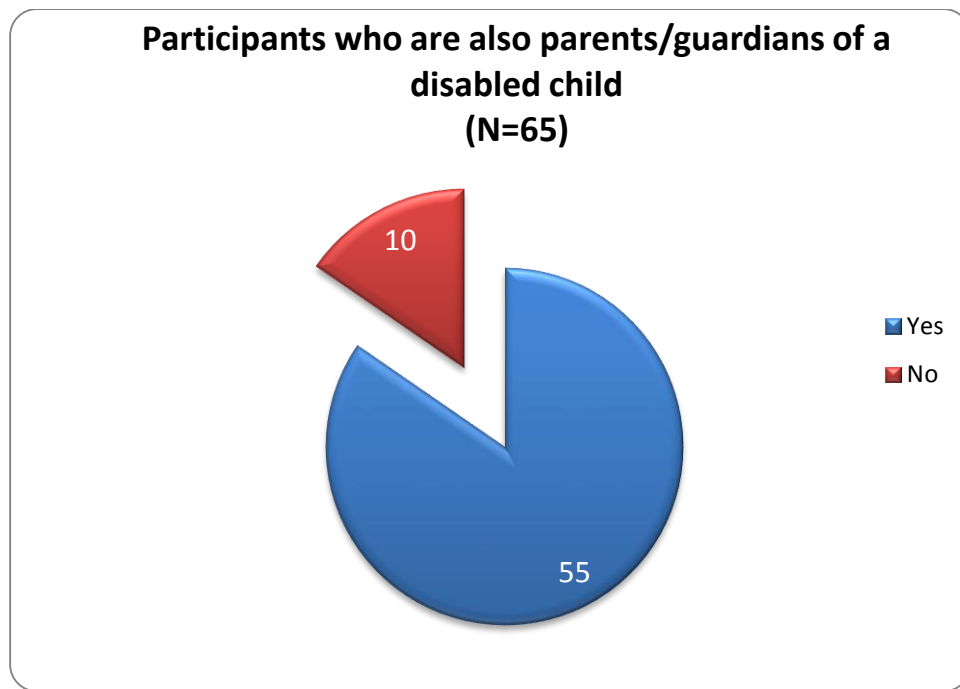


Figure 5 Participants 'profession (n=65)

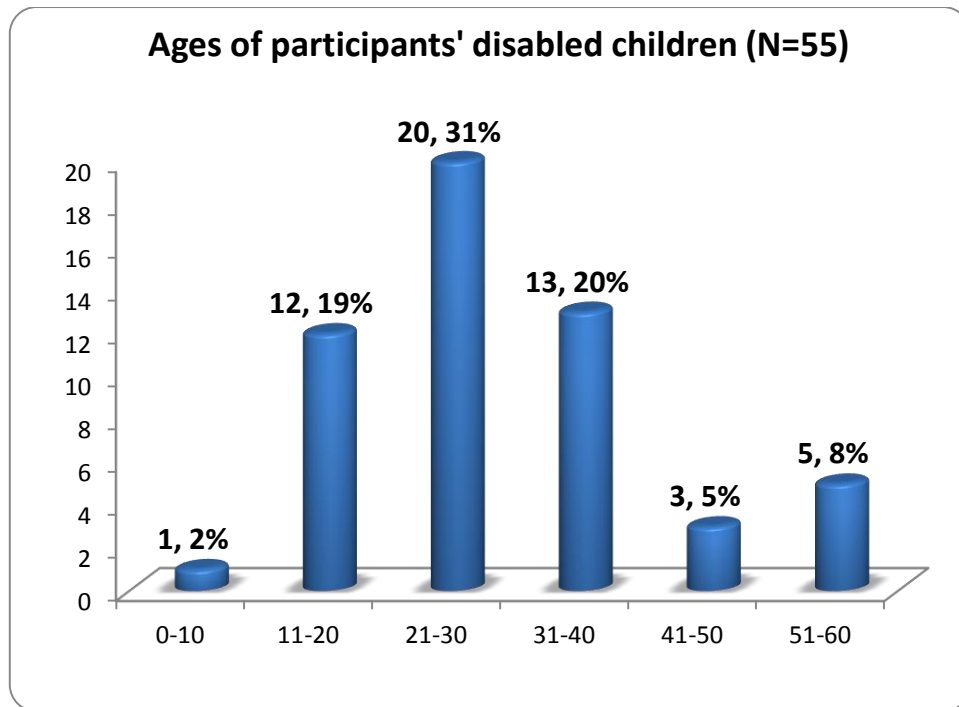
#### 5.6.1.4 Family composition

Some associations also include friends of disabled people and accept them as members; therefore it was important to make sure of the exact number of participants that were actually parents/guardians of a disabled child. As shown in the chart below (Figure 6: Participants who are also parents/guardians of a disabled child), 55 of the respondents were parents or guardians of a disabled child and 10 respondents were 'friends' of the association. At this point we have to note that from the 10 respondents that were not parents, four of them were siblings of disabled children hence they also had similar experiences of the difficulties faced by a family with a disabled child.



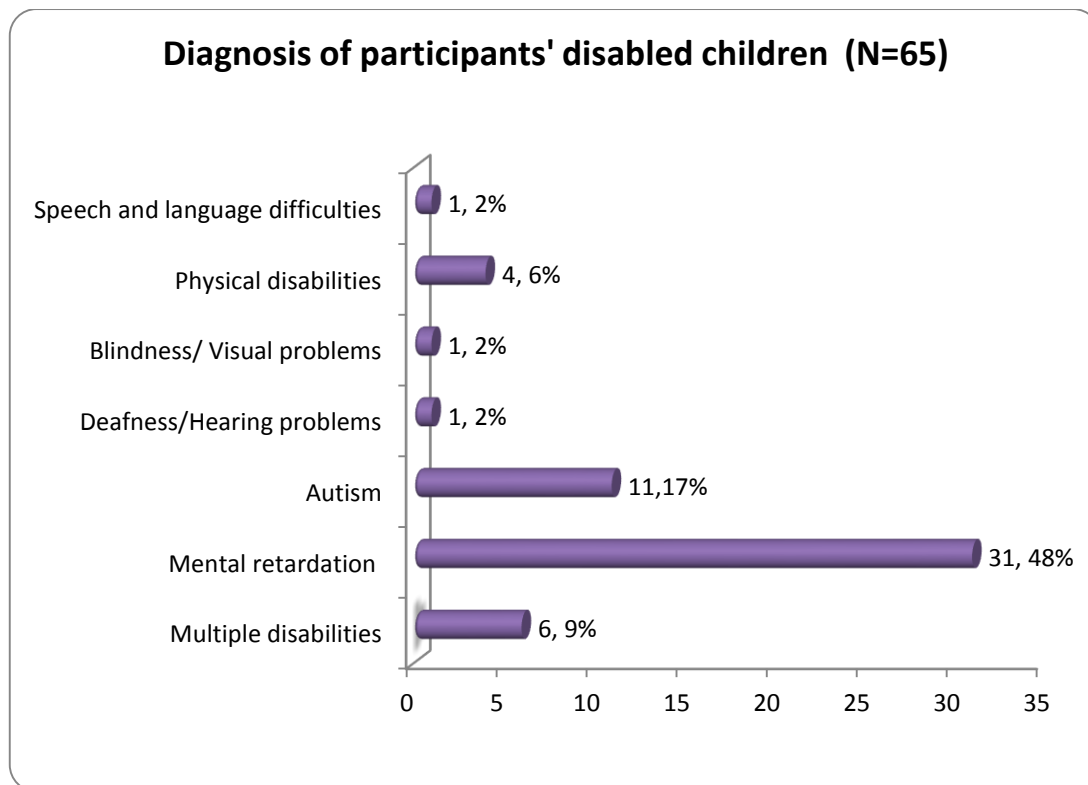
**Figure 6 Participants who are also parent/guardians of a disabled child (n=65)**

The participants who were also parents of a disabled child/adult have in their majority disabled children/adults aged between 21 and 30 years old (20, 31%) followed by the ages of 31-40 (13, 20%) and the ages of 11-20 years old (12,19%). Only one parent has a child of a very young age and few are the parents in the associations that have children/adults aged between 41-50 years old and 51-60 years old (Figure 7: Ages of participants' disabled children).



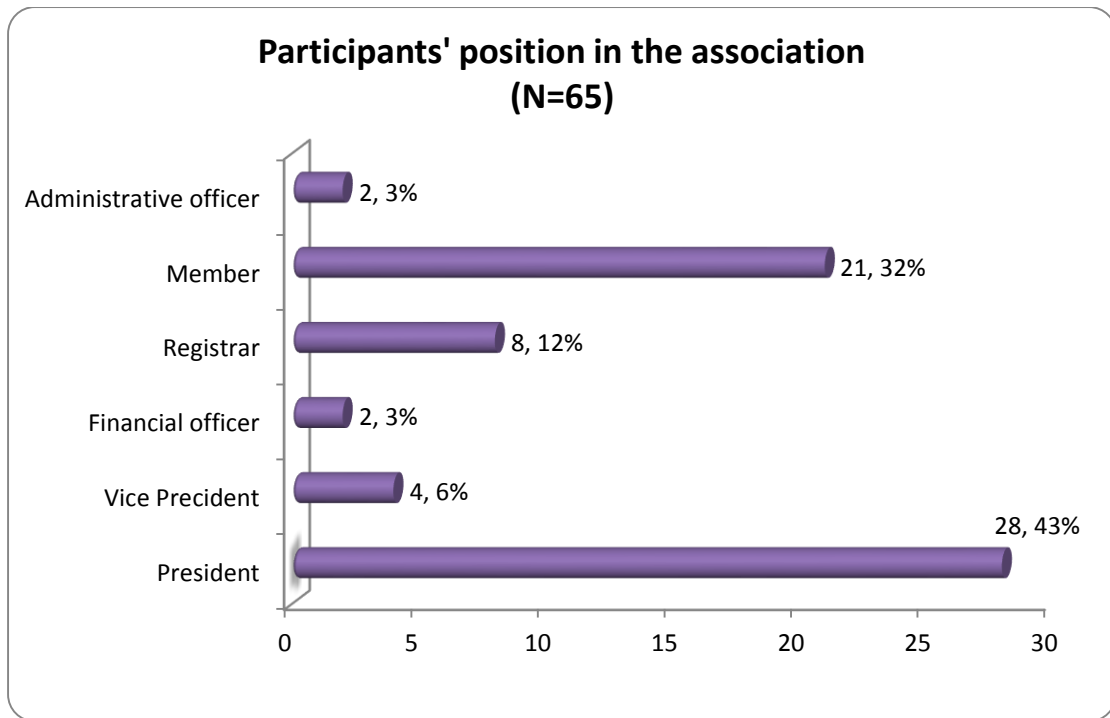
**Figure 7: Ages of participants' disabled children (n=55)**

In the same section in the questionnaire participants who were also parents of a disabled child/adult were asked about their children's diagnosis. Most of the respondents were parents of children and adults with learning disabilities (31, 48%) and autism (11, 17%). Moreover, the survey included 6 parents of MD children and adults. Parents of children and adults with other disabilities were also included in the sample: physical disabilities (4, 6%); sensory disabilities (2, 4%); speech and language difficulties (1, 2%) (Figure 8: Diagnosis of participants' disabled children).



**Figure 8 Diagnosis of participants' disabled children (n=65)**

The majority of the returned questionnaires were completed by the Presidents of the associations (28, 43%) (Figure 9: Participants' position in the association). The reasons why the presidents took the time to get involved in the survey can be located either on the recommendations from the former FPGA for SMDP president, a person well known and respected amongst the association members for his contribution, or because a part of the role of presidents within the associations is to promote the public image of the associations and be concerned with all communication matters. In addition it should be noted that some associations are so small that the president may be the only one in charge. The number of presidents that took the time to complete the questionnaire may reassure us that it was given the appropriate consideration and that the numbers and information provided are close to the reality.

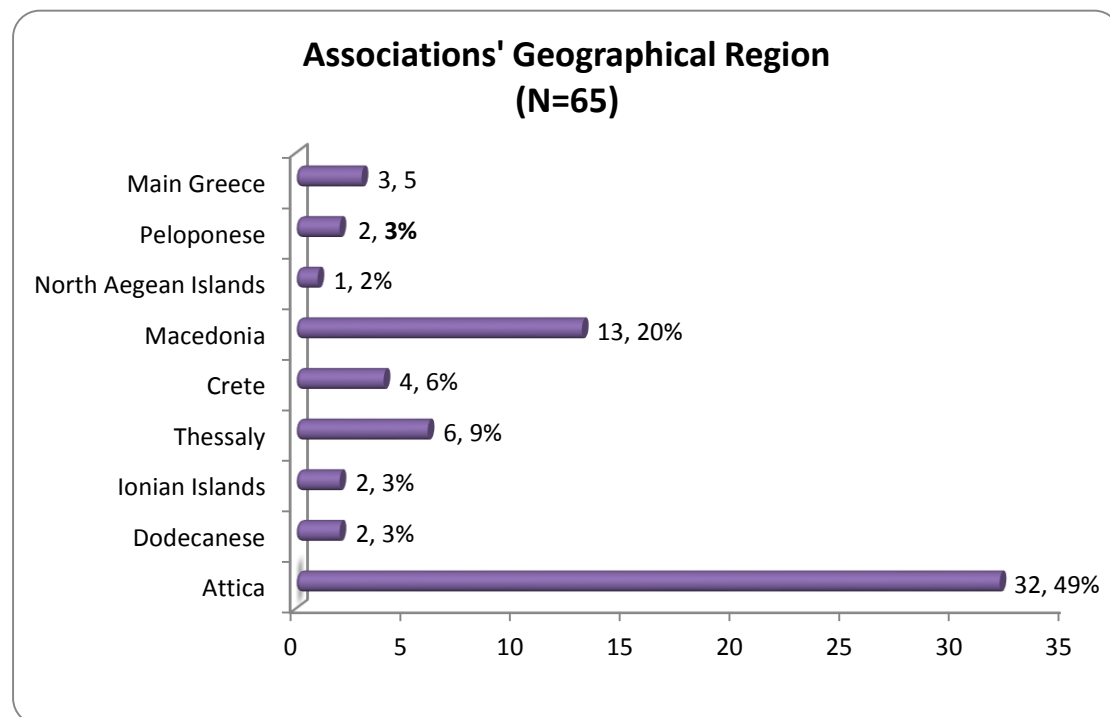


**Figure 9** Participants' position in the association (n=65)

## 5.6.2. Parent Associations' General Information

### 5.6.2.1 Geographical location

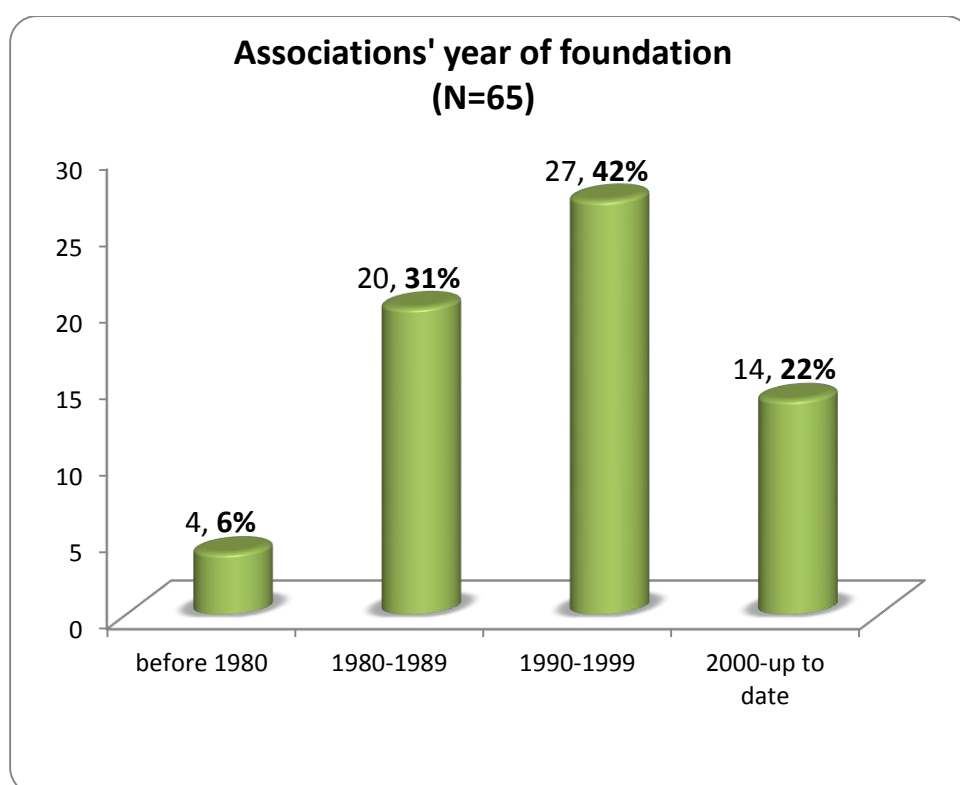
The associations that participated in the survey were mainly located in the region of Attica (32, 49%) and Macedonia (13, 20%) as it was originally expected, since from the FPGA for SMDP statistics it becomes clear that the majority of associations are located in the above mentioned regions (Figure 10: Associations Geographical Region). It is important to highlight the fact that the completed questionnaires collected represented almost all the Greek geographical areas: Thessaly (6,9%), Crete (4,6%), Main Greece (3,5%), Peloponnese (2, 3%), Ionian Islands (2,3%), Dodecanese (2, 3%) and North Aegean Islands (1, 2%). Therefore, the sample included the experience and perspectives from members not only from the two main urban centers but also from the province. The regions that did not reply to the questionnaire, and therefore not represented in the survey are: Thrace, Epirus and Cyclades



**Figure 10 Associations' Geographical Region**

### **5.6.2.2 Year of foundation**

During the decade of the 80's and the 90' we can observe an increasing number of associations being formed (1980-1989: 20; 31%; 1990-1999: 27, 42%) and it is important to link these dates to the political climate of those times and the existing legislation, and this aspect will be further elaborated in the discussion section. Few are the associations that were founded before the 80' (4, 6%) and only 14 associations were founded after 2000 to the present day (Figure 11: Associations' year of foundation).



**Figure 11 Associations' year of foundation (n= 65)**

### 5.6.2.3 Number of registered members

The average number of members in the associations undulates between 51-100 (29, 45%). Only 6 associations account less than 50 members. Also, 11 associations account more than 200 members (Figure 12: Associations' number of members).

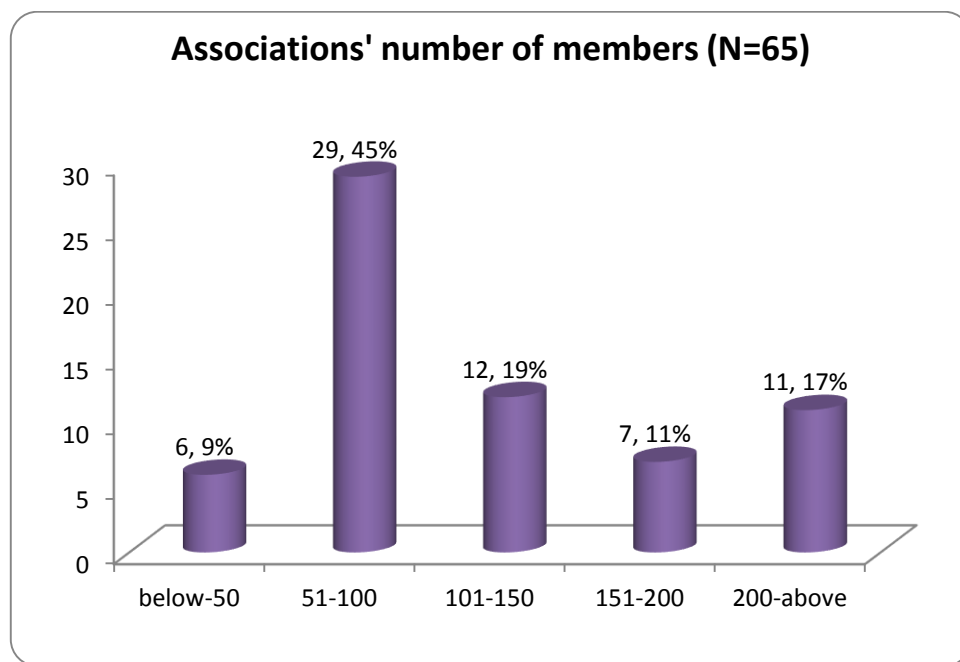


Figure 12 Associations' number of members (n=65)

### 5.6.2.4 Registered members with disabled children

More than half of the whole sample population of the associations who participated in the survey includes as registered members of the associations parents of children and adults with learning disabilities (75%) (Table 3: Registered members with disabled children) ; this is followed by parents of children/adults with multiple disabilities (57%); parents of autistic children/adults (52%) and parents of physically disabled children/adults (45%). Parents of children/adults with other disabilities are also member of associations: Speech and language difficulties (32%); learning difficulties



(28%); epilepsy (28%); behavioral problems (23%); AD/HD (22%); sensory disabilities (38%); health problems (18%); psychological problems (17%); environmental and social problems (17%) and mental disorders (17%).

<b>The associations include parents-members of children with</b>	<b>Frequency</b>	<b>Percent %</b>
Intellectual disabilities	<b>49</b>	<b>75%</b>
Multiple disabilities	37	57%
Autism	34	52%
Physical disabilities	29	45%
Speech and language difficulties	21	32%
Learning difficulties	18	28%
Epilepsy	18	28%
Behavioral problems	15	23%
AD/HD	14	22%
Deafness/Hearing problems	13	20%
Blindness/Partially sighted	12	18%
Health problems	12	18%
Psychological problems	11	17%
Environmental/ Social problems	11	17%
Mental disorders	11	17%

**Table 3 Registered members with disabled children (n=65)**

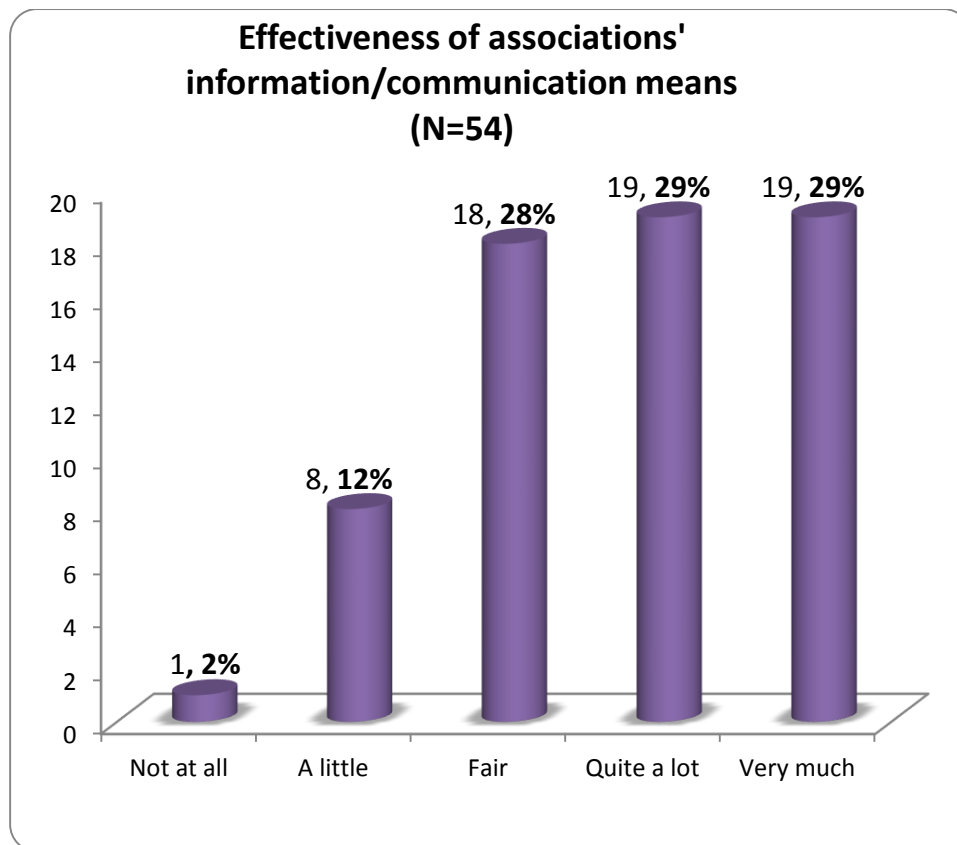
#### **5.6.2.5 Sources of information and communication about the existence and action of the associations and their effectiveness**

The vast majority of the respondents identify as the basic source of communication and information concerning the existence of the associations the family and friends environment (94%) (Table 4: Sources of communication of associations existence and action). This is followed by schools (48%) and local authority structures (46%). Only 16 respondents consider the diagnostic centers or CEDDAS a valuable source of information. Other means of communication of the existence of the associations are the internet (43%); information flyers (43%); media (34%) and the hospital units (32%).

<b>Source of information/communication of associations existence/action</b>	<b>Frequency</b>	<b>Percent %</b>
Family environment/ Friends	61	94%
Schools	31	48%
Local authorities/ Municipalities	30	46%
Internet	28	43%
Information flyers	28	43%
Media	22	34%
Hospital Units	21	32%
Diagnostic centers/ CEDDAS	16	25%

**Table 4 Sources of communication of associations existence and action (n=65)**

From the chart below (Figure 13: Effectiveness of associations' information/communication means) we can see that the participants believe that the existence and function of their associations is communicated effectively (very much effective: 29%; quite a lot effective: 29%, fairly effective: 28%). Only 9 member of the associations consider that these communication and information methods need to be revised and changed (a little effective: 12%; ineffective: 2%). This question was included in the questionnaire with the aim to investigate whether the members of the associations, especially the ones that hold important positions within the administration, have identified and recognised gaps or limitations in the communication procedure concerning the existence and work of the PAs since in the interviews conducted with parents of multiple disabled children and adults none of the participants mentioned that they were aware of the PAs for severely and multiple disabled children and young adults or that they were members of a PA association. On the contrary they expressed the need for support and guidance. It was interesting to find out that the PAs board members are under the impression that their work and purpose are communicated effectively and that they are well known to the public.



**Figure 13 Effectiveness of associations' information/ communication means (n=54)**

#### **5.6.2.6 Financial contributions**

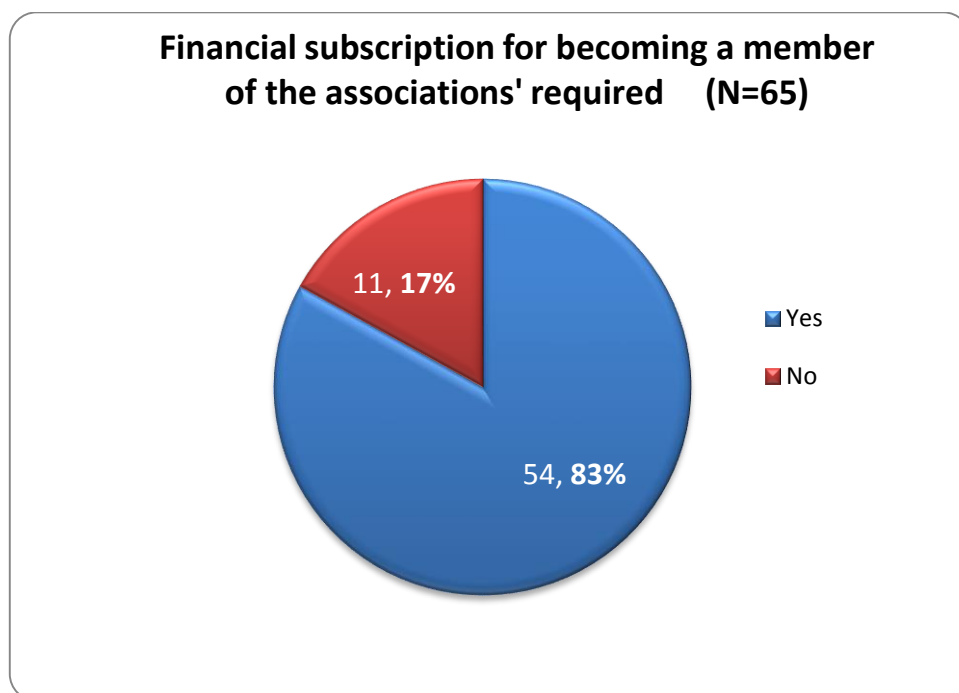
The vast majority of the associations require from their members an annual financial subscription (83%) (Figure 14: Financial subscription for becoming a member of the associations'). The amount of financial subscription required undulates between 10 euros (10, 15%), 15 euros (9, 14%) and 20 euros (18, 24%). From the chart (Figure 15: Amount of financial subscription required by the associations) we can observe that in general the amount of financial subscription is not fixed but may vary from 9 up to 50 euros. Five participants expressed their queries concerning the importance and aim of this specific question by adding a note for the researcher on the side of the page. This issue was also raised while piloting the questionnaire. The decision to

include this question was firstly in order to investigate how the associations cover their functional expenses and secondly to explore the possibility of high subscription costs excluding parents with financial difficulties. The reasons why the participants were concerned with this specific question and requested further explanation cannot be accurately analysed through the information provided from this questionnaire but it remains an issue that may need further investigation as the participants appeared to hold a defensive stance when asked to provide more information.

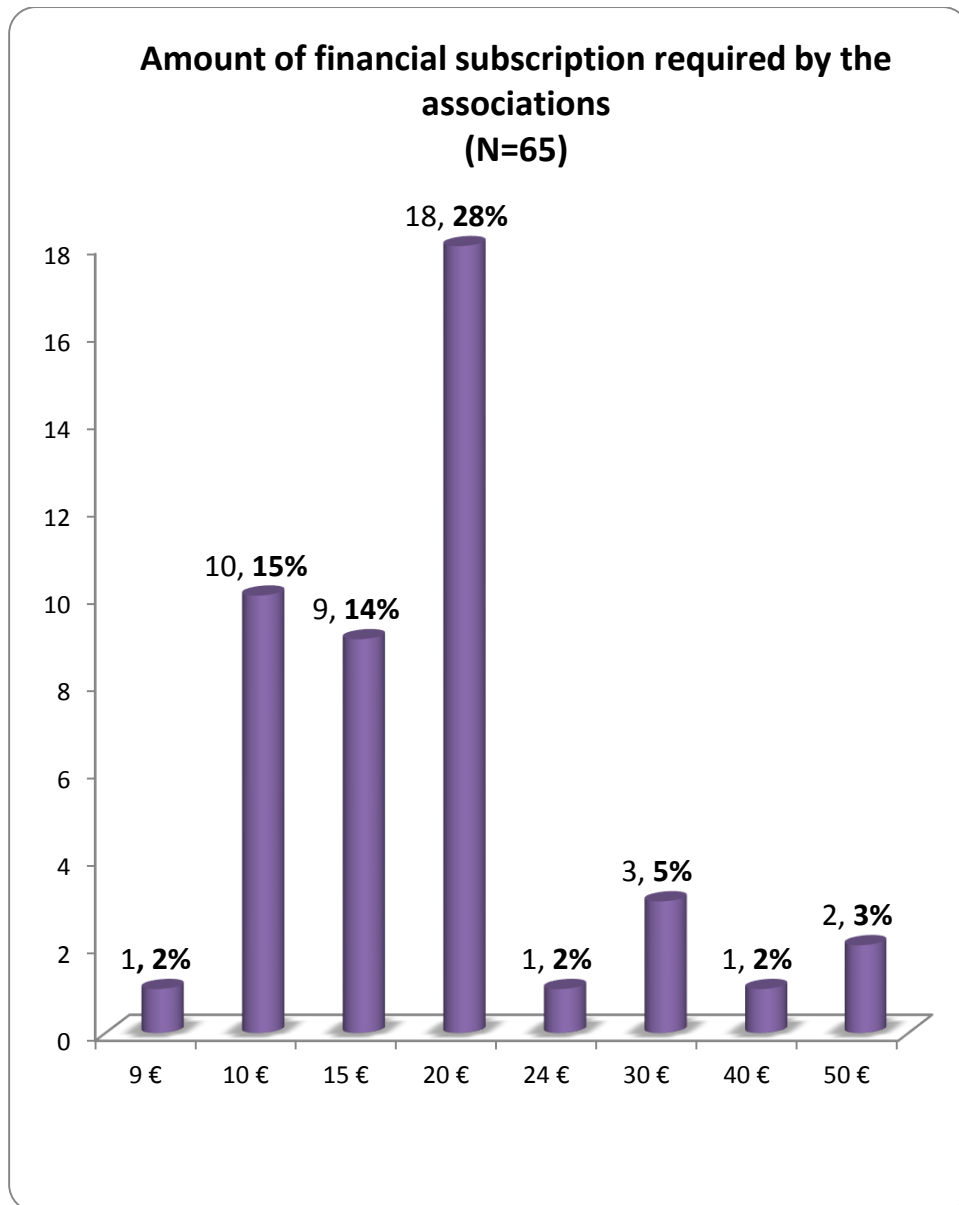
*'I don't understand how it is of your concern how much our members need to pay' (q3).*

*'All the associations have financial subscriptions, it is a common policy and it is an amount fixed by the legislation' (q 39).*

*'I provided the amount of the subscription but in the future I refuse to answer similar questions' (q 42).*



**Figure 14 Financial subscription for becoming member of the associations' (n=65)**



**Figure 15** Amount of financial subscription required by the associations (n=65)

#### **5.6.2.7 Reasons and needs leading to the foundation**

The need that led to the foundation of the associations was primarily the demand of solutions from the Ministry of Education, the Ministry of Health and Social Welfare and the Ministry of Employment (58%) and the promotion of the right of disabled students to access mainstream education (49%) (Table 5: Basic need that led to the foundation of the association). Other associations were concerned with highlighting

the problems of families with multiple disabled children and adults (35%) while some associations pinpoint the main reason for the foundation of their associations on the need of providing information to the parents (28%) and representing the parents (26%). Another 18% of the participants note that their main reason for creating their association was to look into issues of care and provision for disabled children and adults. Fifteen participants chose to add more reasons than the ones provided in the questionnaire and attribute the need leading to the foundation of their association to the promotion of socialization of the children outside of the restriction of their home environment and their inclusion to the community life;

*'The social inclusion of disabled people' (q 8).*

*'The social and vocational rehabilitation of disabled people' (q 12).*

*'To promote children's communication, interaction and socialization, in general, through camps and various activities' (q 54).*

*'Because back then we lived in different times and no one wanted to admit our existence' (q 28).*

*'To provide services to the parents that they could not find elsewhere (q 25).*

*'The area of West Attica was degraded and then we decided to take action, this area until today remains degraded and we are still needed' (q 47).*

to the need of supporting other parents;

*'For parents to support each other' (q 15).*

*'The psychological support of parents (q 17).*

*'To strengthen the families' (q 27).*

*'To support children with autism and their families' (q 41).*

and to the need of creating educational settings and other structures in order to occupy disabled children and adults out of their houses.

*‘There wasn’t an appropriate school for our children in the island. We created one in a building that was granted to us’ (q 48).*

*‘To provide educational opportunities’ (q 55).*

*‘Children needed to get out of the house more and we needed to find ways to occupy them’ (q 60).*

*‘To keep the children busy outside of the house’ (q 34).*

Basic need that led to the foundation of the association	Frequency	Percent %
The demand of solutions from the Ministry of Education/ the Ministry of Health and Social Welfare/Ministry of Employment	38	58%
Promoting the right to access in mainstream education	32	49%
Highlighting problems	23	35%
Informing parents	18	28%
Representation of parents	17	26%
Care/Provision	12	18%
Other	15	23%

**Table 5 Basic need that led to the foundation of the association (n=65)**

### 5.6.2.8 Main activities and actions

In this question participants were asked to prioritise the main activities of their association but during the data analysis a difficult in analysing and interpreting the data emerged. Some of the participants ticked the provided boxes without prioritizing the activities. Therefore it was decided to analyse the information shared in two ways: first by the number of times that parents chose each subject and secondly according to order of priority. Through this double analysis it is noteworthy that while 80% of the participants included in their answers the social activities of the associations (Table 6: Main activities of the associations’), in fact only 11 of them placed these activities as a first priority (Table 7: Main activities of the associations’ in priority order). On the other hand it seems that activities concerning the education of disabled children and adults (N=20) and issues concerning welfare (N=13) are the ones that were considered a first priority. Activities concerning the vocational rehabilitation (N=5),

support between parents (N=5), medical (N=3), autonomy (N=1) and the financial support of families (N=1) appeared last in the list. None of the respondents identified legislation as a main priority.

**Table 6 Main activities of the associations (n=65)**

<b>Main activities of the associations</b>	<b>Frequency</b>	<b>Percent %</b>
Social	52	80%
Education	48	74%
Support between parents	41	63%
Care/ Welfare	40	62%
Vocational rehabilitation	33	51%
Autonomy	26	40%
Legislation	25	38%
Medical	17	26%
Financial support of families	15	23%

<b>Main activities of the associations in priority order</b>	1st	2st	3rd	4th	5th	6th	7th	8th	9th
Education	20	12	8	2	0	1	1	0	0
Welfare	13	5	0	6	1	1	1	0	0
Social	11	7	13	10	6	2	0	0	0
Vocational rehabilitation	5	11	3	6	2	2	2	0	0
Support between parents	5	6	9	5	5	5	0	2	1
Medical	3	5	8	1	2	1	3	0	0
Autonomy	1	2	5	5	3	2	1	0	3
Financial support of families	1	1	3	1	1	0	2	3	1
Legislation	0	7	3	5	5	1	0	2	0

**Table 7 Main activities of the association in priority order (n=65)**

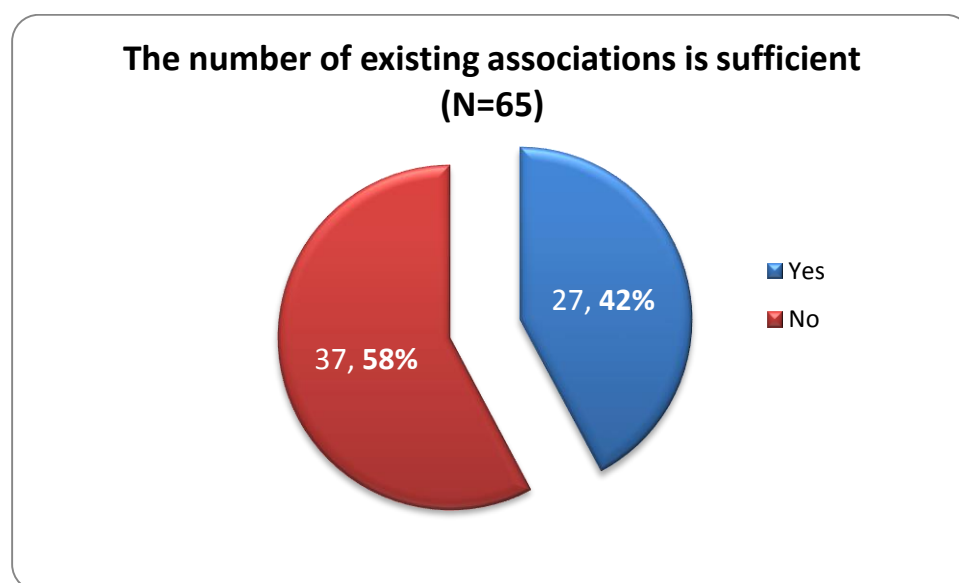
### **5.6.3 Information concerning all parent associations for disabled children:**

#### **5.6.3.1 Number of existing associations and sufficiency**

From the quantitative data the participants' views concerning the sufficiency of parents' associations in Greece are almost equally divided (Figure 16: The number of existing associations is sufficient). Thirty seven percent of the whole sample



considered them sufficient and 27, 42% considered them insufficient. However, when the participants were asked to elaborate more on their answers in the open section, they moved beyond quantitative terms, i.e. whether the amount of existing PAs is enough to accommodate all the families in need, by addressing also issues of efficiency (Table 8: Parental associations' sufficiency).



**Figure 16 The number of existing associations is sufficient (n=65)**

Ten participants referred to the issue of collectivity and unity amongst the associations. According to them the number of associations is irrelevant if the existing ones do not work alongside, promoting the same goals and expressing the same demands for all disabled people.

*'The associations are divided, each one deals with their own problems' (q 38).*

*'No, it would be better if the different associations could find a way to form common goals, create links and offer their services collectively to all people with disabilities' (q 24).*

Moreover, they explained how this division between PAs has affected not only the strength of the collective force, an fundamental strength for PAs, but it has also affected the significance of these associations as viewed by society.

*'Many associations have been created in order to meet personal and individual interests and not in order to meet the needs of all children in a collective level. This is why great disbelief has been formed between the different associations' (q 64).*

*'As the number of associations increases so are the negative consequences of this increase. The action and strength of the associations is shuttered, we are not united, and instead the associations often appear in opposite sides due to interest conflicts and along with that the disbelief of the public opinion and the relevant stakeholders grows' (q36).*

Five respondents raised the concern of the continued increase of the percentage of the population considering the fact that there are also families who are not yet registered or officially accounted for and usually make their appearance after their children have reached adulthood when the parents are no longer able to accommodate and take care of them. In the opinion of those participants the existing associations will not be enough to cover this existing demand for support and help from the families.

*'The needs and the numbers of families with a disabled child increase every day and we are not referring only to the registered families, the ones that at some point have enrolled their children to school or any care centre or educational setting, there are families that make their existence known after their children have reached adulthood and they cannot longer take care of them' (q 43).*

*'Given the fact that the disability percentage in our country a great percentage of those above the age of 22 years old remain confined in their houses and that has terrifying effects on their social and family life'(q 55).*

Six participants referred to the state contribution both in terms of support and most importantly in terms of financial provision. They also explained that the main responsibility of the associations is to record the problems and the demands on behalf of the families with disabled children and promote these to FPGA for SMDP;

therefore, it is then their responsibility to address these issues by bringing them to the policy makers, politicians and various stakeholders.

*‘The main problem is that there isn’t a financial reinforcement for the associations’ (q 45).*

*‘If the central organisation (FPGA for SMDP) is consisted of people with knowledge-experience-awareness and capacities in order to get involved unselfishly towards the highly responsible that they are called to serve’ (q 46).*

*‘Associations are not here to solve all problems. The parents who are members of the association have managed somehow to find their way. What associations can do is to transfer their demands to FPGA for SMDP for promotion’ (q 48).*

Eleven participants highlighted the distinction between evaluating the sufficiency of the associations quantitative and qualitatively. In terms of numbers the associations are considered plenty but in terms of effectiveness the question remains on defining which amongst them actually promotes and demands the rights of disabled children and their families.

*‘They should be enough, if they are working effectively’ (q 53).*

*‘The amount of associations is sufficient, now it is urgent that all these associations work intensively’ (q 57).*

*‘Quantitatively yes, they are enough. Besides, this number is increasing every day. The issue here is that not all associations work focused, with the same pace and energy’ (q 65).*

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**Parental association are/aren’t sufficient in order to meet the needs of families with disabled children and especially families with a multiple disabled child**

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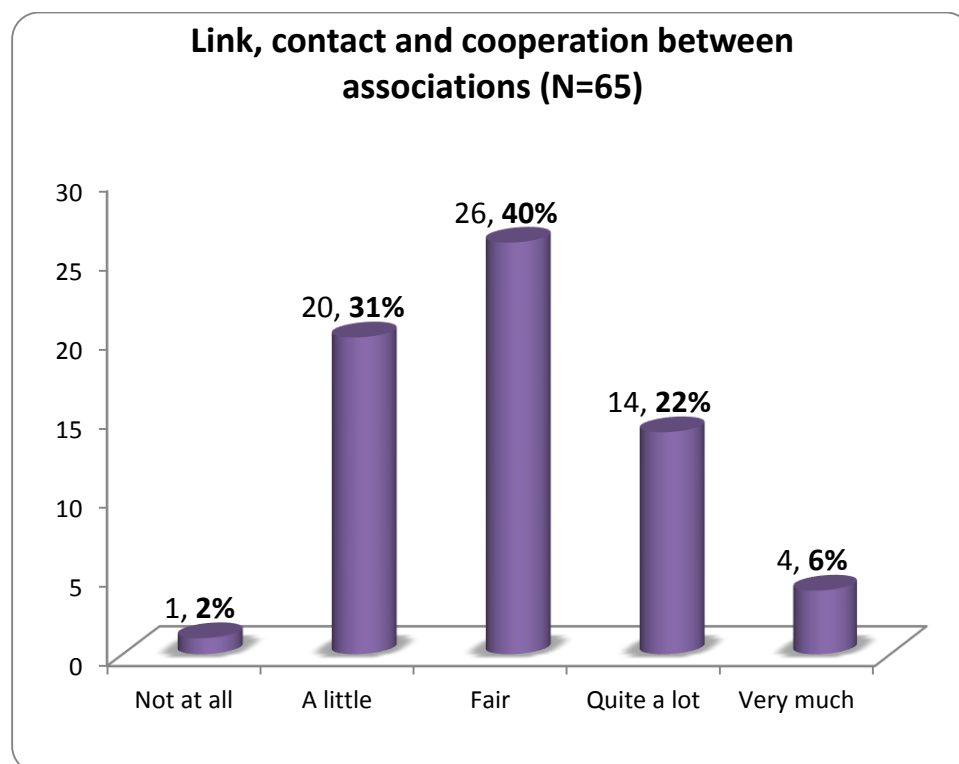
Lack of state funding/ state concern	15
Quantitative sufficient but qualitative insufficient or inactive	16
FPGA for SMDP is inactive/ineffective	5
The growing population of the disabled	8
Creation of associations based on personal interests	9

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**Table 8 Parental associations sufficiency (n= 53)**

### 5.6.3.2 Link, contact and cooperation between the associations

Based on the answers the associations cooperate with each other to a fair degree (26, 40 %). Only one participant stated that the cooperation between associations is non-existent and four participants believe that the cooperation, contact and link between associations are exercised to a great level (Figure 17: Level of link, contact and cooperation between associations). Again in this question more information can be drawn from the answers provided in the qualitative data concerning the reason, level and nature of this cooperation.



**Figure 17 Level of link, contact and cooperation between associations (n=65)**

The majority of the respondents (N=16) explained that a link between associations of the same geographical area or associations who focus on the same disability group is crucial due the increasing needs and the limited state support (Table 9: Cooperation between parental associations for disabled children and young people).

*'The associations of the province we are trying to be united because we are alone, we vegetate not like the association in the big urban centres, they have access in the ministries, they have other links to support them, we only have each other' (q 16).*

*'Due to the island exclusion it is very difficult for us to communicate and cooperate with other associations outside our region' (q35).*

*'Of course we cooperate, very much indeed, and I mean with associations who represent the autistic spectrum disorders... with the other associations not so much' (q 27).*

This is followed by participants (N=6) who believe that the cooperation amongst different associations should be promoted and organized through the tertiary organizations of FPGA for SMDP and NCPD.

*'The only existing connection between the associations is through the central organisation of FPGA for SMDP and that only becomes possible in the case of promoting common aims and goals of all the associations' (q 46).*

*'Unfortunately in practice we lack coordination. It is FPGA for SMDP role to promote the cooperation, communication and solidarity amongst the associations and this should be reinforced through appropriate and mutually accepted routes' (q 55).*

Five participants agreed that associations do work closely in promoting equal needs and forming demands, mainly in order to support each other, as they are all parents of severely disabled children.

*'The cooperation and communication is necessary amongst all associations because we are all parents, we need to support each other, we need to feel that we are not alone in this and we need to fight together for the better future of our children' (q18).*

*'Parents experience the same difficulties and they wish for the establishment of a meaningful cooperation between amongst us all, we are trying to support each other' (q59).*

On the contrary, four participants consider that most associations are not concerned with the issue of linkage and cooperation and prefer to maintain their autonomy due to personal interests.

*‘Many associations are founded only to cover individual and personal interests and not to support all the children in a collective level. And that is the main reason for the creation of disbelief amongst the different associations’ (q 60).*

In addition, two respondents stated that the cooperation cannot be achieved due to the lack of state support and they added that in many cases the state does not wish for this linkage amongst associations to exist and therefore hinders any attempt towards that direction. Two respondents added that associations cooperate mostly during the organization of collective benefit events, of symposiums and conferences (N=4, other).

*‘We try to cooperate but we need time to do that, from the state every day we experience cutting in our resources, it is like they are trying to divide us. Now it is each association on its own, we need to survive’ (q22).*

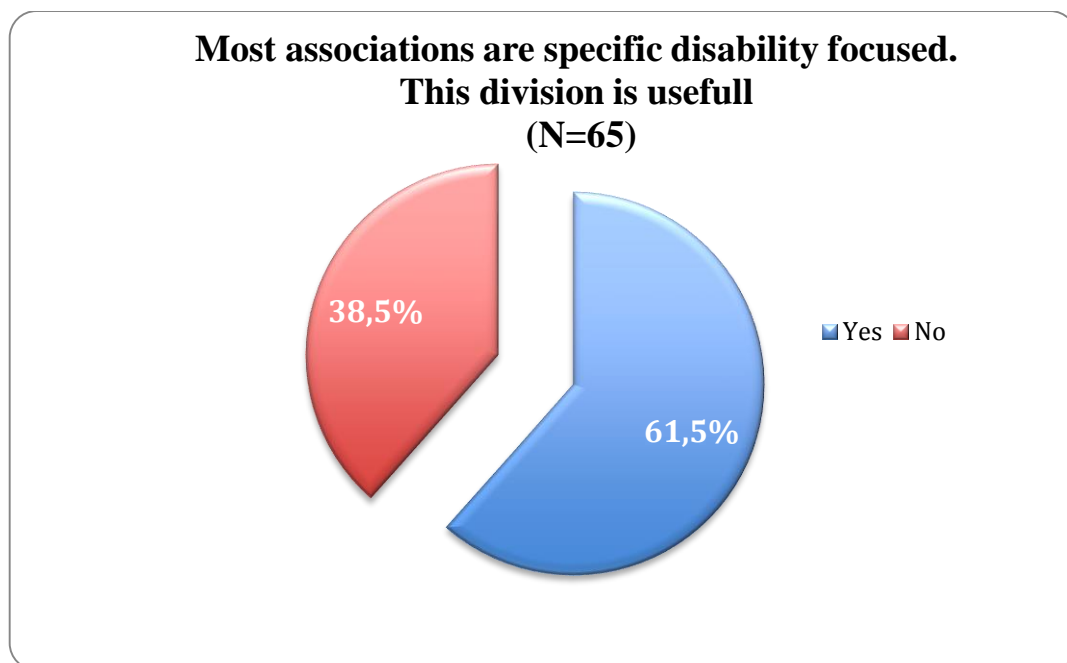
*‘Attempts are being made mainly when we are thinking of organising common events, but truly, in practice every association is trying to promote his individual needs’ (q42).*

<b>Cooperation, link and communication between parental associations for disabled children and young people</b>		
	Frequency	Percent %
Cooperation between association in the same geographical area or of the same disability group	16	25%
Cooperation only through NCPD and FPGA for SMDP	6	9%
Mutual needs and demands	5	8%
Most associations function alone	4	6%
OTHER	4	6%

**Table 9 Cooperation between parental associations for disabled children and young people (n=35)**

### 5.6.3.3 Parent Associations' types

In the survey 40% of the population agreed that the division between associations in order to represent a particular category of disabled people rather than maintaining a strict line and working for the demands of the rights of the disabled population is useful (61,5%) (Figure 18: The division between associations is useful/not useful). This is in alignment with the preliminary analysis statistics based on the associations list provided by FPGA for SMDP (see section 5.4) where it is shown that 38,5 % of the associations are focused on specific disability groups, with the vast majority being associations for children with learning disabilities and autism.



**Figure 18 The division between associations is useful/not useful (n=65)**

Participants were asked to elaborate on their answer and 60 of them provided their personal explanation (Table 10: The division of parental associations for disabled people is helpful). Participants who consider this division to be helpful placed their answers mainly on the fact that different disability groups have also different needs,

different priorities and objectives, therefore the associations have the opportunity need to specialize and focus in one disability area (N=26).

*'In our association primary concern is the education and socialization of the children and the awareness of parents on issues concerning autism and the wider public awareness. In other disabilities they have different problems and different priorities' (q9).*

*'An association specializing in a specific disability can essentially meet the specific needs of disabled children and their parents and more completely for sure. For example our association and the day care centre that we run are certified and specialize in children and young people with mental retardation and additional disabilities' (q 52).*

*'Already each disability is divided, and that is tones of information for each and every one, it is only wise for associations to be divided as well' (q 1).*

*'The problems are different for every association. For us basic priority is to help families of autistic children and their parents who are disabled themselves and have financial difficulties. We want to give to them what we didn't have 30 years ago' (q52).*

*'Every parent, for better or for worse, is specialised and knows better the problems of his child, because he lives with them and he is tired of them' (q60).*

Six more participants explained that the division is crucial because in their opinion the nature of each disability is different and because certain disability groups cannot co-exist. Here emerges the critical issue of exclusion and discrimination even between the associations for disabled people.

*'People with mental retardation are facing many problems, they cannot self-represent and they need specific associations to represent them fierce fully and essentially, we are a different association we cannot support everyone' (q 48).*

*'Of course the division is helpful because, for example, we cannot expect for blind people to co-exist with autistic people, or deaf people to co-exist with people with mental retardation' (q 17).*

*'The representation of each disability separately minimizes the problems, if things were different we would need more personnel and even then the results may not be satisfactory. Imagine the new problems to be expected when in the same place you will have people from different disability*



*categories where their behaviors are so different that they would end affecting each other negatively' (q 19).*

*'The multiple disability of our children is so complex and demanding that needs specialised knowledge and care' (q 44).*

*'In the degree that the associations come to cover for the incapability of our society in terms of SEN provision it is only expected that the association will represent specific disability groups. The representation works positively only when aiming to provide specialised services (q 55).*

On the other hand participants who consider this division unnecessary state that all associations should have common goals for all disabled people (N=16). Furthermore five parents explicated that the power and strength of the association lies in their unity and that it is against all the disabled population's best interest if they remain divided.

*'The protection of human rights, the care and SEN provision concerns all disabled people, it doesn't "see" categories, as it is also included in our association's statute and in line with the European standards. All children should be given the opportunity to be with other children' (q 26).*

*'An association counting 200 members is much more powerful and has greater appeal than an association representing specific disabilities and counts only 15 members' (q 33).*

*'The problems are the same for everyone. Division only brings conflicts' (q36).*

*'Collectively we work under the FPGA for SMDP umbrella but as association we should also be united in our demands for all disabled people, especially in provision and care issues, a problem common for everyone, no exceptions' (q 42).*

*'If we believe that the parental associations exist to demand solutions then we should be working side by side like a punch' (q 58).*

*'Some rights are universal for all children, especially in educational and social matters then what is the point of a division and specializing in promoting the rights of only specific people?' (q 63).*

Six participants provided other reasons to support the need of united associations such as the lack of state support which needs to be addressed collectively, the equal

allocation of financial resources to all associations, the better cooperation amongst associations and the elimination of discriminatory phenomena.

*‘The truth is that we cannot afford to include other disability groups, we simply don’t have the financial resources, and so we are forced to choose a specific disability. Nevertheless no association should replace the state and take over the responsibilities that the state mechanism should take on all these delicate matters. Unfortunately, what the state won’t do- the parents are forced to do. And so we organize associations on our own, in order to provide some solutions in our problems, the problems that we experience everyday with our own disabled child. But a division, no it shouldn’t exist’ (q 12).*

*‘Dividing the associations according to specific disabilities is not helpful, it is a temporary, quick fix, emergency solution, the only one that parents and the associations could find since the state is not able to deal with all these problems from the beginning, with the assistance of scientific and specialised experts’ (q 46).*

*‘This division has a purpose some associations always have the money to move forward, one sponsorship after the other. Other associations are considered small and then their funding gets cut. Who decides who needs money? Which disability is more privileged? We all need to be equal and fight the same cause’ (q14).*

*‘So many times we experience “racism” amongst the associations and against specific disability groups, this division should be forbidden, only then we would be certain that everyone is working for the benefit of all disabled children’ (q 2)*

*‘In addition the associations work antagonistically by promoting the demands of specific disability groups and then we have phenomena of exclusion within the disability movement, amongst disable people. Also we often see how the legislation favors only those who hold the power of self-representation’ (q47).*

The division of parental associations for disabled people is helpful		
YES	% from 40	
Different needs/priorities/more specialized in one disability area	26	65%
Discrimination between the different disability groups	6	15%

	NO	% from 25
Common goals	16	64%
Strength in unity	5	20%
OTHER	6	24%

**Table 2 The division of parental associations for disabled people is helpful (n=65)**

#### **5.6.3.4 The influence of parent associations' action**

The actions of PAs for disabled people have fairly affected issues concerning the legislative framework of the country (N=40) (Figure 19), the education (N=33) (Figure 20), welfare (N=27) (Figure 23) and care (N=24) (Figure 22). Parents, nevertheless, agree that their action has affected quite a lot the social context of the country (N=26) (Figure 21) and only a few issues of employment (N=23) (Figure 24) and the creation of independent/ semi -independent living structures (N=24) (Figure 25).

Some participants took the time to make notes next to this section of the questionnaire in order to provide explanations or add their personal comments:

*'The tertiary organisations need to place more pressure to the government' (q 2).*

*'The associations have a limited pressure capacity; the main force should be through the unions' (q 7).*

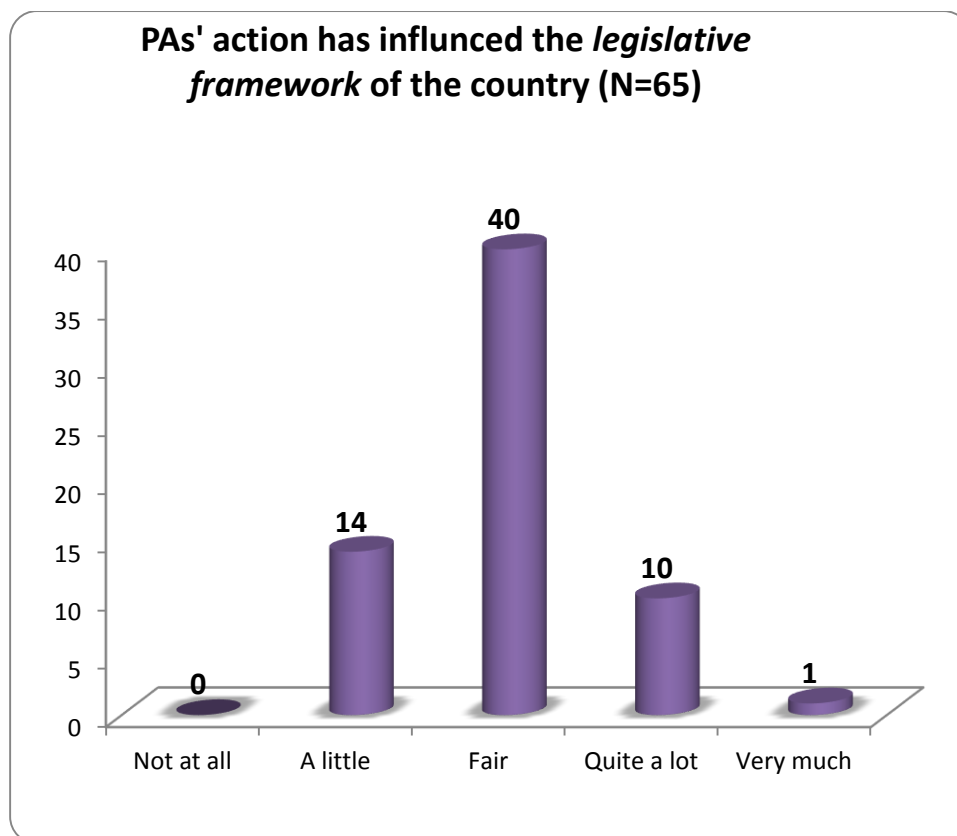
*'My greatest fear is that we will start to move backwards than keep progressing, I don't see how our effort will be continued. Who amongst the young people today will be able to accept and withstand to continue the work of our association when they have to deal with so many financial and other personal problems?' (q16).*

This question did not provided clear information and this is understandable if we consider what exactly is asked here. Participants are asked, in a way, to access their role and influence within the wider political, social and cultural context, thus it should be difficult for them to evaluate their own work and actions.

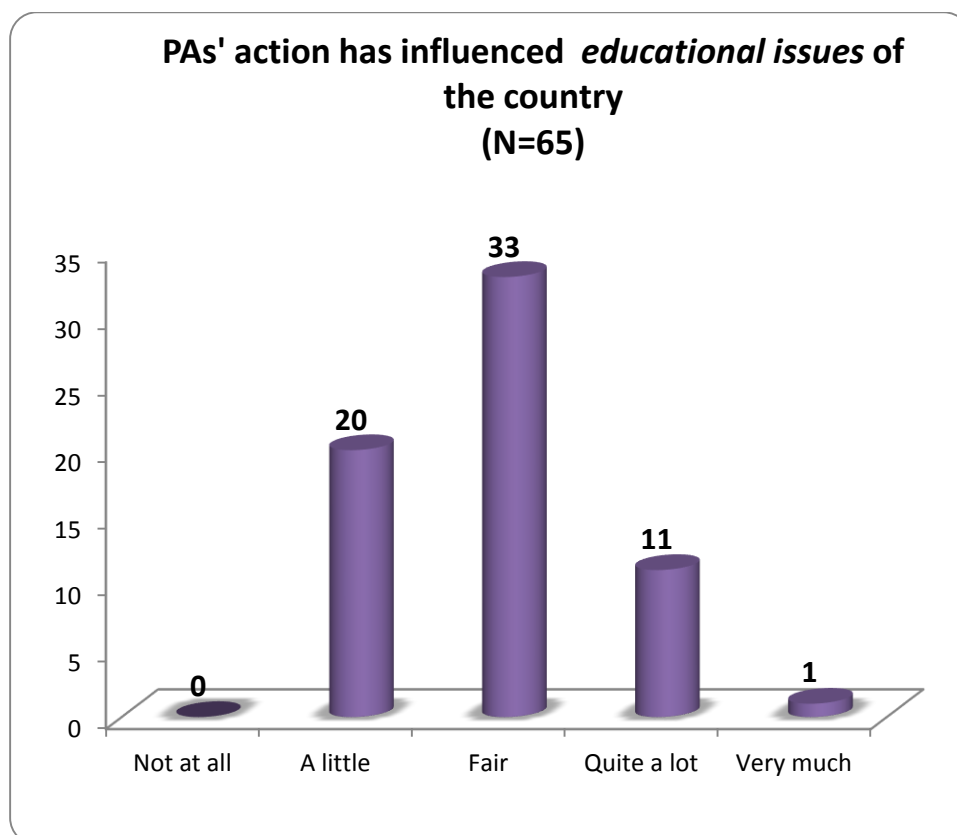
Most associations were formed to place pressure on the government and demand solutions, as it was elaborated earlier on this chapter, if the participants disclose that the actions of the associations were not at all able to influence reforms and changes at all, then their function would be considered pointless.

On the other hand they need to be realistic and therefore the participants do not exaggerate concerning their accomplishments, they appear modest in their answers presenting an image where they try for the greater good, maintaining their status and value but emphasising on the fact that there is need for more pressure for essential changes to occur. Most participants therefore chose to select the more neutral answer of 'fairly' in most sections.

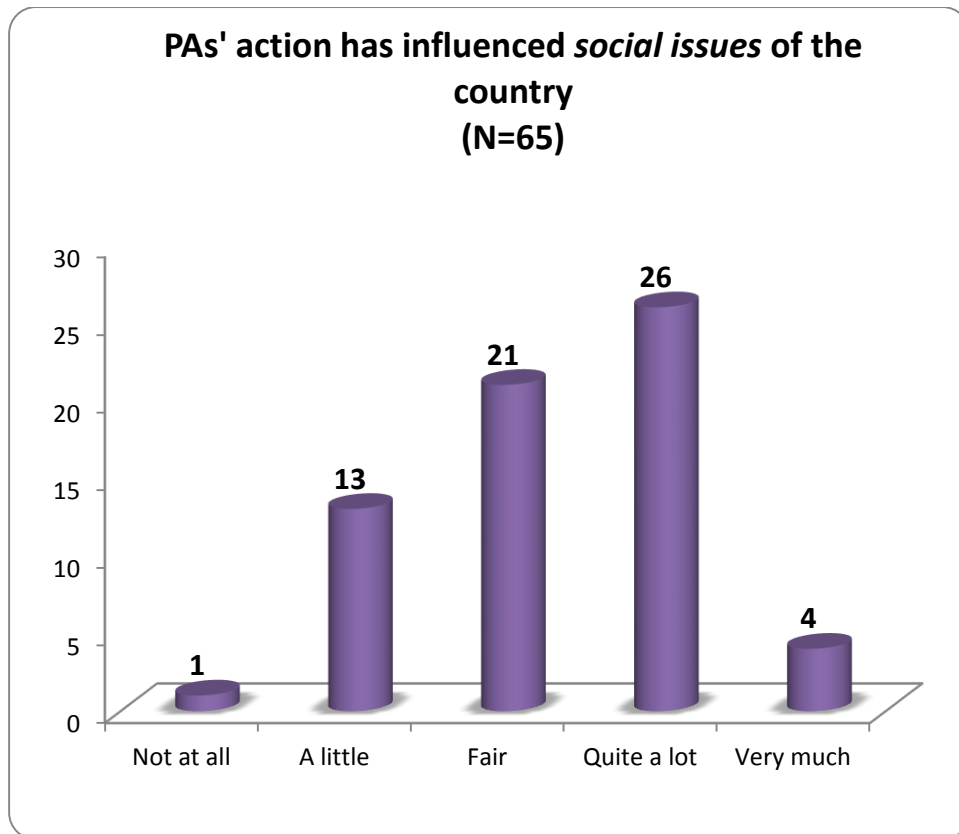
The only sections where the participants move away from the neutral zone and provide more useful information is on the section concerning the social context of the country where twenty six participants agreed that the actions and the persistence of the associations have influenced quite a lot the current situation. Also participants appear concerned about the level of influence they have managed to inflict concerning employment issues (N=23: a little; N=8: not at all) and the creation of independent/ semi-independent living structures (N=28: a little; N=5: not at all).



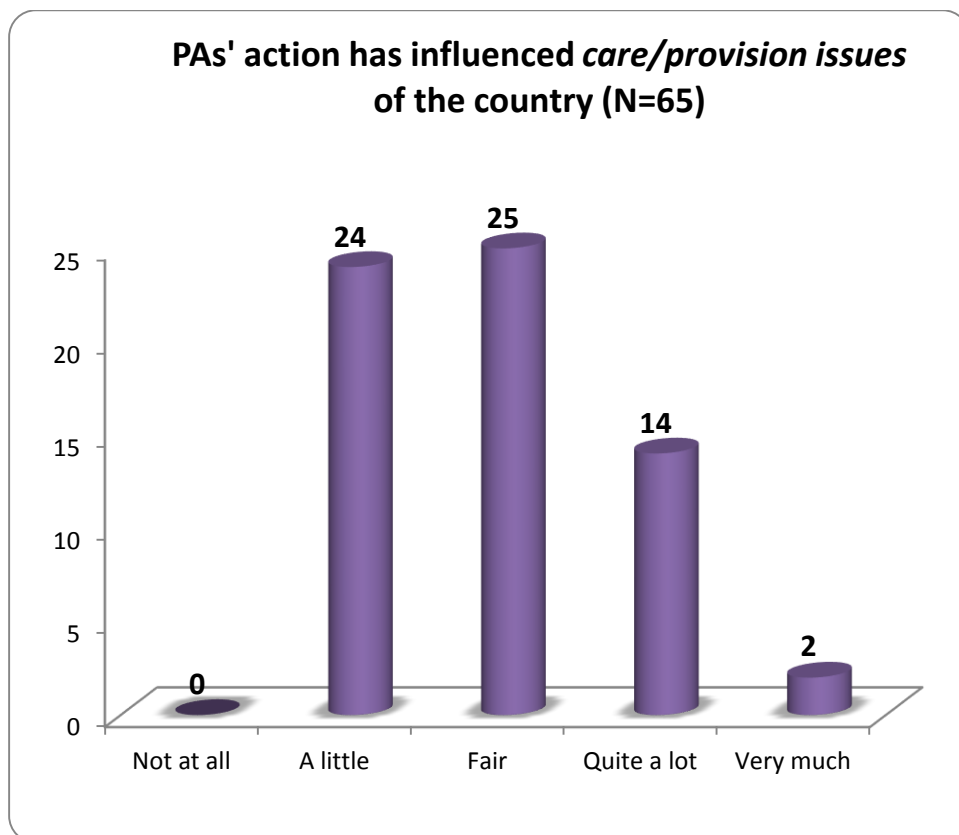
**Figure 19** PAs' action has influenced the legislative framework of the country (n=65)



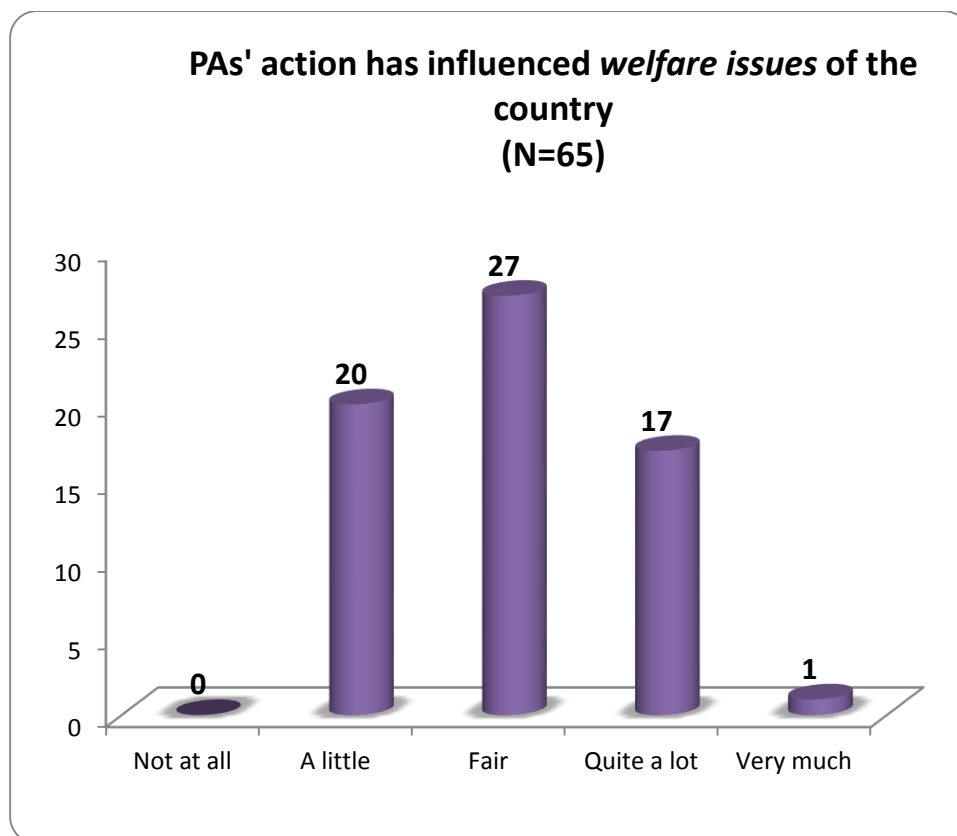
**Figure 20** PAs' action has influenced educational issues of the country (n=65)



**Figure 21** PAs action has influenced social issues of the country (n=65)



**Figure 22** PAs action has influenced care/provision issues of the country (n=65)



**Figure 23** PAs action has influenced welfare issues of the country (n=65)

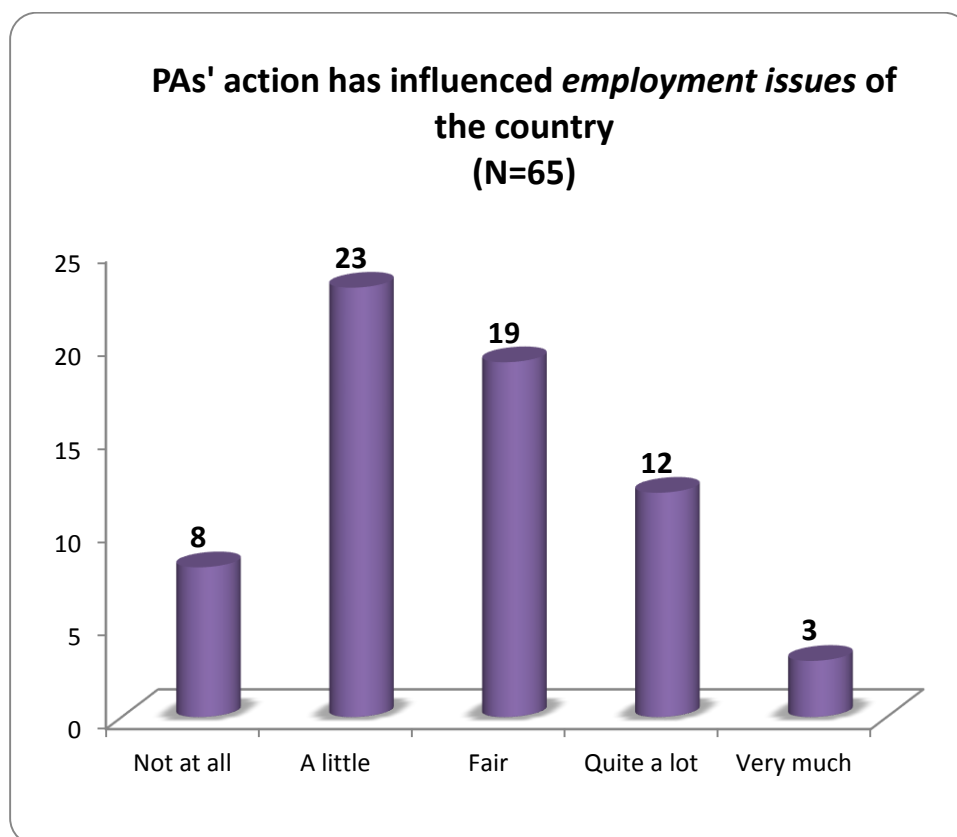


Figure 24 PAs action has influenced employment issues of the country (n=65)

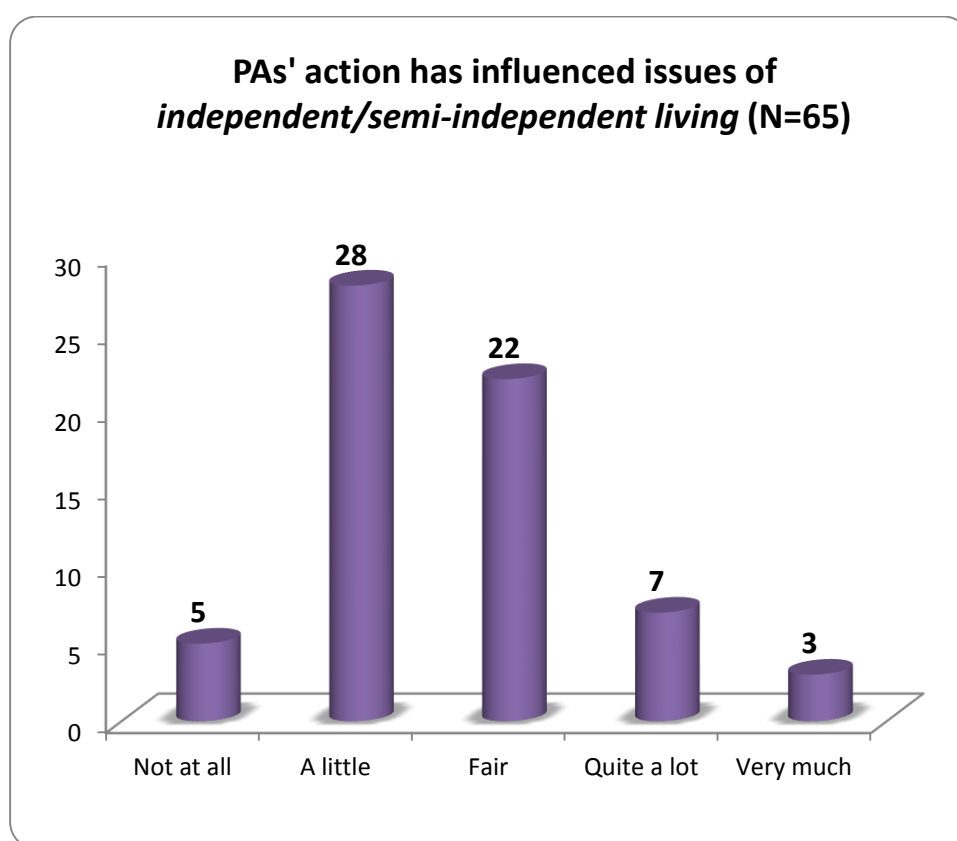


Figure 25 PAs' action has influenced issues of independent/semi-independent living (n=65)

#### 5.6.3.5 The promotion and claim of rights amongst different disability groups

Many participants maintained that specific disability groups claim their rights to a greater extent than others and therefore have achieved more (Table 11: Disability groups claiming their rights in a greater or lesser degree). To be more precise, respondents believe that people with physical disabilities (N=28), blind or partially sighted people (N=29), deaf or hard of hearing people (N=17) and people with long term health problems (N=5) have managed to secure better benefits and to promote their rights. On the other hand people with learning disabilities (N=22), people with multiple disabilities (N=19) and people with autism (N=3) are considered the least supported and least heard by the state and society. Moreover, thirteen of the participants believe that all disabled people claim their rights equally.



<b>Disability groups claiming their rights in a greater Extent</b>		
Physical disabilities	28	43%
Blind	29	45%
Deaf	17	26%
Long term health problems	5	8%
<b>Disability groups claiming their rights in a lesser extent</b>		
Multiple disabilities	19	29%
Learning disabilities	22	34%
Autism	14	22%
Other	3	5%
<b>All disability groups claim their rights equally</b>		
	13	20%

**Table 3 Disability groups claiming they rights in a greater or lesser extent (n= 65)**

What is more interesting is the variety of explanations provided by the participants in order to support their answer (Table 12: Differentiation of rights claim success between disability groups). The majority (N=22) connected the power of claiming ones rights with the level of self-representation abilities and skills. Therefore, they appear certain that people with learning or multiple disabilities and people with autism cannot advocate for themselves and that is the main reason why their demands remain widely unaddressed.

*‘Everyone has the same demands, but maybe the ones that hold the ability of self-representation hold also an additional pressure tool’ (q 61).*

*‘Because people with special needs without mental retardation problems can on their own claim their rights’ (q 20).*

*‘Because the disabled people with mental retardation cannot demand something on their own’ (q25).*

*'Because as adults some disabled people continue to claim their rights and make demands on their own, without the help of their parents. This is not the case for all disabled people' (q 31).*

*'Physically disabled people, deaf people, blind people can make their own demands and fight' (q 53).*

*'Because the first group that I mentioned has the ability of self-representation, on the other hand the second team that I mentioned unfortunately doesn't and therefore on their parents are left to interfere. The same parents who face every day the most difficult conditions in our country concerning the education of their children and the lack of social inclusion structures in general' (q 55).*

*'In some associations were the children don't have a voice of their own people take advantage of them and instead of making demands for the children benefit 'some' find the opportunity to promote their personal interests' (q28).*

This is in sync with the participants placing the extent of disabled people rights claims on the will and action of their parents (N=8). If their parents have the strength to promote and demand their children's rights then there is a way to move forward, but when the parents are no longer able to support their children then every chance of this pressure to be continued is paused.

*'People with special needs (for example the quadriplegic) are able to claim rights by themselves. Parents of children with more severe disabilities are organized in small associations according to their children disabilities and that divided them. As a result they lose their focus and their voice is not heard due to their size' (q3).*

*'The parent is the one who need to create the best conditions for his child. The state as the main organisation will not help. We had enough of all the laws-prophets, the ones that ensure that only a couple of us will be comfortable (q15).*

*'Their parents no longer have the strength to fight for them' (q34).*

Seven respondents believe that the discrimination amongst disabled people is growing and along with this increase comes the suppression of certain disability groups' voices and the reinforcement of others.

*'The disabled people themselves create casts, walls between them. They have raised barriers, consciously or unconsciously against the weaker ones, the ones who are depended. Instead of supporting them, taking them under their wing and fighting collectively. No, some disabled people are putting their 'egos' first. This overcomes even the turpitude of their families and of the society' (q 26).*

*'Not even the disability population works as a punch, united and strong' (q 58).*

*'Specific interests are promoted within the disability population, some are always pleased and some are always left out' (q64).*

From a different perspective respondents explain this differentiation based on the different levels of experience between disability groups within the collective disability movement, for example they believe that blind or partially sighted people were the first to raise their voices and therefore were the first secure their rights.

*'Blind people have constructed a strong front pressure' (q31).*

*'Blind people have the privileged of being the first to make demands' (q 28).*

*'Deaf and blind communities, are older in experience and they are better organised' (q 21).*

Other reasons include the differences in the severity of needs (N=6) and in this case respondents attempted to prioritise the possibility of some issues to actually be solved in the Greek context and the needs that they consider impossible to be resolved; and the size of the different disability groups (N=2) where the parents also appear trapped in the debate between the needs of the majority and the minority.

*'It depends on the degree and the disability severity and of course on the nature of the demands. For example the demand for quality education to be substantial needs a lot of work. It is not a demand that can find a quick fix solution' (q 57).*

*'More people equals more pressure. The government is not interested in individual cases, in few people, with the exception of when someone well known, someone famous is involved' (q16).*

<b>Reasons for the differentiation of rights-claim success between disability groups</b>		
Not the same ability to self-represent themselves	22	34%
Depends on the will and action of parents	8	12%
Discrimination issues amongst disabled people	7	11%
Oldest in "rights-claim" experience disability groups	6	9%
Different severity of needs	6	9%
Different populations in size	2	3%

**Table 4 Differentiation of rights claim success between disability groups**

#### **5.6.3.6 Disabled students position within general/mainstream education**

Participants were also asked to identify the disabled pupils who in their opinion can attend mainstream education (Table 13: Disabled pupils who can attend mainstream education). Although the questionnaire did not provide an open comment section in this specific question, nevertheless, many participants felt the need to add their own personal comments and a selection of their quotations will be included in the analysis.

According to the parents answers students with learning difficulties (95%); environmental and social problems (83%); physical disabilities (82%); speech and language difficulties (74%); behavioral problems (72%); and blind/ partially sighted children (71%) are high on the list of being able to be educated within mainstream educational settings.

*'In general the state holds a racist perspective concerning the education of disabled students when 89% of our children are excluded of the education system. We need to have a law to make the education of disabled children obligatory and to implement that law effectively' (q 22).*

*'My answer is based on the fact that we are referring to 'mild' disabilities and that accessible structures are available' (q 12)*

As we continue interpreting the results we can observe how the check answers reduce, therefore suggesting that students with psychological problems (66%), deafness/hearing problems (65%), AD/HD (65%) and epilepsy (52%) are less probable according to the participants' views to be educated in mainstream education.

The students that were less selected as being able to attend mainstream schools are those with learning disabilities (49%), health problems (48%), autism (38%), mental disorders (38%) and multiple disabilities (26%).

*'For autistic children and after the primary education the situation is very difficult' (q 7).*

*'If we want to be realistic, only a few disability groups, or more likely none of the above, can attend general education' (q 64).*

Keeping in mind that the participants are well aware of the disabled children's rights in education, by being active in the associations, and the growing demand for school inclusion, we cannot be certain whether the parents answered based on who amongst the disabled students 'can' or 'should be able/have the right' to attend general education settings. Also, it is debatable whether they interpreted the use of 'can' as students having the skills required to attend general education or as structures being accessible and ready to meet the students' needs.

*'We believe that ALL children should be educated in mainstream education but with the appropriate support and structures' (q 8).*

*'Of course as long the educationalists in those structures have the right attitudes, values and they are specialised (q 20).*

*'All children, based on the legislation, have the right of enjoying free public education' (q 31).*

*'When and if the educational settings and their participants change their ideology and their attitudes' (q 42).*

*'All disable students. It is their constitutional right' (q54).*

*'All disable children can be educated, some can only be trained to develop on self-service skills and others may reach higher educational levels' (q 19).*

Even in this group of participants who are more informed and educated on the social aspect of disability we can again make the observation, based on the answers provided, that not all pupils with disabilities can attend mainstream education; again students with learning disabilities, autism, mental disorders and health problems are considered the least able to attend mainstream education. The most interesting finding in this section is that the category that was least selected is the one of multiple disabled students.

*'It is impossible for me to answer because in our institution the 22 disabled people living here are aged between 15-65 years old, they have an average I.Q of below 30% and additional disabilities. All these characteristics do not allow them to be educated in the general education settings' (q 15).*

*'All disabled children depending on the level of severity of their conditions and their level of communication. But most importantly we need to ensure that they will get the support that they need' (q 43).*

*'During primary education all disabled children can attend general education. The problems start during secondary education. In some cases students may need special education schools, especially in the case of multiple disabilities and severe mental retardation' (q46).*

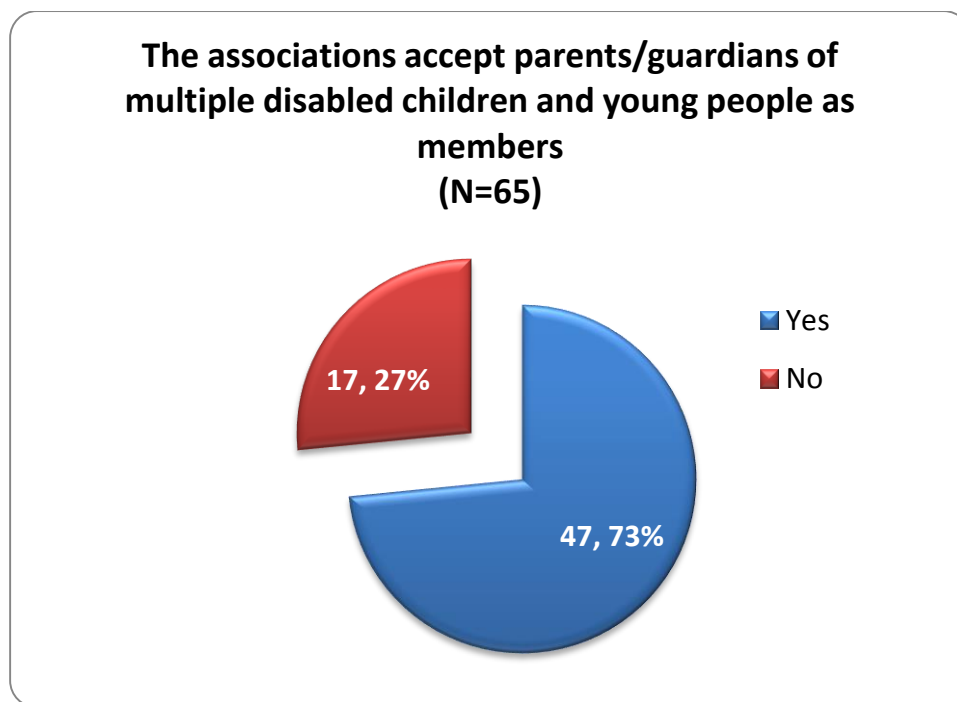
<b>According to the participants' opinions and experiences the disabled pupils presented in this table can attend mainstream education</b>	<b>Frequency</b>	<b>Percent %</b>
Learning difficulties	62	95%
Environmental/ Social Problems	54	83%
Physical disability	53	82%
Speech and language difficulties	48	74%
Behavioral Problems	47	72%
Blindness/Partially Sighted	46	71%
Psychological Problems	43	66%
Deafness/Hearing Problems	42	65%
AD/HD	42	65%
Epilepsy	34	52%
Intellectual disabilities	32	49%
Health problems	31	48%
Autism	25	38%
Mental disorders	25	38%
Multiple disabilities	17	26%
Other	9	14%

**Table 5 Disabled pupils who can attend mainstream education (n= 65)**

#### **5.6.4. Information concerning children with multiple disabilities and their needs:**

##### **5.6.4.1 Members/parents of the association with multiple disabled children**

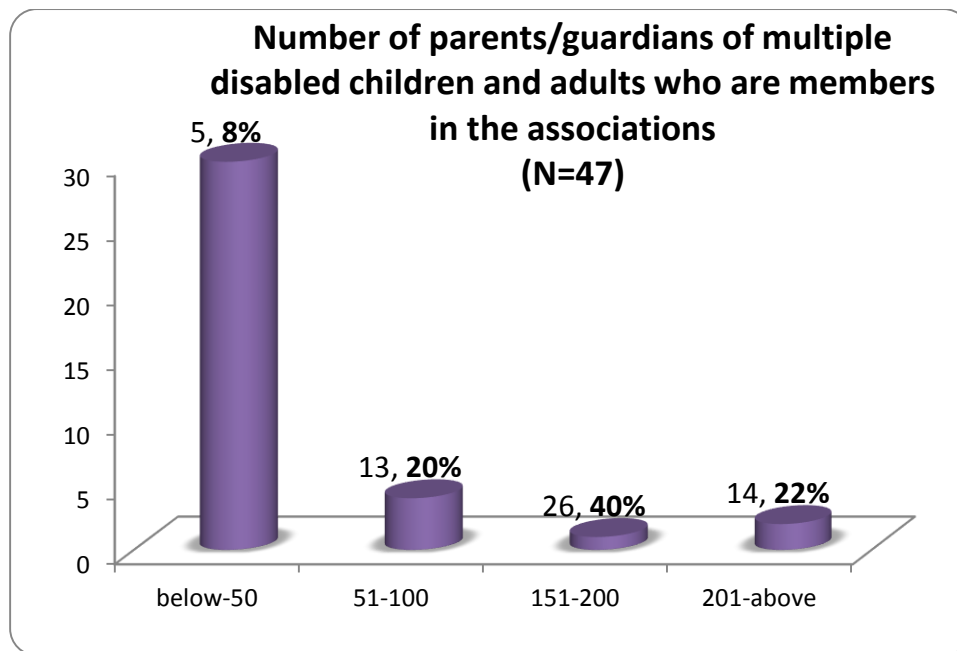
Almost 48% of the associations participating in the survey include as members parents of children with multiple disabilities (Figure 26: Percentage of associations that accept parents/guardians of multiple disabled children and young people as members). This information is valuable in order to confirm that the answers provided from the participants are not merely based on their ideological or theoretical perspectives but also from practical experience with families of multiple disabled children.



**Figure 26 Percentage of associations that accept parents/guardians of multiple disabled children and young people as members (n=65)**

An important percentage of the participants provided details concerning the number of their members who are also parents of a multiple disabled child (Figure 27: Number of parents/guardians of multiple disabled children and young people who are members in the associations). According to the following chart the parents/members with a multiple disabled child in the majority of the associations do not exceed 50 members, with a small percentage of associations (14%) who include more than 200 members with multiple disabled children.





**Figure 27** Number of parents/guardians of multiple disabled children and adults who are members of the associations (n=47)

Participants also provide specific details on the types of multiple disabilities included in their associations. The aim of asking the participants to name specific types of multiple disabilities was not to create categories of multiple disabled children but to investigate through a different perspective how parents describe and therefore define multiple disability. In 26 out of 31 answers the combination of two or more disabilities is clear. The respondents use the connecting words: *and* or *with* to express that. In five cases the combinations are not clear because of the use of commas between words. From this it is obvious that parents in their majority agree that multiple disability is a combination of disabilities. Parents use the terms '*mental retardation*' or '*mental impairments*' to convey the meaning of learning/cognitive disabilities, and also use the terms '*quadriplegia*' and '*paraplegia*' to convey the meaning of physical disabilities. The combination of learning disabilities and physical disabilities appeared 16 times in the answers of the participants. Six times we come up against the combination of learning/cognitive disabilities and additional disabilities and only five times the combination of autism and learning disabilities. The terms:

*'severe case of autism'* and *'severe case of epilepsy'* appear alone in order to describe a multiple disabled child. The terms *'and other disabilities'*/ *'and accompanying disabilities'* /*'and additional disabilities'* also appear often in the descriptions of the participants to complete the main disability in which they are referring (N=10), for example *'Visual disability and additional disabilities'* (q 44).

The associations who do not include parents of MD children and young people in their associations provide specific reasons for this decision. Some associations have aim to support daily care centres, workshops, special schools and institutions for disabled children, but the enrollment in these structures is guided by explicit conditions and regulations, therefore, not all disabled children can be included but only the ones with the specific characteristics agreed in the statute of each association.

*'Because as part of our association we have constructed and organised workshops for the professional rehabilitation of people with mental retardation, the involvement with other disability categories would cause many problems in our smooth function'* (q 20).

*'We run a workshop and we can only accept certain children'* (q 15).

*'Our day care centre and our institution attend only children with mental retardation, it is the regulation of our association'* (q 17).

*'Our day care centre accepts children with mild mental retardation and basic self-service skills'* (q 29).

*'We have an institution and here we can only accept disabled people with: an average I.Q of 30 and above , who are over 18 years old, whose state insurance covers their expenses and have a legal representative'* (q 34).

Other associations are specific disability focused and they wish to remain concentrated on specific aims and objectives for a certain group of disabled children and their parents.

*'We are dealing with mental retardation. In some cases, as an exception and in very few occasions, we also accept children with multiple disabilities' (q 2).*

*'Our association includes only parents of autistic children (q 21).*

*'The needs of autistic children in Crete and the growing population do not allow us to involve other disabilities' (q 45).*

*'In our association main aim is to create and support semi-independent living structures. There we want to provide care and education for disabled children who have disabled parents, are in great need, they only have one parent, are in a very low financial situation' (q 52).*

*'Our association has specific goals concerning children with autism and the creation of a specialised educational centre' (q 57).*

#### **5.6.4.2 The most appropriate association for parents with a multiple disabled child**

The majority of the participants were not aware of a specific association most appropriate for parents of multiple disabled children and adults (N=26) or where the parents should refer to in order to be provided with more information (Table 14: Parental associations most appropriate for parents with MD children and adults).

*'The association which will promote and demand their rights, away from syndicalism and personal interests' (q 26).*

*'All associations should accept all disabilities' (q 26).*

*'Children with aggressive autism cannot fit anywhere, for other children there has to be an association responsible' (q 34).*

Fifteen respondents answered that they should refer to associations specializing in multiple disability matters but only five of them provided specific associations' names. Other participants (N=12) explained that this information can only be provided by the tertiary organisations of FPGA for SMDP and NCPD who are responsible for the record keeping and the activities of each parental association.

*‘This question should be better answered by FPGA for SMDP’ (q 20).*

*‘You need to address to FPGA for SMDP for more information’ (q 45).*

Finally twelve respondents believed that all the associations without a specific disability focus should accept parents of multiple disabled children as members.

*‘I would suggest an association without a specific disability orientation, but the best would be for every disability to have each own association’ (q.27).*

*‘An association compatible with the parents’ ideology and that works towards demanding education and future rehabilitation for multiple disabled children’ (q 37).*

*‘There isn’t an appropriate or inappropriate parental association. But parents should at all times avoid profit organisations disguised as associations’ (q 41).*

<b>Parental associations most appropriate for meeting the needs of parents with multiple disabled children and adults</b>		
Don’t know	16	25%
Associations specializing on multiple disability matters	15	23%
They need to address FPGA for SMDP and NCPD for information	12	18%
Associations not specific disability oriented	12	18%

**Table 6 PAs most appropriate for parents with MD children and adults (n= 55)**

#### **5.6.4.3 The main challenges for multiple disabled children and adults**

Participants consider equally important the challenges concerning legislation, education, vocational rehabilitation, welfare and provision, medical and health issues, social, autonomy and the existence of independent/semi-independent services (Table 15: The main challenges for MD children and adults). The social (94%) and

educational challenges (92%) are the ones that were selected more frequently. Only four participants chose to extend the list by providing other answers than the ones included in the questionnaire. Those participants consider as challenges: the need of psychological monitoring and support; and the danger of exploitation or abuse by the staff caring for children with multiple disabilities. Only one participant explained that there is no need to prioritise the challenges but there is an urgent need to face them.

*‘Children and their parents need to be followed and supported by psychologists from the very first time that their diagnosis is concluded’ (q 3).*

*‘Appropriate care by a specialised and expert staff, with love and sensitivity and the avoidance of any form of mistreatment of these children due to their lower defense mechanisms and abilities (q 20).*

*‘I don’t believe that there is a greater or lesser priority in the above issues. We need to attend and find solutions for all of them-yesterday and simultaneously (q 15).*

<b>The main challenges for MD children and adults according to the participants opinions and experiences</b>	<b>Frequency</b>	<b>Percent %</b>
Legislative	51	78%
Educational	61	94%
Vocational Rehabilitation	50	77%
Welfare/Provision	55	85%
Medical/Health	52	80%
Social	60	92%
Autonomy	55	85%
Independent/ Semi -independent services	51	78%

**Table 7 The main challenges for MD children and adults (n= 65)**

Again in this answer the main objective was for the members to number these challenges based on priority (Table 16: The main challenges for MD children and adults in priority order). Through this perspective we come to the conclusion that 13 parents were consistent and again prioritized education as the greatest challenge, while this is followed by issues of care and welfare (10). As the least priority parents

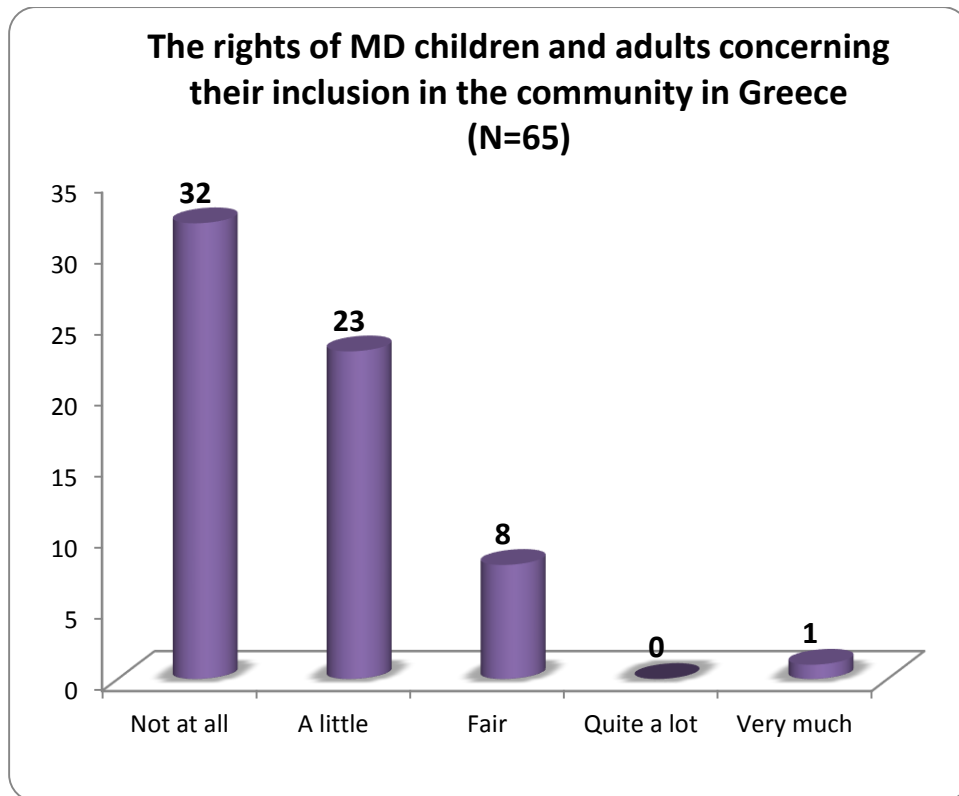
considered issues of vocational rehabilitation (4), social issues (5) and issues concerning the autonomy of multiple disabled children and adults (7).

<b>The main challenges for MD children and adults according to the participants opinions and experiences in priority order</b>								
	1st	2nd	3rd	4th	5th	6th	7th	8th
Education	13	13	9	5	7	8	3	1
Care/Welfare	10	12	5	9	4	9	3	2
Legislative	8	5	4	4	5	8	16	8
Medical	8	4	4	2	2	6	7	16
Independent/ semi-independent living services	7	12	4	7	7	2	3	7
Autonomy	7	9	12	14	7	1	3	2
Social	5	6	18	10	13	5	0	2
Vocational rehabilitation	4	1	4	6	7	10	11	6

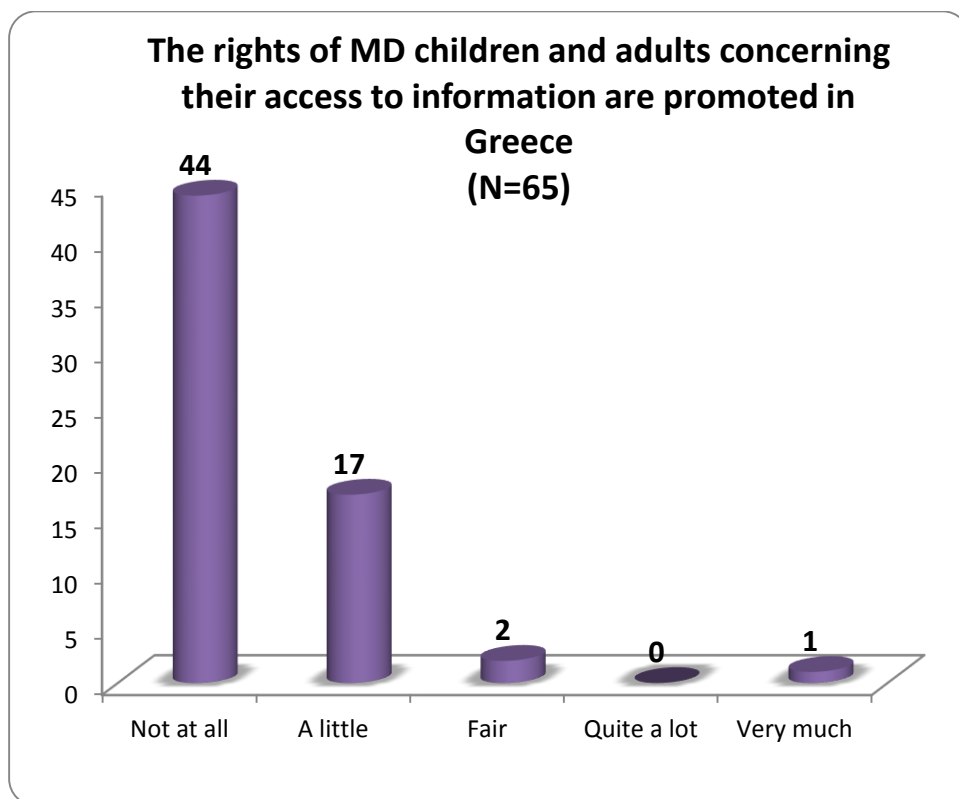
**Table 8 The main challenges for MD children and adults in priority order (n=65)**

#### **5.6.4.4 The promotion of multiple disabled children's and adults rights in Greece**

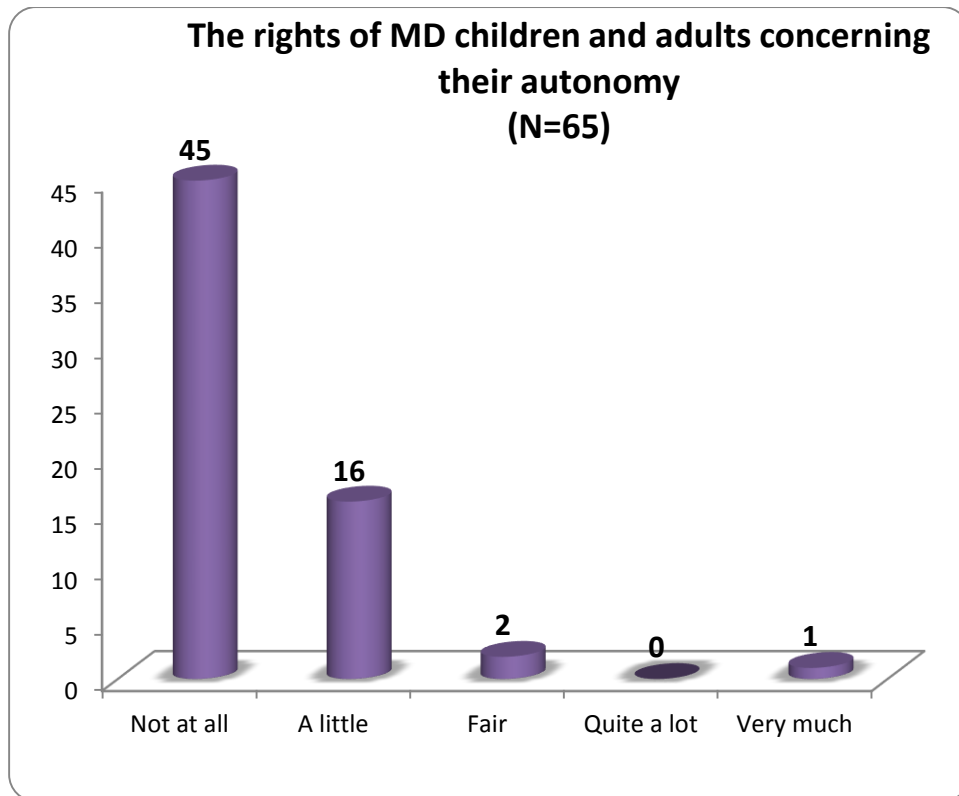
Overall, the promotion of multiple disabled children's and adults' rights in Greece raises concerns amongst the participants. Rights regarding their inclusion in the community (N=32) (Figure 28) , their access to information (N=44) (Figure 29) and their autonomy (N=45) (Figure 30) are not at all promoted according to the majority of the participants' experiences.



**Figure 28** The rights of MD children and adults concerning their inclusion in the Greek community (n=65)



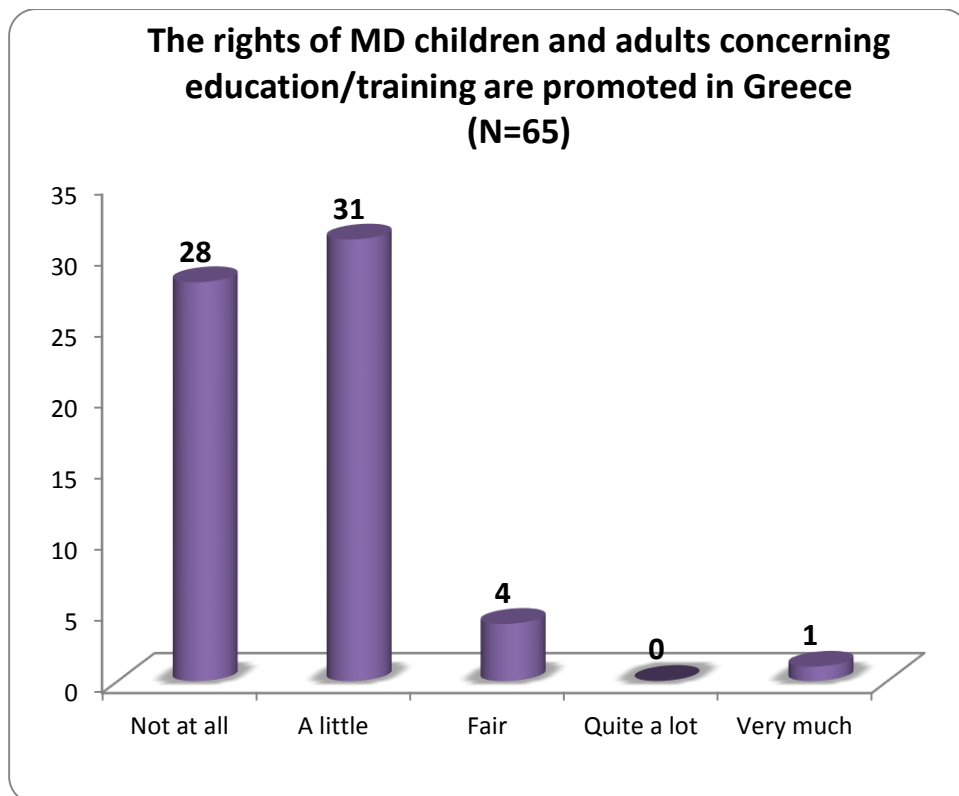
**Figure 29** The rights of MD children and adults concerning their access to information (n=65)



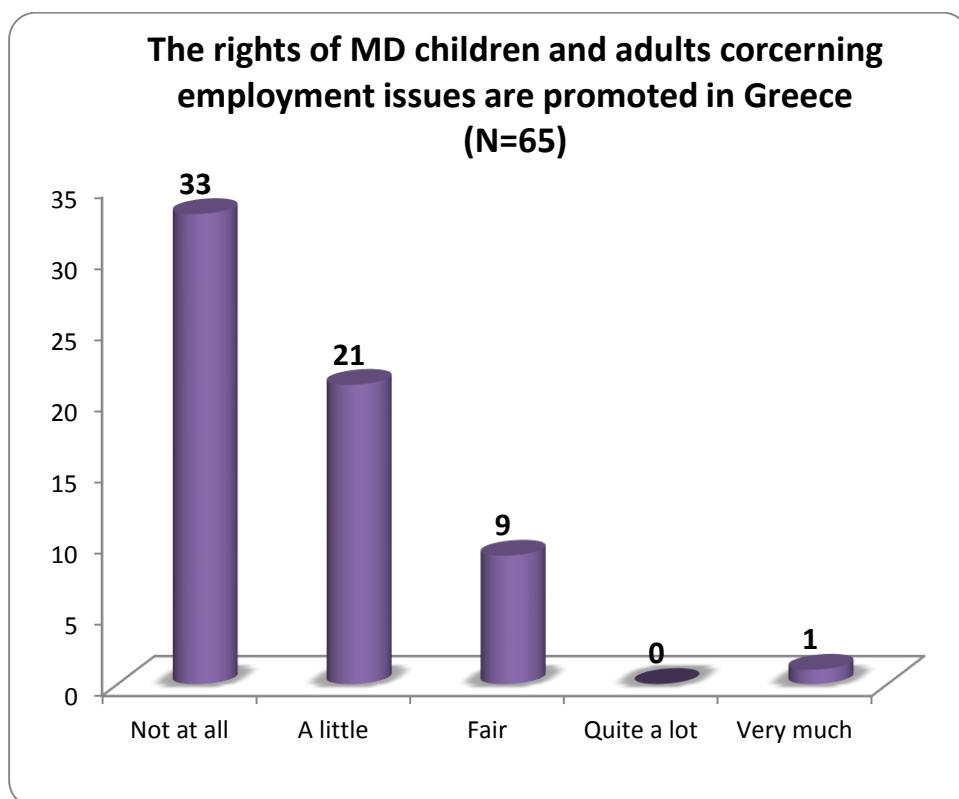
**Figure 30 The rights of MD children and adults concerning their autonomy (n=65)**

Similar results are presented when the respondents are asked to evaluate the promotion of multiple disabled children's and adults' rights regarding education and training (N=31: a little; N=28: not at all) (Figure 31), employment (N= 21: a little; N=33: not at all) (Figure 32) and the development of daily living skills (N=33: a little; N=24: not at all) (Figure 33). Here the participants state that they can detect a very slow move towards change while others believe that these rights continue to remain completely unaddressed.

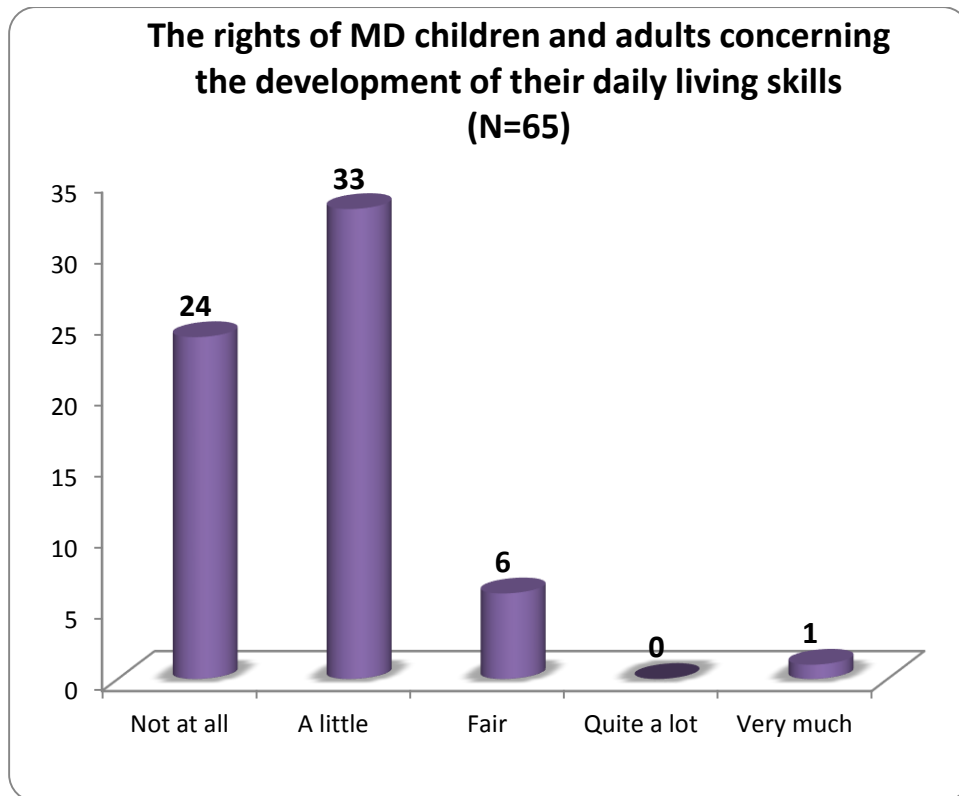




**Figure 31** The rights of MD children and adults concerning education and training (n=65)

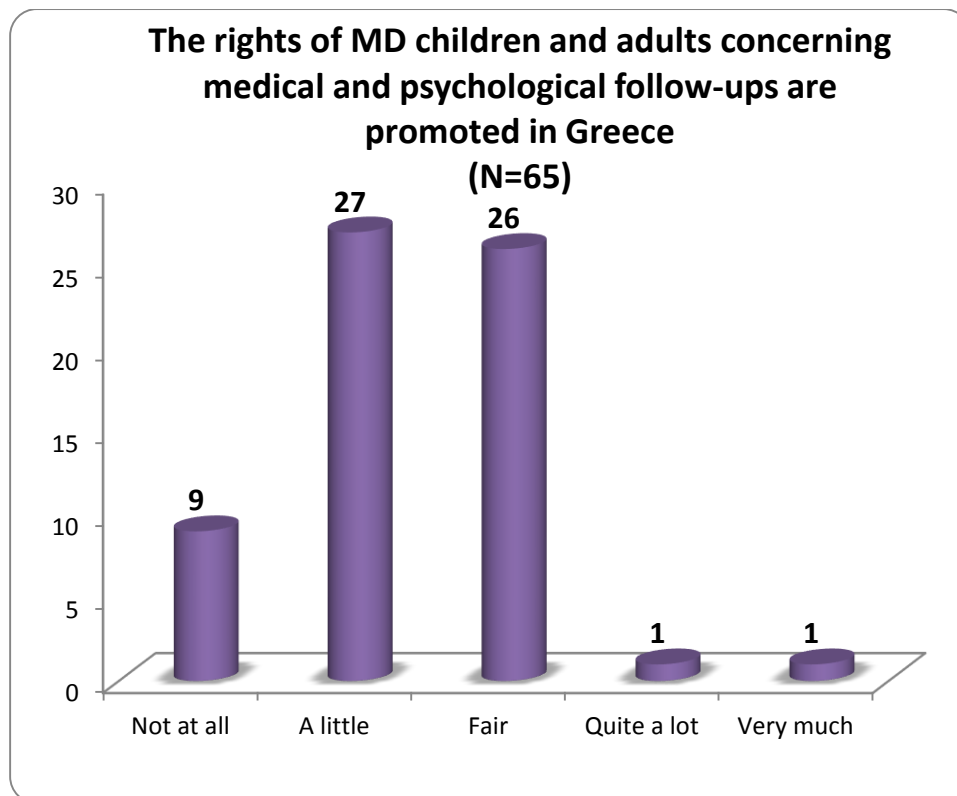


**Figure 32** The rights of MD children and adults concerning employment issues (n=65)



**Figure 33 The rights of MD children and adults concerning everyday living skills (n=65)**

The only set of rights where participants noted progress was the one regarding the medical and psychological follow up of the children (Figure 34). Here again, we notice that the rating is low but in comparison with the above-mentioned rights, the care and provision offered to multiple disabled children appears more elevated. It is the only section where many participants considered that the rights of multiple disabled children are promoted fairly (N= 26) and others noted a little progress (N=27).



**Figure 34** The rights of MD children and adults concerning medical and psychological follow-up (n=65)

Participants in this part of the questionnaire were asked to evaluate the promotion of multiple disabled children rights according to their experiences and opinions. If we compare this question with the previous one concerning the influence of the parental associations' actions towards the promotion of disabled children's rights in Greece, we can notice that the participants answered without restrictions. In the previous question the restriction may have been that the parents interpreted the question as an assessment of their own actions and value, therefore needed to be more careful in their answers. In this case participants are asked to evaluate the participation and influence of the state and society in the promotion of the above mentioned rights and thus drew a more realistic picture of the current situation.

#### **5.6.4.5 The appropriate educational context for students with multiple disabilities**

The participants provided different opinions when discussing the issue of the most appropriate educational placement and context for MD students (Table 17: The appropriate educational context for MD students). Again, the majority (19%) appeared indecisive or uncertain to provide a specific answer. Participants either are not aware of which educational context would be appropriate for the education of MD students or they considered that the appropriate setting can only be determinate based on each child individually and depending on his/hers specific multiple disabilities.

*'It depends on their types of multiple disabilities' (q 35).*

*'It depends on the nature of the disabilities that the child is experiencing' (q 38).*

*'It depends on the severity of the case' (q 42).*

*It depends. Maybe inclusive settings for primary education and special schools and workshops, semi-independent living structures later on (q 56).*

*'This depends on whether there are inclusive educational settings with the support of special teachers along with the general education teacher, teaching assistances, effectively working CEDDAS. Since all of the above do not exist then the children are dumped in special education' (q 59).*

*'We have to look into the combination of disabilities first and then we can direct the child to the appropriate educational setting and program' (q 55).*

*'I cannot provide an opinion, I am not an expert in this field' (q 60).*

*'There isn't a general answer; it depends on the needs of each child' (q 44).*

Amongst the respondents that provided an answer, nineteen of them identified the daily care centers structures and sixteen of them the special education structures, as appropriate to provide education for multiple disabled students.

*'Special schools or day care centres' (q 30).*

*'Special educational structures with specialised teaching and other staff to meet the needs of multiple disabled children' (q 37).*

*'A specialised on multiple disability centre' (q 57).*

*'Special schools until the age of 15 years old and for the secondary education after the age of 15 years old, special settings for training and development of skills along with the appropriate consultant and psychological support. Nevertheless it is a primary demand to educate the society first in order for these students to be accepted everywhere' (q 53).*

*'Special schools consisted of different experts' (q 54).*

*'The children that are considered trainable can attend special education, but only until they reach a certain age' (q 45).*

Fourteen participants were confident that multiple disabled students should be included in the general education system through inclusive educational structures.

*'Co-education and educational inclusion, so that we can succeed in ensuring social inclusion' (q 1).*

*'All children should be able to attend general education settings regardless of their disabilities, in a wider school. Children with disabilities progress and have opportunities to socialize with other children and non-disabled children learn to co-exist with disabled children' (q 7).*

*'An inclusive educational context with the aim to escape isolation' (q 31).*

*'General school. Almost all the new researches on disability show that the co-education with children of typical development helps children with disabilities in the higher degree possible and in all levels (education, socialization, etc.) (q 41).*

Less participants believed that MD students should be placed in independent or semi-independent living structures (N=4) and vocational training structures (N=3).

*'Day care centre or semi-independent living structures' (q 22).*

*'Specialised centres and appropriate structures of vocational rehabilitation' (q 62).*

Two participants do not name a specific educational structure, as they maintained that any school environment that is welcoming, provides security, love and support and is staffed with trained and well-educated educationalists, will be appropriate for all MD children and adults.

*'In any structure where the educationalists are working as professionals and at the same time with humanity and love to these children, educationalists cannot consider their work a chore' (q 16).*

*'An educational context which will offer motivation, flexibility and creativity, development of children's self-confidence, promotion of their abilities, connection with the society, interaction with other children. The development of skills away from the strict academician contexts' (q 26).*

Only one participant in the survey referred to early childhood intervention structures.

*'We need appropriate educational settings for early intervention and preschool education, which do not exist and could help children with multiple disabilities develop some skills and then we can start talking about educational settings. Today I don't believe that an appropriate educational setting for children with multiple disabilities exists, since no one is supporting the children in their first steps' (q28).*

Another interesting point is that five of the participants did not name a specific educational context for multiple disabled children due to the fact that they did not believe that it exists.

*'An appropriate and accessible structure, specialised teaching staff, legislation for the education of children with multiple disabilities. What is now considered as obvious in Europe is still nonexistent in Greece' (q 12).*

*'It doesn't exist; children with severe disabilities remain isolated in their homes' (q 32).*

*'For children who have a good cognitive development there are, but for children with severe disabilities none' (q 33).*

*‘There isn’t one, if we could count on state support to create appropriate workshops maybe something better would happen’ (q 34).*

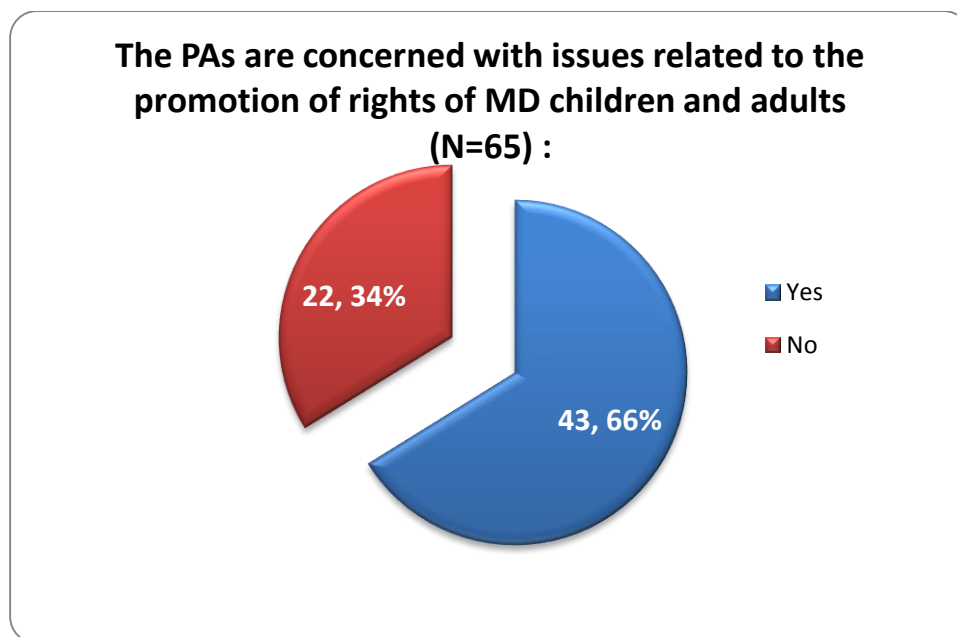
*‘When we are referring to children with multiple disability problems, severe mental retardation or mental health problems there are no schools in any case’ (q 52).*

<b>The appropriate educational context for MD students</b>		
Don't know/depends	20	31%
Daily care centres	19	29%
Special education structures	16	25%
Inclusive education structures	14	22%
Does not exist	5	8%
Independent/ Semi-independent living structures	4	6%
Vocational training structures	3	5%
Any school environment that will provide love and support	2	3%
Early intervention structures	1	2%

**Table 9 The appropriate educational context for MD students (n=65)**

#### **5.6.4.6 Actions towards the promotion of multiple disabled children’s and adults’ rights**

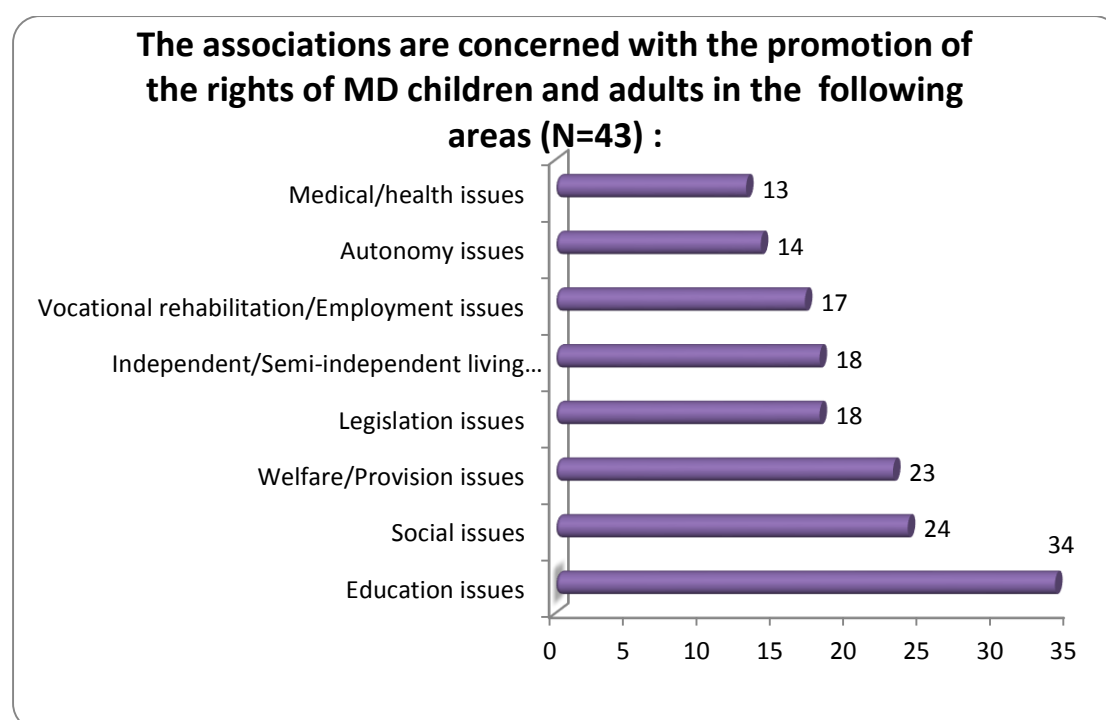
Amongst the participants of the survey 43, 66% stated that their parental associations are concerned about issues related to the promotion of rights of MD children and adults (Figure 35: The associations’ involvement with the promotion of MD children’s and adults’ rights).



**Figure 35 The PAs' involvement with the promotion of MD children's and adults' rights (n=65)**

Their main action is based on promoting the rights of children in education (34) by placing pressure on the state to create more school buildings, increase the quality of education provided for MD children and adults; the social rights of children and adults (24) and the rights in care and welfare through the creation of daily care centers, (23). Associations are also concerned in changing the existing legislation (18), the creation and function of independent/semi-independent living structures (18) and the vocational rehabilitation of MD people through their training in protected vocational workshops. Associations who have an interest in promoting the autonomy of MD children and adults (14) or who are concerned in medical issues (13) are considerably less in number (Figure 36: Areas of PAs involvement regarding MD children and adults).





**Figure 36 Areas of PAs involvement regarding MD children and adults (n=43)**

Additionally, the participants were asked to provide a list of their main actions and activities towards the promotion of MD children's and adults' rights. The participants, while providing more details concerning their main activities, took also the time to note how many of their efforts have now been paused due to the lack of state support and funding. Most of the associations (N=18) are dealing with programs and events aiming to raise awareness on disability issues and provide information to schools and communities.

*'We organise events and symposiums for the awareness of our community' (q 24).*

*'Information and awareness on disability issues through the organisation of symposiums and events, social benefits, also we regularly make our demands and problems known to the appropriate ministries (q 27).*

*'Society awareness. Our children have been included equally in our community, they have fun, they participate in the community life and they are accepted. We organise events, lectures, experts' visits' (q 48).*

Twelve associations have prioritised the need of creating and organizing independent and semi-independent living structures for MD people and their main activities aim towards accomplishing this goal (Table 18: Specific actions of parental associations for MD children and adults). Nevertheless parents reported that even after continuous efforts, lack of state support and limited funding prevent them from implementing their plans.

*'We are trying to create an independent living structure but we keep stumbling on new obstacles' (q 16).*

*'The creation of contemporary sheltered, fulltime or part time workshops (...) the creation of permanent independent and semi-independent living structures (not in the form of institutions)' (q 26).*

*'We are trying to create shelters and a boarding school of long term hospitality' (q 56).*

*'Living shelters with educational services: self-care, communication and socialization. Our aim is to develop and improve the skills of the children (q 64).*

*'All the problems have the same gravity in our opinion. When we find a solution to a problem we make new priorities. At this moment our concern is to create and operate a centre of open hospitality' (q 36).*

Also some associations (N= 11) are trying to create daily care centers, boarding schools and sheltered workshops (N=8) in order to accommodate multiple disabled children and adults and relieve their families for certain hours in the day.

*'The promotion of educational matters. We need day care centres where the children will be creatively occupied and then return to their homes in the evening. So that the parents will have the opportunity to find a way out', some moments of peace (q 33).*

*'Just yesterday we finally managed to secure a beautiful place for the children but we do not have the necessary funding to maintain and staff it, a place where our children will be able to spend their time creatively' (q 28).*

*'The establishment of a day care centre for children with autism and mental retardation' (q 45).*

*'We support a special education workshop and rehabilitation for children with mental retardation and accompanying disabilities. We provide vocational training, special education, consultancy, psychological support, lifelong education and care. And a boarding house where the accommodation is provided free of charge to disabled people who have lost their parents' (q 53).*

*'We try to raise money to support the operation of the boarding house' (q 19).*

Other associations are more focused in the composition of demands and proposals addressed to FPGA for SMDP for their further promotion to the government and the ministries responsible (N=11).

*'We present the problems of children with multiple disabilities and we inform constantly all stakeholders and ministries' (q 24).*

*'We continue to construct proposals, mostly concerning legislative issues, which are a main concern for the parents' (q 55).*

*'The promotion of problems to the organisations' (q 40).*

*'We are making efforts, we submit our demands but the state doesn't really support our efforts ideologically or financially, so every plan we make cannot be actually implemented' (q 39).*

Ten associations are organizing entertainment and leisure activities for MD children and adults, for example field trips, theatre visits, sports activities.

*'We organise summer camps where all the services and the accommodation is free' (q 7).*

*'(We organise) Daytrips, theatre visits, contacts we non-disabled children' (q 26).*

*'We try to get the children out of the house, for them to change environments. In a small community it is so cruel, it happens even today... you want to get your child and go for a walk and people keep telling you: 'put your idiot child back in the house'. We want new parents to have opportunities' (q 32).*

*'We provide the right to the children to participate and enjoy activities when in earlier times they didn't have access in (theatre, concerts, exhibitions, camps, entertainment)' (q54).*

Four associations provide support for the parents of multiple disabled children.

*'Help in the house. It is a complete program of whole family support. Also we have arranged to occupy the children during the day, because the municipality cannot cover these needs and they ask for our help, and we do it because we cannot but support these children and their families' (q 47).*

*'The support of the parents psychologically and financially' (q 50).*

Only four associations are dedicated to the promotion of multiple disabled children's and adults access in education through lectures, demonstrations and the composition of specific demands.

*'Effort in the level of protestation for the inclusion of children with multiple disabilities as equals in the educational and social life of the country' (q 38).*

*'We had accomplished many things (...). We demand equal educational opportunities and we yell all the time but the truth is that the state doesn't care even a little bit, not at all in fact, no matter how much we protest or how active we are. We are the minority, we are so few, they don't care to get out votes so we are left dealing with our fate alone' (q 14).*

Also four of the associations are involved in research projects with the aim to investigate the needs of multiple disabled children and adults, researches that have now been paused also due to lack of funding.

*'We encourage and pursue the planning and implementation of researches on disability matters' (q 26).*

*'We fund research programs on disability matters' (q 1).*

<b>Specific actions promoting the rights of MD children and adults planned and implemented by the participating associations</b>		
Society awareness and information/Inclusion to the community	18	28%
Creation of independent/Semi-independent living structures	12	18%
Creation of daily care centers	11	17%
Proposals to FPGA for SMDP in order to promote them for voting in the Greek Parliament	11	17%
Entertainment/ leisure activities	10	15%
Creation of sheltered workshops	8	12%
Parents' support	4	6%
Promoting the right to access in education	4	6%
Research interests	4	6%

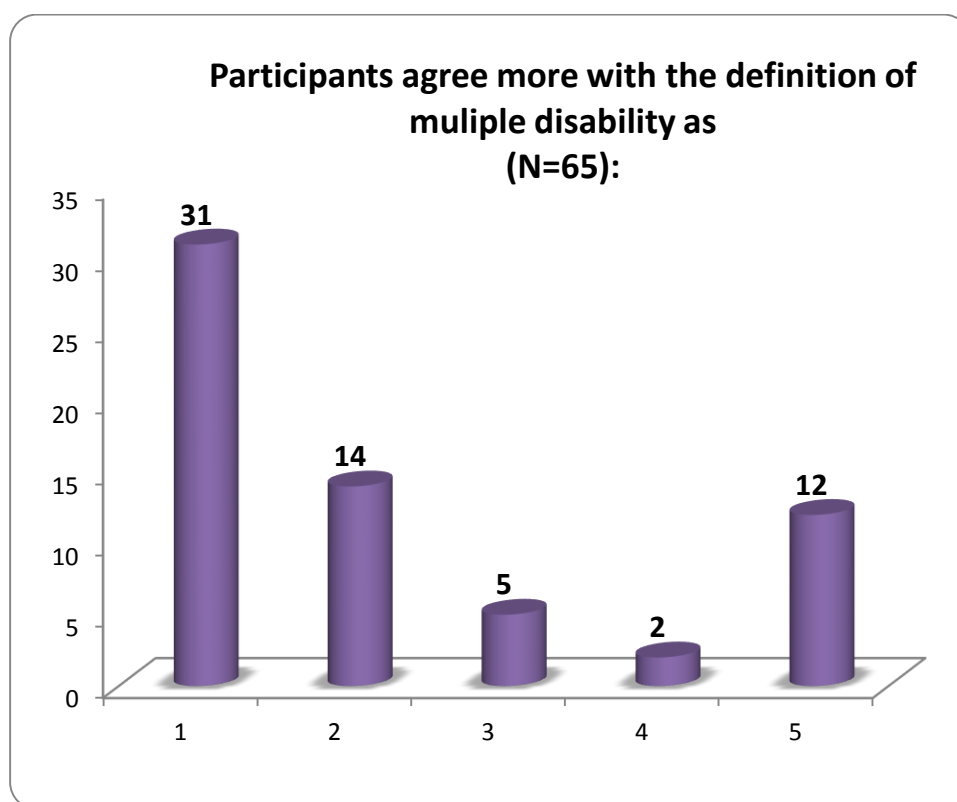
**Table 10 Specific actions of parental associations for MD children and adults (n= 65)**

#### **5.6.4.7 The definition of multiple disability**

In the final section of the questionnaire the participants were presented with a list of definitions describing multiple disability:

- 1) Multiple disabled people experience more than one disability, including physical, intellectual, communicative, sensory, and/or emotional;
- 2) People with multiple disabilities need constant medical care and need ongoing support to more than one sector of life in order to participate in social activities and enjoy life with their fellow human beings;
- 3) A person with multiple disabilities is defined as someone whose additional disabilities, physical, intellectual, sensory, behavioral is so severe that each one individually affects their normal development or education;
- 4) Children and adults with multiple disabilities are those who do not fit into another category of disability;
- 5) The term multiple disabilities describes students who have severe intellectual disabilities and more than one additional disability (visual impairment, hearing impairment, epilepsy, physical disability, chronic illness).

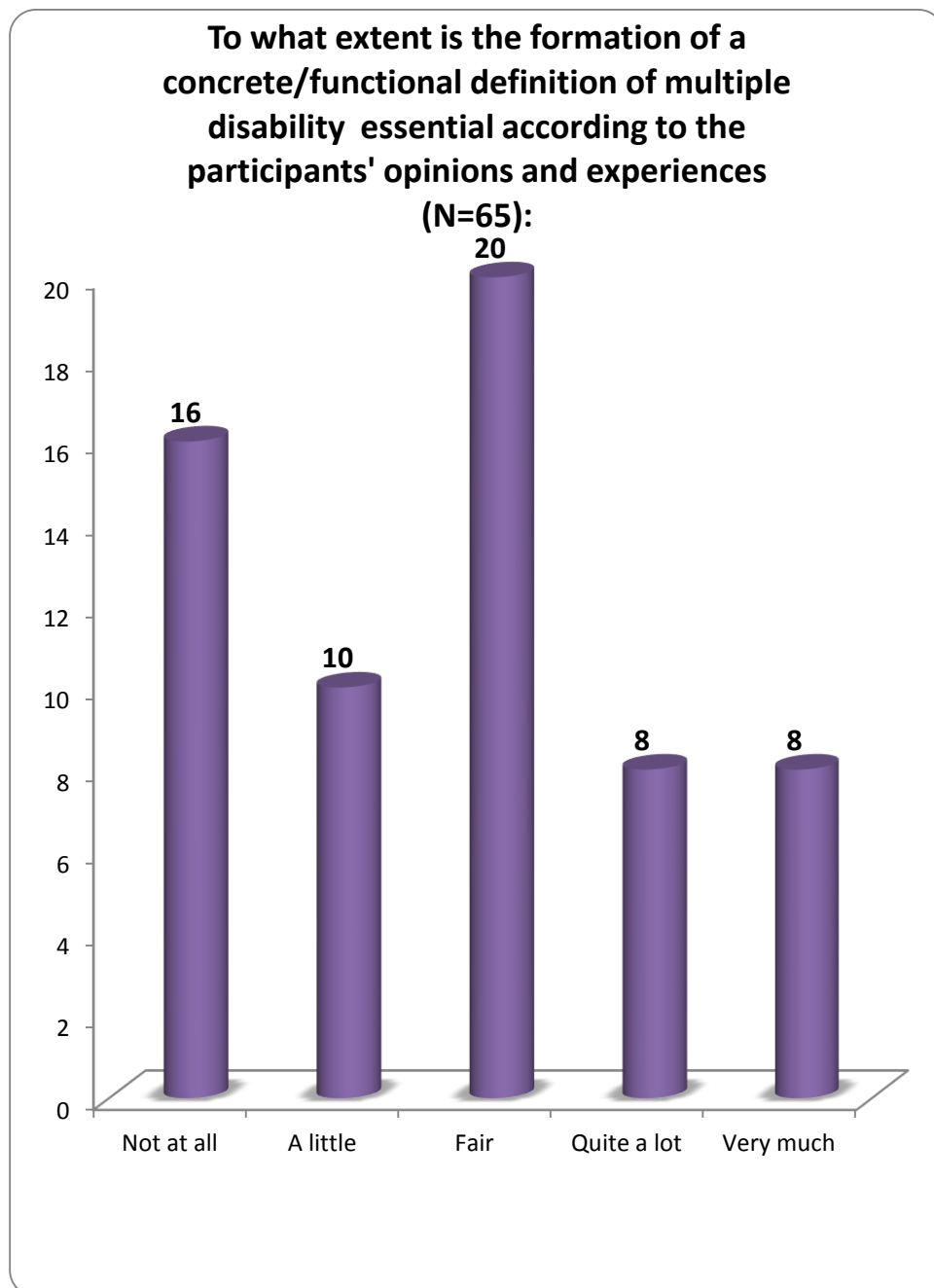
The participants were then also to select the definition that is closer to their understanding of multiple disability (Figure 37: The definition of multiple disability according to participants). The majority of the participants agrees more with the definition that multiple disabled people experience more than one disability in their lives. Fourteen respondents connected the meaning of multiple disability with issues of constant medical care and the need for ongoing support. Also, only twelve respondents considered intellectual disability as a main component of multiple disability.



**Figure 37 The definition of multiple disability according to the participants (n=65)**

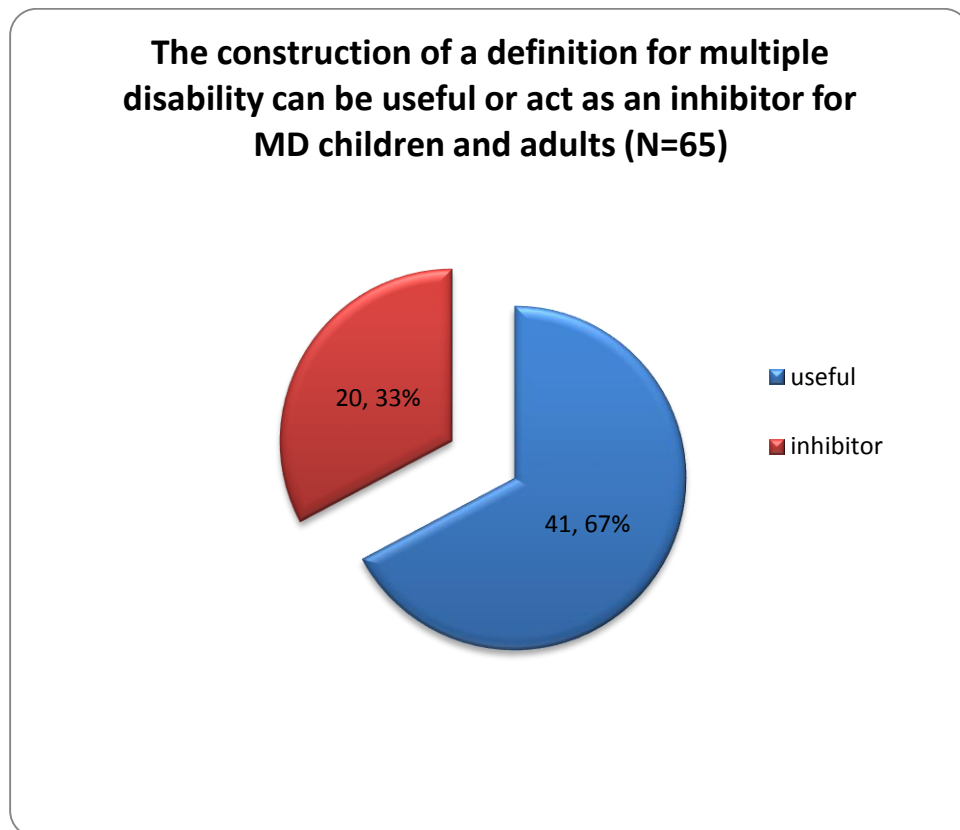
In the question concerning the need of formation and use of a consistent and functional definition of multiple disability participants do not provide clear

information (Figure 38: The extent to which the formation of a definition of multiple disability is essential). More specifically, twenty parents appear neutral in their views on how essential this formation will be while others appear very strict about this issue and state that a representative definition of multiple disability is not at all essential (16).



**Figure 38 The extent to which the formation of a definition of multiple disability is essential (n=65)**

In order to elaborate on the previous enquiry, respondents were asked to consider whether the formation of a multiple disability definition can be helpful or act as an inhibitor for people with multiple disabilities and why (Figure 39). And so 41, 67% of the respondents considered a definition to be useful and 20, 33 % believed that it will act as an inhibitor.



**Figure 39 The construction of a definition of multiple disability can be useful/ an inhibitor for MD children and adults (n=65)**

Participants who believe that the use of a specific definition is useful, justified their answer based on the fact that the students who will be classified as multiple disabled will be able to claim benefits, allowances and rights as provided by the legislation and relevant policies created to support their specific needs (N=7) (Table 19: A definition of multiple disability can be useful/act as an inhibitor).

*‘So that they will be able to be included clearly in a specific category and benefit from allowances and demand their rights’ (q 43).*



*'In legislative issues' (q 65).*

*'In order to demand specific allowances' (q 21).*

*'Concerning the benefits that they may use' (q 31).*

*'Especially regarding the legislation, so that it is made clear who amongst the disabled are entitled to use it and who this legislation concerns (q 25).*

Most importantly, respondents supported that it will be an opportunity for all MD people to form a collective group and demand their rights more effectively (N=14).

*'In order for them to claim their rights' (q 55).*

*'Maybe in order to display their special needs' (q 60).*

*'When it is known what multiple disability includes and what problems it causes to a child it is helpful in the sense that these problems can be addressed early in the child's life (q 20).*

*'Only in the case of creating an educational setting with specialised staff accepting these children, otherwise constructing a specific definition makes no sense' (q 48).*

*'We must find a way to include people with severe mental retardation or autism and additional disabilities in a group because they cannot be included anywhere else' (q 47).*

*'It depends on how it will be used' (q 44).*

*'With the use of a specific definition we may be able to control or eliminate the existing confusion and vagueness concerning multiple disabilities. This vagueness allows self-characterization against the best interests of people who actually experience multiple problems due to their multiple disabilities' (q10).*

The participants who were against the construction of a definition for multiple disability fear that it will increase phenomena of exclusion and it will create more excuses for labeling certain children and adults (N=8).

*'I never understood the use of dividing disabled people' (q 2).*

*'It may lead to wider ghettoization' (q 4).*

*'In addition, the construction of a common definition is a very difficult task and will not be easily accepted by everyone due to the differences between multiple disabled people' (q 4).*

*'We cannot experiment on groups, and we cannot place all children in herds. It is a general population of children and we must support all of them and we must promote the interactions between them' (q 6).*

*'We return again in issues of allowance policy and this is a significant indication that we are moving backwards' (q 16).*

*'A specific definition will lead many multiple disabled children out of context and in an unfair system' (q 33).*

*'I don't understand how this will be helpful, unless we are referring to allowance policy issues' (q 39).*

Additionally, they stated that most certainly the creation of a specific definition in their opinion is not a priority and they cannot imagine in which sense it will be able to provide real solutions for multiple disabled children and adults.

*'I don't believe that a definition will make any difference. The education of the ones responsible and of the society is the key to accept children with multiple disabilities and to meet their needs' (q 41).*

*'A definition cannot define people with multiple disabilities (q 35).*

A definition of multiple disabilities will be useful		
Benefits		
policy/Allowances/Legislation	7	17%
Opportunity to demand their rights and to address their specific needs	14	34%
A definition of multiple disabilities will act as an inhibitor		
It will lead to phenomena of exclusion and labeling	8	38%
A definition will not solve the problem	6	29%

**Table 11 A definition of MD will be useful/act as an inhibitor**

### 5.6.5. Participants' concluding remarks

The questionnaire given to the parental associations for severely and multiple disabled people included one last section where the participants had the opportunity, if they wished to, to provide their general remarks and/or comments concerning the issues discussed. Participants in their majority (N=41) used this space and provided a variety of information. Due to the space limitation a selection of these comments is presented here, the ones where the participants focused specifically on the existing situation for multiple disabled children and adults and their families.

Many participants (N=19) felt the need to express their disappointment at the state provision on matters concerning disabled people in general and most importantly multiple disabled people. This frustration expressed by the respondents was focused mainly on funding issues, the lack of educational structures and structures for early intervention.

*'The associations will continue their work despite all the difficulties but the state must also assist actively (in terms of legislation, financially, educational provision for multiple disabled children) in all matters affecting disabled people' (q 12).*

*'Funds for disabled children are approved and then magically disappear or taken back. The allowance is very low and they don't even give it to us anymore, not even a dime for disabled children. Most parents of multiple disabled children, especially if they live away from the major urban centres have nothing, no interventions, no schools for their children' (q 28).*

*'State care is nonexistent and as they keep on making budget cuts for the general population even more the disabled people will continue to lose even everything that they have come to secure after so much fighting (...)' (q 32).*

*'Someone needs to convince them that this lack of early intervention and educational structures affects the progress and development of all children and especially children with multiple disabilities' (q 63).*

*'Disable people do not need new labels and titles. I believe that they have been attributed many so far. What we all need to understand is that*

*disabled people and their parents have had enough of big statements and promises for the ones 'responsible' and the 'policy makers' who think of everything else but of resolving the problems caused for disabled people' (q 3).*

*'The institution that we created as association, in fact the institution that we created after many struggles is on its way to be shut down due to underfunding' (q 2).*

Other participants referred to the feeling of isolation and exclusion experienced by all the families with disabled children and especially those with multiple disabled children. They maintain that the hostile attitudes of a disabling society affect their lives and the lives of their children and that there is an urgent need for change and development of positive behaviors and action.

*'I imagine that all parents with multiple disabled children, like ourselves, feel isolated. We are a family with two autistic children and with additional disabilities and two disabled parents. That is why we created this association, this effort for the awareness of the public and to take action in order to escape this isolation' (q52).*

*'The culture of a country is crystalized in the behaviors and attitudes they hold towards people with disabilities, we have failed as a country' (q 54).*

*'The problems of severely disabled people, especially the ones suffering from severe mental retardation are not only centred around education but also around employment and entertainment, which in this case is directly connected to their social inclusion. What I mean by inclusion (...) is on one hand the creation of organisations that could provide multiple disabled children with moments of joy and satisfaction in their everyday life and on the other hand to expand the 'shelters of supported living'. In order to implement the above we need to deal, besides the common problems caused by the state, with the retrograded attitudes and behaviors of our fellow citizens, who react on the idea that a supported living structure for people with multiple disabilities might be constructed near their neighborhood' (q 10).*

Respondents stressed the need for support and help. In the Greek reality, families and especially the parents with multiple disabled children are considered the only ones

responsible for the upbringing, education and future of their children. It has become a private burden of the families, who are left alone and unsupported by the state.

*'It would be a wish come true if the state undertook the care of disabled people through organised and decent institutions, so that the parents could be relieved of this unsustainable burden, a burden that has severe psychological implications for all the family members and especially for the siblings (q 19).*

*'What the future holds for the children with multiple disabilities is the greatest fear of parents, how will we be able to secure a future for our child after we die' (q 6).*

*'Parents of multiple disabled children are tortured, feel hopeless and unsupported. (...) Family cannot manage anymore alone, they don't get financial help, and they don't get support, they are dissolving. Parents, especially mothers need help' (q34).*

#### **5.6.6 Correlations between sections of the questionnaire**

The main objective while constructing the questionnaire was to secure the data necessary in order to answer the specific research questions of the study. During the data analysis and with the use of SPSS software program certain links between questions became clearer. The correlations and cross tabulations between data produced fruitful results and these are presented in the following section.

- **The correlation between the age of the parents participating in parental associations for disabled children and adults and the age of their children**

There was a statistically significant correlation between the age of the parents and the age of their children. Specifically we observe a highly significant correlation ( $r=0,598$ ,  $p<0,001$ ) and with positive sign (appendix 7, table 7a). To verify this hypothesis a  $\chi^2$  independence control was carried out and revealed that this correlation is statistically significant ( $X^2(BE=20, n=54)=52,603$ ,  $p=0,000$ ) (Appendix 7, table 7b).

As it is expected, as the parents' age increases so does the children's ages but what is important is the fact that almost half of the sample population (55%) has children aged between 21-30 years old. Parents with children within this age frame are more active in parental associations and there are a few hypotheses of why does this happens.

One possibility is that the parents by the time that their children reach the age of 21 have managed privately to meet their basic needs and now they have the time available to form collective forces and move to syndicalism in order to secure rights for their children in a political, legislative and provision level.

Another hypothesis is that when their children move closer to adulthood, the educational and care centres able to accommodate them become less, so the parents need to form associations and through those to create new structures for the continuous education and care of their children.

A third possibility may be that while their children are getting older, parents are getting older as well and by then the fear and anxiety about their child's future without them becomes more real. So again, the parents turn to the composition of associations in order to create living structures for their children to be accommodated and secure their well-being even when they themselves won't be able to support them anymore.

- **The correlation between the age of the respondents and their views on the level of influence that parental associations for disabled children and adults have achieved in educational matters for multiple disable children and adults**

There was a statistically significant correlation between the age of the participants and their views on the level of influence that parental association for disabled children and adults have achieved in educational matters for MD children and adults. Specifically we observe a highly significant correlation ( $r=-0,460$ ,  $p=<0,001$ ) and with negative sign (Appendix 8, table 8a). This means that there is a reverse relationship between the age and the views of the participants. As the age of the participants increases their views concerning the influence that parental associations' for severely disabled children and adults have achieved in educational matters decreases. To verify this hypothesis an  $\chi^2$  independence control was carried out and revealed that this correlation is statistically significant ( $\chi^2(BE=12, n=64)=21,317$ ,  $p=0,046$ ) (Appendix 8, table 8b).

As the participants' age increases so their views on the level of influence of associations concerning education decreases (their answers were 'a little' and 'not at all'). To be more specific, 67% of participants aged 70 years old and above considered that the associations have had a very low influence on educational matters, and maybe the reason for their answer is based on their long-term experience within the collective movement and the fact that they could evaluate the current situation in total, because they have witnessed and were a part of this process.

On the other hand 60 % of the younger participants aged between 30 and 39 years old have more faith in the influence of the associations' actions in educational matters for multiple disabled children and adults. They maintain a moderate (their answers were close to 'fairly') hope and belief that they have contributed more essentially in this

direction or they may be placing more emphasis in educational matters. Another hypothesis is that these members are still new in the collective movement, they may not have created a complete picture of the situation and therefore may not be able to provide specific answers.

- **The correlation between the number of members in the associations, their location and activities**

The number of associations is connected with their location and their activities. The associations counting 200 members and above are the ones located in the province and the Greek islands, away from the major urban centers. There, the needs of the whole disabled population of the association's area and the ones from surrounding areas are all concentrated in one association. On the other end, associations with 50 members and less are the ones that amongst their main activities include the function and support of special care centres, special schools, institutions or independent living structures. Since they can only accommodate a limited number of children and/or adults consequently they can only accept a limited number of members.

- **The correlation between the influence of parental associations on multiple disability issues in Greece and the associations' main activities**

A statistically significant correlation was observed between the answers of participants concerning their association's main activities and their views on the level of influence that parental associations have on issues concerning multiple disabled children and adults in the Greek context. Specifically we observe a highly significant correlation ( $r=0,269$ ,  $p<0,05$ ) and with positive sign (appendix 9, table 9a). To verify this hypothesis an  $\chi^2$  independence control was carried out and revealed that this



correlation is statistically significant ( $X^2(BE=4, n=65)=5,969, p=0,202$ ) (Appendix 9, table 9b).

Participants who prioritised educational matters in the main activities of their associations tended to believe that the actions of parental associations have influenced positively the social context of the country. Participants who were interested and promoted educational issues in their associations had a clear view of their influence in the social context of the country. This could indicate that these respondents approached the notion of disability from a social perspective but this hypothesis needs further discussion since other parameters should be also examined. For example in a different part of the questionnaire when participants were asked to provide the specific actions of their associations those who referred to educational issues stated, in their majority, that their main actions include the construction of day care centres, special schools and workshops, thus adding to practices of separation and segregation of disabled students. This comment does not intent to question the intentions of the parents and their stated ideology nor to blame the parents for wishing to accommodate their children in educational structures, even if those structure are separate, since it is understandable that this is a basic concern of the parents. Instead, this comment simply intents to place a question mark and state the need of further investigation of the multipart connection between personal values and ideologies, needs, actions and outcomes.

No other statistically significant correlations were observed and this may indicate that the associations who prioritise issues of legislation, professional rehabilitation, medical issues, welfare and provision either don't believe that they have achieved to

influence the context of the country in a great level or that their activities are not targeted towards achieving a specific change.

## **5.7 Summary of survey main findings**

The survey conducted on the parental associations for severely and multiple disabled children and adults in Greece aimed to provide more broad arguments and to add to the detailed picture described by parents of multiple disabled children and young adults through the interviews. At this point, the main objective was to examine the current situation from a collective perspective, to move away from the restrictive frame of individual families and examine how members of parental associations for disabled people collaborate and promote multiple disabled children's and adults rights.

Sixty five parental associations for severely and multiple disabled children and adults, from various Greek geographical areas, participated in the survey. As expected from the first observations made, the majority of these associations were located in the two major urban centres of Attica and Macedonia, however representative questionnaires were collected from almost all around Greece. The participants' sample included in an almost even distribution, both males and females.

The majority of the associations were created around the 90' and this is expected due to the fact that the first law of general education ever to include matters of special education was introduced in the year of 1985 (Law 1566/1985). Within this law, the

constitution and function of parental associations is included as is the request that these associations will cooperate with the Ministry of Education in all matters concerning special education and special vocational training. Only few new associations were created after the year 2000, as it becomes clear from the data analysis, and this confirms in a way the concern of older parents about the survival of parental associations.

Parents of multiple disabled children and adults participate in the parental associations' collective movement and this becomes evident from the fact that 48% of the parental associations participating in the survey, stated that they include as registered members parents of multiple disabled children.

The primary need and the main aim for the foundation of the parental associations, as elaborated by the participants, was to promote disabled students' rights to mainstream education and to demand solutions from the relevant ministries in terms of education, care and provision and employment issues. On the other hand, when describing their main activities and actions, only twenty of the associations place the education of disabled children as their main priority. Also, while the majority of the associations included in their activities the promotion of social inclusion of disabled children and adults only 11 of them set this objective as their first priority.

It appears that the parental associations for disabled people have not formed solid links between them. Links that are vital in establishing a strong front towards the

promotion of all disabled people rights. With the division of associations according to specific disabilities, certain groups of disabled people remain excluded from the collective force. Parents in various sections of the survey refer to discriminatory phenomena amongst the population of disabled people and this becomes more obvious in the section where the participants are asked to consider who amongst the disabled people population claim their rights in a greater or lesser extent. Here, the participants identify multiple disabled people and people with intellectual disabilities as the ones who have demanded and secured their rights in a lesser extent due to their level of self-representation skills, the discrimination they experience by other disabled people and their exclusion from the collective rights demands.

As pointed out earlier, the main need for the creation of parental associations for disabled people was to promote the right of their children in mainstream education but when asked who amongst the disabled pupils can attend mainstream education, the majority of the respondents believed that students with multiple disabilities cannot be educated in the general/mainstream educational settings. Here arises the issue of how the participants have interpreted this question: either as the students not being able to attend mainstream education due to their difficulties or that the existing general educational structures cannot support multiple disabled students. This is a difficult subject to determine, given that even from the participants quotations some refer to the abilities of the children and others on the existing educational structures. The important conclusion at this point remains that children with multiple disabilities are considered unfit to attend mainstream education according to the respondents' opinions.

Concerning the challenges for multiple disabled children and adults, participants mentioned more often the need for change and revision of the existing legislation but on the other hand none of the associations prioritized amongst their main activities, the promotion of legislative issues. The second challenge in the lives of multiple disabled children and adults, according to the respondents, remains their education. Fewer are the respondents who prioritized as important the challenges faced by multiple disabled children and adults regarding their social inclusion, their autonomy and the creation of independent and semi-independent living structures and services.

When participants elaborated on the specific actions undertaken by their association concerning the promotion of multiple disabled children's and adults' rights the majority of the activities were centred on society awareness and information and the inclusion of multiple disabled children and adults in the community. Only ten associations organized actions towards the promotion of multiple disabled children's and adults' rights in education. At the same time, many associations focus on the creation of daily care centres, institutions, boarding homes and workshops. By these actions they move further away of demanding the inclusion of all disabled children in the general educational system, which was the primarily need that led to the creation of the associations in the first place, as it has been stated by the participants.

The intent at this point is not to put the blame on parents for the creation of private education and care centres and therefore the isolation of multiple disabled children. It

is understandable that parental associations need to create structures in order to accommodate children and adults with multiple disabilities, when the state fails to care for them. But at the same time it is essential to show that the majority of multiple disabled children and adults are educated and accommodated in private structures and excluded from the public educational and provision system. And this mainly applies to multiple disabled children and adults whose parents are active in associations or have connections with these associations without being able to predict the living situations of other multiple disabled children and adults and their families.

A description of multiple disability was also a key objective of the survey, not for the purpose of constructing a specific definition but in order to apprehend how participants understood multiple disability. The vast majority of the participants considered multiple disability a combination of two or more disabilities. And even though only a few parents accepted a definition of multiple disabilities where severe learning disability is a major component, in fact when they described examples of multiple disabilities the majority of the cases included the existence of learning disabilities. The majority of the respondents (N=31) agreed with the following definition: *'Multiple disabled children and adults have more than one disability, including physical, learning, communicative, sensory, and/or emotional'*.

As a final remark, families of disabled children, continue to feel isolated, unsupported and excluded from the social and political frame of the country. The state continues to enforce further budget cuts. Furthermore, the cutting of allowances, salaries and provision for disabled people and their families hinder the work of parental

associations. Additionally, participants expressed their anxiety concerning the future sustainability of the associations and the future of their disabled children.

The interconnected issues raised across the two phases of the study are presented in greater detail in the following chapter. The discussion is structured based mainly on the research questions of the study and interpreted through the lens of the social model of disability and the need to reinforce the role of parents in an equal and active participation in the educational procedures. The strengths and limitations of the study are discussed as well as implications for policy and practice and suggestions for further research.

# CHAPTER 6: DISCUSSION

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## 6.1 Introduction

This chapter attempts to present the arguments in response to the main research questions. In which ways does the Greek educational system shape opportunities for learning and social inclusion for MD students, examined through the views and experiences of parents of MD children and adults? What is the role and influence of parents of MD children and adults and PAs for disabled people in the educational process and in the promotion of the rights of multiple disabled people in the school and social life? Can education sit in isolation from other concerns and areas of exclusion/inclusion for MD children and adults?

The findings from the two parts of the study are drawn together and discussed in relation to the theoretical background of the thesis, the national, and the international education policy for multiple disabled children and adults. The study was conducted in two phases, each highlighting different perspectives of the topic under investigation. Interviews conducted with parents of multiple disabled children and adults provided a more personal account of the situation and described the steps and the methods that they used to cope with challenges and secure an educational placement for their child. In the second phase of the research the same topic was approached through a survey addressed to representatives of all the Parent Associations for people with severe and multiple disabilities in Greece, with the aim to investigate the efforts of the disability movement in promoting the rights of multiple disabled children. From the findings it becomes clear that even though the



associations, ideologically, have adopted a more social perspective concerning the rights and barriers of multiple disabled children in education and regardless of their intentions to promote educational and social inclusion, they are forced to assume the role of filling the gaps of the social provision, thus focusing most of their actions towards the construction of separated settings to accommodate disabled children and the construction of independent or semi-independent structures. The findings of the study raised themes for discussion and further dialogue, as it will be presented in the next session.

The strengths and limitations of the study are discussed in the following section while the concluding part of the chapter focuses on the implications of the findings for policy and practice and suggestions for further research.

## **6.2 The educational course of multiple disabled children and adults: Excluded amongst the excluded?**

Parents of multiple disabled children and adults are often forced to agreeing in a school placement not suitable for their children's needs simply because they are not given a choice, despite their objections (Furneaux, 1998). In Greece, pupils with severe and multiple disabilities are almost exclusively educated in special schools and it is extremely rare to find multiple disabled pupils in mainstream schools (Strogilos et al, 2011). From the findings of this specific study we may deduce that it is very difficult to locate multiple disabled students also in special schools.

According to Furneaux (1998) the school years are by far the least stressful period for the parents with children with disabilities. Even if the educational opportunities

provided for their children are limited, school symbolizes the end of their isolation and the beginning of support, but the same does not apply for parents of multiple disabled children and adults. Parents in the first phase of the study explained how finding the right school is not an easy process. Parents are in conflict between finding a setting that is appropriate and able to meet their children's educational needs, a place that would not be isolated and separated and also a place where their children could find a sense of belonging. They spend a great deal of energy and effort into finding a school that would provide the right fit for their children's needs (Kalyanpur and Harry, 2004). Parents have to choose from a wide range of schools, from fully separate to fully inclusive at the beginning of a child's school course (Hess et al, 2006). In Greece there is a strong assumption that support-rooms and part-time withdrawal are the most effective ways for promoting the educational and social inclusion of children defined as disabled children (Vlachou 2006). But according to the Pedagogical Institute database (2004), there are no separated rooms available, or dedicated rooms equipped to function as integration classrooms.

The parents who participated in this study at the beginning of their children's educational course wished for their children to be educated in mainstream education along with their non-disabled peers, and wanted to ensure that their children will not be labeled and segregated (Kalyanpur & Harry, 2004), therefore they made every possible attempt and used every mean available in order to enroll their children in the neighborhood school. This finding is in agreement with the research conducted by Grace et al (2012) where all parents wanted their children to attend mainstream early childhood education settings in order for them to have the same preschool experience as their non-disabled peers, but the search for a welcoming classroom was hard,

required time, energy and resilience. An alarming observation is provided by Boutskou (2008) concerning the situation in Greek inclusive classrooms where educators, driven by their fear of losing their work positions, act as advertisers and promoters of this new product called inclusion, and invite parents to purchase it. In this situation, the teacher needs disabled students in order for the inclusive classroom to remain active, and at the same time parents wish for their children to be enrolled in the mainstream school to avoid stigmatization and exclusion. Educators present the opportunity to them even when the necessary reforms, adjustment and resources are not available. At this point parents are grateful and not concerned about the educational program of the school, furthermore keeping their demands low, because what they want the most is to take advantage of this opportunity (Boutskou, 2008). All issues concerning the development of autonomy, positive interaction with non-disabled students and academic skills come second, while the first concern is the placement of the child.

However, parents in the interviews, quite similar to the findings of the research by Kalyanpur and Harry (2004), reported changing their attitudes and expectations and understanding their children's actual educational needs and interests. Parents moved away from their wish to enroll their child in the existing general education, shifting towards finding an accepting and appropriate school environment for their children. The study of Thompson and Emira (2011) revealed that everyday practical challenges faced within mainstream education overwhelm the parents, who would rather accept a separate special provision for their children than force the inclusion of their child. In their estimation, special education structures could have provided a more effective school placement for meeting their children's needs. As it was elaborated by the

interviewed parents in the study, public special education classrooms were proven to be a source for more disappointment and frustration for both parents and children. Special education should focus on providing skills and knowledge to children, in order to help them cope with everyday situations and to empower them for the transition between school and community life, and gradually integrate academic skills (Benz and Halpern, 1993), but parents came up against a totally different reality and an educational program focused on literacy not different than the one provided in general education and with little efforts for program differentiation based on the students' abilities and interests. Parents expected that special education school settings would be accustomed and prepared to include multiple disabled students and ready to meet their educational needs and that the fact that they needed to make greater effort in order to achieve even the smallest things would be not only accepted but valued (Esdaile & Greenwood 2003), but their experience was very different. Even special schools had limited spaces for multiple disabled pupils and the educationalists and support staff were not trained or confident to accept an md student in their classroom. Thus parents, even though they fought hard at the beginning to find a good match between the children's needs and the school placement, eventually came to the realisation that their options were actually very limited. Several mothers described simply going along with the recommendations of the CEDDAS's representatives, despite their original disagreement and objections, and they accepted any conditions just to secure a place in education for their children (Grace et al, 2012), while others reacted by totally withdrawing their children from the public school system. Research conducted by Ftiaka (2008) in Cyprus about the parental satisfaction regarding the new legislation about special education supported that in general parents declared were pleased with the school placement of their child.

According to Ftiata (2008) this answer is based either due to their unawareness of the existing conditions within the classroom, or because they are satisfied with ensuring the minimum right for their children to be able to participate in a classroom, regardless of the existing conditions. In the present study even though the parents were asked to describe a school day and share information concerning the educational program for their children, they provided only few mentions on the specific programs, the kinds of interventions, or the quality of education, but never hid their dissatisfaction towards the educational system and their intention to enroll their children in private educational structures as soon as they would be able to afford it. Another reality is that the number of the schools available for multiple disabled children and young adults is not enough, putting these children in danger of total exclusion from the educational system. In both phases of the study it was stated that the available educational structures are insufficient, especially in the province where parents have even more limited choices and they are forced to turn to private educational structures.

Apart from the above difficulties it should be noted that from the parents' personal stories and the parent associations' representatives statements, primary education, and mostly early childhood education, is more likely to include their children even in mainstream education settings, while it is considered almost next to impossible to discuss the educational inclusion of multiple disabled students in the secondary education and beyond. It is true that primary education, at the kindergarten level in particular, is considered less competitive than the ones that follow, it is more flexible in terms of expectations and academic achievements and it can provide the space for accepting and valuing difference. At the same time kindergarten is the first

educational level, the place where the individual meets the social and this first experience may mark the relations, expectations and reservations from all parts, students-parents and teachers. Nonetheless in their majority early childhood education structures have failed to create opportunities for social inclusion and to provide quality education due to lack of resources, lack of trained staff members, and lack for collaboration with parents (Grace et al. 2012).

Moses and Croll (1987) have reached the conclusion that parents of multiple disabled children and young adults, due to the fact that their disabilities are identified prior to their school entrance, have a better chance of reaching an agreement with teachers and other professionals concerning their needs. On the contrary, parents of children with less severe disabilities place the responsibility of resolving all problems that arise in school to the school. During in the present study, parents identified those educationalists that welcomed their children in the classroom and made an effort to include them, regardless if this attempt was successful, as an opportunity, since in their views these educationalists provided the opportunity for their children to feel included. Interestingly, it was not the teachers' level of expertise or years of experience that were emphasized, but rather the teachers' openness for communication and cooperation that were deemed as most important (Kalyanpur & Harry, 2004). Parents blame the teachers who have rejected their children a priori, but they are thankful to those who made an effort even if they failed. In both the interviews and the survey, the participants concluded that teachers and support staff need to be further educated and trained in meeting the needs of different learners. At the same time parents tend to acknowledge the fact that teaching and care staff are

overworked and cannot afford the time for training and expanding their knowledge on disability issues (Grace et al, 2012).

Additionally, in their majority, the interviewed mothers admitted that they were aware of the fact that their child did not fit in the classroom and was not accepted by the teachers and staff but their presence was simply tolerated. From the research findings and relevant literature it becomes evident that two main reasons prevail and cause problems in communication and cooperation between parents and teachers. One issue that emerges is the inflexible nature of the Greek educational system and curricula: the traditional Greek education system follows common curricula, same textbooks, officially set timetables and teacher-centered teaching approaches (Vlachou, 2006).

A second issue is that teachers need to battle their own prejudices, personal predispositions, attitudes or stereotypes, lack of experience, and their feeling of inadequacy and insecurity, in order to meet the needs of diverse learners. The nature of the child's disability affects the attitudes of professionals and teachers regarding inclusion. Educationalists appear more reluctant to include multiple disabled students (Koutrouba et al, 2012; Vlachou & Mauropetalias, 2008 York & Tundidor, 1995). Avramidis and Norwich (2002) reached the same conclusion by reviewing the relevant literature, indicating that teachers are more willing to make an effort to include students with mild disabilities but the same does not apply in the cases of students with more severe or multiple needs.

Strogilos et al (2011) identifies two main barriers in the education of children with severe intellectual disabilities in the Greek special schools. For one, the educationalists are not familiar with working in teams. Additionally, professionals only ask for help from each other when a problem occurs or in a time of crisis, instead of working collaboratively in order to prevent difficulties and problems. Especially for multiple disabled students, the expansion of a model of multidisciplinary collaboration between experts is considered imperative, in order to effectively include the students in the educational system. These suggestions were also expressed by the mothers in the study, in the frame of fading out the limits of individual disciplines, setting common goals, and involving the parents in the process (Carpenter, 2000).

### **6.3 Is there a limit to educational inclusion for students with multiple disabilities?**

The inclusive dimension of education is based on the fundamental principle that all disabled people, regardless of the nature or severity of disability, must be educated. The role that education is called to serve is also dependent on the political needs of each nation, the aim to create equal societies with active citizens, versus the aim to create and recruit new employees to support the economical growth and exclude those not viewed as valuable in the productive procedure, and whose education will cost more than it will give back (Barton and Armstrong, 2001). While considering the experiences of the participants another question arises; what kind of students are entitled to education (Apple, 2003)?

*'Despite the simplicity of its message, inclusion is highly contestable ...Its effectiveness is closely related to managing students by minimizing disruption in regular classrooms and by regulating failure within the educational systems...and has been limited in controlling...While social policy is dominated by the rhetoric of inclusion, the reality for many*



*remains one of exclusion and the panacea of “inclusion” masks many sins’* (Armstrong et al, 2011: 29-30)

The participants, both in the interviews and the survey, used the term inclusion referring to the right of all children to be a part of the education system. They attributed higher values to the general notion of inclusion, the value of autonomy, dignity and social inclusion. Inclusion is not simply the placement and co-existence; the process of inclusion aims in a qualitatively upgraded school environment that will meet the needs and abilities of every child (Deropoulou, 2004; Resch et al, 2010). Multiple disabled children and adults, due to their multiple and often developmental disabilities along with the lack of quality education and training programs, experience difficulties in self-representation and advocacy and therefore are vulnerable to various forms of negative discrimination and exclusion and often their rights are ignored or violated, even within the disability movement, as it was commented by the members of parent associations. In the case of MD children and adults, the current policies continue to locate the deficit within the child rather than focusing on barrier removal (Goodley & Runswick-Cole 2011).

As Hansen (2011) noted, inclusion as a vision has been promoted as limitless. But in reality and in practice, as it was also demonstrated by the findings of this study, inclusion in its current form and implementation has limits. There are categories of students, and multiple disabled students are among them, who are not permitted to pass the doorstep of mainstream education. The notion of exclusion cannot be conceptualized away from the notion of inclusion (Hansen, 2011; Armstrong et al, 2011); therefore we need to examine the practices of exclusion in order to understand

inclusion. The vision of inclusion has been criticized as utopic and the proof could be attributed by some exactly to the case of educating multiple disabled students. Teachers as it was shown above, are reluctant to educate multiple disabled pupils, the legislation makes an exception for them and maintains special schools to accommodate them, and parents have lost their faith and have been convinced that their children cannot attend mainstream education, at least not in its current form. But if education is in fact a political act (Oliver, 1990; Freire, 1998) then the oppression and exclusion of multiple disabled children and adults from schools will lead to their exclusion from community life, equal opportunities and the chance to live a quality life of choices and freedom. At the same time the education policy makers sooth their moral obligation of including students even with the most severe disabilities in the education system by maintaining the existing and creating even more special schools. So where does the problem lie in the Greek context? Are the schools unprepared to accept multiple disabled students? Can multiple disabled students be educated and what does their education look like? Can they benefit from mainstream education? Are their rights being disregarded due to the fact that they are a minority or due to the fact that they do not communicate their rights in conventional ways? Or, to borrow the queries of Graham and Sweller (2011), *'If we do not embrace full inclusion, where do we draw the line? Who should be included and who should not? Where does severe end and profound begin?'*

Previous research has indicated that parents of disabled children hold a positive attitude concerning the inclusion of their children in general education classrooms (Tafa and Manolitsis, 2003). Their main worries focus on the issue of whether their children will receive qualitative education (Leyser and Kirk, 2004). Additionally a

significant percentage of mothers while believing that inclusion could prepare their children for the real world at the same time they express concerns that their children would be isolated by their peers and that the teachers will not be qualified to meet the needs of their children (Guralnich, 1994; Kokaridas et al, 2008). Parents of children and adults with severe and multiple disabilities when asked their views about inclusion their answers were differentiated depending on the existing general education system, how well it is prepared for this inclusion and the level that they trust it. On the one hand parents consider that their children can benefit from an inclusive educational environment but on the other hand worry that their children would not feel the welcomed (Palmer et al, 2001).

Parents of multiple disabled children often experience feelings of anger, frustration and confusion mainly as a result of verbal assaults from parents of typically developed children who are convinced that MD children do not belong in the general school (Stark et al, 2011). Parents of typically developed children due to their own attitudes and views concerning disability may lead to the social exclusion and discrimination of disabled children (Stark et al, 2011). They are concerned that the inclusion of disabled student especially when the disability is considered severe by them believe that their own children will loose interest in the lessons due to the slow rhythm of the classroom and that their children will be sad if the teacher are positively discriminating disabled students by providing higher degrees and by giving them more of their time (Shipley, 1995).

The personal stories of parents in the interviews and the comments in the questionnaire from the members of parent associations described incidents indicating that the culture of the Greek society remains one that fears and rejects difference and disability. Prejudice and stereotypes were central in the teachers' views when they were explaining to the parents that their multiple disabled child cannot progress in education because he/she doesn't have the abilities to do so, and the same prejudice and stereotypes were central in the views of parents of non-disabled children when they would ask the parents with disabled children to leave the school because they feared that their children's progress and personal development might be affected, or when they would refer to multiple disabled children as crazy or abnormal. The views and attitudes of parents with typically developing children concerning disabled children are considered crucial within the inclusion debate. Bezevegkis et al (1994) investigated these views within the Greek context and their research concluded that parents with non-disabled children are less positive towards inclusion when their own child might be involved in a common activity with a disabled child.

Some parents stressed the fact that inclusion has helped their children to develop social relationships and has fostered meaningful interactions with their peers (Bennett et al., 1997).

In another study conducted in Crete in 2003 the results showed that parents of non disabled children have greater concerns when a student with severe intellectual disability or severe behavioral problems is included in the classroom or severe behavioral problems (Tafa & Manolitsis, 2003). Another concern raised by the

study of Peck et al (2004) revealed that parents worry that teachers would spend more time with the disabled students thus neglecting their own children. A positive outcome from the reviewed researches was that younger parents hold more positive attitudes towards disabled people. Mothers of multiple disabled children, as they stated in the interviews, when given the opportunity to discuss with mothers of typically developed children, could find common grounds, talk and lead them to view their child as a child and not as a disabled person, thus reducing some of the fears, misconceptions, and superstitions still existing in people's minds (Furneaux, 1998).

The hypothesis that emerges from the current study and the information provided by the participants inform us that even though the above questions are part of the problem, the most serious assumption is that the Greek community has not yet reached the level of accepting and equally including difference, and even when difference is celebrated rhetorically, in reality there is still a dominant culture which dictates who is superior and who is inferior. As Hansen (2011) concludes: *'the pedagogical practices ... can never be fully inclusive. They need to exclude as well in order to secure their own existence by avoiding too much diversity'* (p.98).

#### **6.4 Categories and stereotypes-Labels and Statements. How do we actually use them?**

One intention of the research was to provide a definition of multiple disability. From the pilot interview it became clear that the creation of a definition was not amongst the concerns of parents and this was also validated by the interviews with mothers of

multiple disabled children and adults. Only from the findings of the second phase of the research we can draw some conclusions concerning the definition of multiple disability. Parents place the usefulness of a definition only within the frame of claiming allowances, benefits, care and provision. The way that we will define multiple disability may influence, form and support the educational policy and practice and the social care provision. Therefore the struggle towards creating specific definitions is not a *word game* but a *power game* and may determine the society in which we wish to live as well as the everyday educational reality (Azizi-Kalatzki et al, 2011:61). Azizi-Kalatzki et al (2011) explains that we categorise people or groups of people in order to be able to adjust our behavior towards them, to anticipate and be prepared for this interaction. Stereotypes are also a phenomenon of creating categories but they have a negative connotation, the danger between categorization and stereotyping presenting itself if we fail to understand that not all the characteristics attributed to a certain group apply to every individual of the group equally or at the same time, and we certainly need to remember that these characteristics do not define them.

The school environment has the power to create identities, and it does so by separating students and categorising them hierarchically, based on abilities, disabilities or achievement, so children from a very young age learn that some are superior and some are inferior in life. Goodley and Runswick-Cole (2011) inform us that the definition of disability is in danger of remaining within the narrative of developmentalism; thus those children that do not follow the typical developmental stages and aims will be labeled as disabled.

Nevertheless the reality as described by the parents in the current research is that the process of assessment and diagnosis is central to their lives and the lives of their children. On the one hand parents want to obtain an official diagnosis in order to put a name to their children's disabilities and prepare for the future, and on the other hand obtaining a diagnosis is the first and mandatory step before entering education, receiving allowances, social provision, health and care provision. Parents narrate many incidents of the bureaucratic procedures before obtaining an official diagnosis. As Van Swet et al (2011) explains, labels are socially constructed; therefore, a negative or a positive connotation can be attributed to them, depending on how society uses them. When labels are used to explain a behavior, indicate respect towards a group of people, and offer explanations and solace to parents, then there is an implicit difference from using these labels with a purpose of excluding certain groups of people. In addition, parents need labels to help them identify the situation that they need to face and cope with the demands (Seligman & Darling, 1997). The certainty of an official diagnosis helps the parents focus on planning the future of their child, future steps and actions by adjusting their previous dreams for their child to the new reality, whereas the previous state of uncertainty was exhausting for the parents and prevented them from being realistic (Graungaard & Skov 2006). Gregory (2000) states that giving a name to your child's condition provides important information, it helps you understand your child better, understand what to accept, and it forces you to finally leave the house and the isolation, expand your communication network and seek other parents with similar experiences, help them and consult them.

## 6.5 Economical crisis or crisis in values?

*'Lives of families with children with disabilities experience inequalities, unequal opportunities and outcomes often characterized by financial hardship, stress and anxiety as a result of social barriers, prejudice and poorly received social services...The social organization disables not just the family member who has an impairment but the whole family unit' (Dowling and Dolan, 2001:21)*

It has been a widely shared perception among the participants of this research that the lack of financial resources poses a significant barrier in providing quality education and quality of life for their children. They view this financial hardship as a vicious circle from which they and their children are not able to escape. Even though the participants of the survey were in their majority employed or on pension, the majority of mothers in the interviews had to leave their work, as primary care givers, due to the responsibilities of catering for their children's needs. Since families with disabled children have more expenses, the working parent needs to work longer hours to complete the income, thus staying away from the home for longer hours (Dowling and Dolan, 2001). Rates of income poverty and limited assets with which to respond to future economic crisis or needs are exceptionally high for all parents caring for their disabled child, leading families to experience social isolation and poverty, lack of support from services and worries about the future and costs of care (Runswick-Cole, 2010). Parish et al (2000) introduce evidence of financial instability and insecurity of parents caring for a disabled child. They further emphasise the fact that the amount of monthly income decreases for the younger parents and the parents who reach the age of retirement (Parish et al, 2010). Extra funding needs to be secured in order to improve support services for parents in terms of education, care, provision and transportation and allow them the opportunity to be equally included in the community, since it is society itself that prevents them from becoming equal members



of it, both economically and socially (Dowling and Dolan, 2001). Indeed, the current policy for disabled children is also set within a wider international context, in which disabled people and children '*are often positioned on the margins of society, excluded from education and care and living in poverty*' (Goodley and Runswick -Cole, 2011: 71). A social perspective needs to be adopted when designing services that will investigate and take into account the needs of the family holistically and move beyond the disabilities of the child alone (Heywood, 2010).

Parents in the interviews have minimized all their personal expenses in order to provide for their children and are afraid that in the future and with the continuous cutting of allowances they will not be able to cope with everyday expenses. On the other end, the members of parent associations explain how the state keeps reducing their funding, funding needed for the financial sustainability of the parental associations as well as for the educational provision for disabled students. An element that may lead us to consider that the education of multiple disabled children and adults and the well-being of families with disabled children is way down in the government's priorities.

According to Oliver (1990), disability cannot be examined apart or beyond the political regulations and social practices; the position of a disabled person in the economical hierarchy can be crucial within the current capitalistic societies. When someone is positioned high on the economical hierarchy and has the financial means, then hers/his disability is not apparent and they are not excluded, therefore not considered disabled.

## **6.6 Is there room for equal participation between parents and professionals in planning, implementation and decision making within the Greek educational system?**

The current legislation for special and inclusive education (Law 3699/2008) and the legislation concerning the cooperation between school and families (Law 449/2007) promotes the parental involvement and participation in all educational matters that may affect their children. It states that this cooperation should be founded on the principle of equal and mutual collaboration between parents, professionals, educationalists and other stakeholders but it fails to propose specific steps for action or specific policies for the implementation of this idea. Through the parents' narrations it is evident that the educational and care provision system has not been prepared to accept the ideal of parental involvement and cooperation.

Instead of empowering the parents in order to undertake an active role in education, parents continue to feel excluded and stigmatised by professionals while professionals continue to maintain their hegemonic role of expertise. They experienced the phenomenon of feeling othered (Johnson and Duffette, 2002). Parents view the birth of a disabled child as a personal case and responsibility and appear disempowered and dependent on experts (Oliver, 1996). The families deal with the educational matters that affect their children alone and unsupported, and unable to break the bond of the 'personal tragedy' (Barnes & Mercer, 2003). Within this social condition the families of disabled children also adopt an identity of disabled family, *a courtesy stigma*, as introduced by Goffman (1963). This stigmatisation of parents with disabled children is one of the most difficult aspects in their experience (Grey 1993); parents feel excluded and marginalised as a disabled unit especially in the level of cooperation between school and family. The exaggeration and fixation on parental stress by

professionals provides only one side of the family life as experienced by parents of disabled children, where they are pictured as captured victims obligated to provide care and support to their disabled child (Grant & Ramcharan, 2001).

This exclusion is widely discussed by the participants of this study. Their experiences involve incidents in schools and encounters with the bureaucratic educational and provision system. The interactions with social services is a long, time consuming and frustrating process, and the source of stress and anxiety. Parents hold anger towards the bureaucratic system, the delays, the lack of support, and they express this anger to professionals as representatives of this system (Hadjiyiannakou et al, 2007). The waiting and arguing often has a negative impact on the mental health of the primary care giver and at the same time can cause fear and anxiety to a child that needs to be confined for hours in an unfamiliar environment (Dowling and Dolan, 2001). Due to long bureaucratic procedures and the parents' perception that they alone should be able to cope with the difficulties and take care of their family, parents feel inadequate and inferior (Burke, 2010) and there is an need for better support and open cooperation.

According to Boutskou (2008) students in special schools have needs, not rights; therefore if the parents want help they need to follow the instructions and the advice of the educationalists and the experts. The dominance of experts is celebrated and parents need to accept this, since from this perspective the parents hold the problem (the disabled child) and the experts hold the solutions. Teachers that have been largely exposed to a deficit or medical model of disability during their own education

will inevitably be affected in the way that they interpret and understand disability. This often leads to professionals trying to fit each child in a specific pre-determined category based on within child factors (Seligman & Darling, 1997). When facing difficulties with educating disabled students, special school teachers fixate on the innate attributes, heredity, immaturity or family circumstances rather than considering school or teacher deficiencies (Vlachou, 2006; Hess et al, 2006). In their research, concerning teachers attitudes, Croll and Moses (1985) found that in 70% of the cases teachers attributed personal 'within child' characteristics as the cause of school failure of children with learning difficulties.

The participants in this study share stories of stigmatization and exclusion in their interactions with professionals and teachers. In addition, they have stated that instead of trying to cooperate with them, experts more than often create walls and see this relationship competitively. The positive outcome in the study was that parents appear more empowered. As they claim, their experience and personal efforts for development has made them stronger and more aware of the actual situation, thus their demands are different now. They make efforts to minimize feelings of guilt and helplessness and instead focus on the societal barriers that prevent the access to education for their children. Parents do not view their children in terms of symptoms but as individuals with possibilities (Graungaard. & Skov 2006). At the same time they do not dismiss personal factors that may interfere with the educational progress and personal development of their child and this does not mean that parents adopted a '*deficit focused*' view of their children (Parsons et al, 2009). For example, the issue of communication is viewed both as personal difficulty of the person who needs to use non-conventional ways to convey messages in his/hers interactions but at the same time it is the responsibility of the teachers and the wider community to try and

understand these messages. Regardless, the parents have begun to approach the notion of inclusion and the educational reality through a more social perspective. This social perspective is detached from the nature or the level of disability and the placement of responsibility to the weaknesses, limitations and intransigence of the Greek educational system (Zoniou- Sideri & Deropoulou, 2008). Vlachou and Mauropetalias (2008) also found that parents identify the dysfunction of the education system to respond to disability and not problems caused by the type or severity of disability to be the barrier in education.

There is an imbalance of power between the Greek school and parents of disabled children (Bouskou, 2008). Only if the relationship between school and parents is seen as a dynamic relationship, which constantly evolves and transforms, driven by mutual respect and open dialogue, then it will have meaning and purpose and will be able to work towards social justice and eradication of exclusion.

#### **6. 7 Are there limits to the social model in the case of multiple disabled children and adults?**

It was elaborated on the literature review chapter that in the case of multiple disability there is a need to move away from the functional limitations of the individuals (Barnes & Mercer, 2003) and from the context of pathology (Ainsow, 1999). Especially in Greece the concepts of the medical model have been widely used and continue to be employed whenever an excuse is needed to exclude a student from the school and social environment. This became clear during the interviews with the mothers in the study and also by the responses of parent associations representatives. The medical model has created fertile ground for the development of guilt emotions to

the disabled people and their families, thus weakening the sense of collective responsibility which is much needed nowadays.

The current study has in most part adopted the perspective of the social model of disability with the idea that if society succeeds in meeting the different needs of people, then also multiple disabled people would be less disabled by society (Thomas & Woods, 2003). There was an attempt to place more attention on the social dimension of multiple disability, since the medical dimension has been overused within the Greek society. The aim was to emphasise on the fact that there is a need to focus more on the need to change the social institutions to include multiple disabled people and not remain concentrated only on the individual characteristics of multiple disabled people, as it so often has been the case. Therefore it is important to explain that the focus of the study on the social model of disability was decided especially because it has been so disregarded within the Greek context in relation to multiple disability and because the issues of reinforcing the collective action of parents has been a basic point of interest aiming to reduce the focus on impairment and reinforce action in order to battle the disadvantages faced by multiple disabled people.

Nonetheless it is clear now, especially after the analysis of the two parts of the study, that the obstacles of impairment cannot entirely be eliminated by societal change (French, 2003). And furthermore the social model alone cannot encompass the personal experiences and the limitations of impairments that multiple disabled people and their families experience every day (Shakespeare and Watson, 1997). Room should be allowed for expressing the personal experiences of the body and of

impairment (Morris, 2001) and no one should be denied the right to express the experiences of their bodies, the individual experience of disability needs to be addressed (French and Swain: 2006, French, 2003). It is also very important to note that multiple disability is not the basic characteristic of a person, there are additional elements such as gender, age, nationality, sexuality, the physical obstacles that impairment can cause to a person that co-exist in the life of a disabled person (Tregaskis, 2002). Most importantly, through the interviews it became clear that not all multiple disabled people are the same. I met different families, with different children, different histories, different problems and expectations and this aspect should also be highlighted.

The complex nature of multiple disability has been evident from the findings of the study, it is multidimensional and affected by the different personal, political, social and cultural experiences of the multiple disabled children and adults (Shakespeare and Watson, 2010).

This research has engaged both to the social dimension of the experiences of the parents and the actions of the parental associations and also to the personal dimension shared by the participants. It becomes more clear now the discussion of Watson (2012) about a need of a new paradigm and a new model to help us investigate what it means to be disabled. A model that would allow room for disabled people to identify what is meant by quality in their lives; incorporate social experiences; follow the disabled person through the changes they experience as they grow up; the different experience of disability categories; the oppression, exclusion and disablement perspective (Watson, 2012). If we succeed in the future to address all of the above dimensions '*by combining the social, the psychological and the biological without prioritising or privileging one over the other.*' (Watson, 2012: 200) then we could

escape the danger of describing the reality of disability only partially.

### **6.8 Collectivism and empowerment: A way to move forward?**

A continuous support network is considered highly crucial for the parents, as they have stated in the interviews. *'Families feel isolated and that is definitely social in nature and not inherent to impairment'* Dowling, M. & Dolan, L. (2001:31). Usually the support may be offered by family and friends, when available, but still parents find interactions with other parents with similar experiences more fruitful and valuable to them. Parents need someone to talk to and need to be heard: sharing experiences, exchanging information and seeking guidance from other parents with similar experiences is highly needed and valued by the parents; it provides them with a sense of comfort and the feeling of empowerment (Furneaux, 1998). Families need opportunities to talk and share their hopes and concerns regarding their children. In fact, many parents commented that they were happy to participate in a study that might add to the general understanding of disability as experienced by families and at the same time in order to help other families in similar situations (Kalyanpur & Harry 2004). In parallel, parents are called to overcome many barriers during their efforts to include their multiple disabled child in the education system, such as the lack of communication with the teachers, limited educational settings, disrespectful behavior when trying to access services and lack of directions (Resch et al, 2010), and they need a support system to guide them through. Parents need to make decisions for their children and they don't always feel confident in doing so. This pressure increases when the parents feel alone in the process, without support (Sloper, 1999). Stone (2008) also emphasizes the importance of providing high quality support for all parents and families of disabled children and highlights the need to create support



systems accessible and open to all families regardless of their educational level or ethnic background. A support system is vital for parents of children with severe and multiple disabilities. It has the potential of providing empowerment to parents while caring for their child with complex needs (Brett, 2004). Parents in the interviews shared stories about the ways that they have found by themselves to support their children in their educational course and how that provided them a great sense of empowerment, even with the lack of an adequate support system. However, these statements came from parents of older children and in previous parts of the interviews the same parents narrated about all the personal time and energy that they have invested in order to become 'experts'.

From the answers and comments from the parent associations representatives we can detect that one of the main reasons and need for the formation of an association is to provide support and a sense of belonging to parents with disabled children. When parents come together to form a group of parents or a parent association, they can reduce the feeling of isolation and have the opportunity to exchange information and to compare their own family with families with similar experiences in a productive way; meet parents who are coping with the existing challenges successfully; and meet families with worse problems, thus developing greater appreciation for their own situation (Seligman & Darling 1997). Professionals should be a part of this process and act as facilitators by providing young parents with multiple disabled children the necessary information, in order to help them find a suitable parent association, or by providing guidelines in order for them to establish a new association (Seligman & Darling 1997). This was not the case in this study, as the parents explained that the CEDDAS, schools and other stakeholders in education and provision rarely shared

and provided these information to parents, either due to their ignorance or their lack of conceptualising and understanding the purpose and value of parent associations.

A second need that led to the formation of the parent associations lies in their efforts to promote the demands and the rights of all disabled people. The practical implementation of policies has failed to inspire confidence and to receive positive responses from parents concerning the present or future of their children. Parents appear as supporters of educational inclusion, but under different conditions than the current ones of inadequate infrastructure and questionable assessment procedures (Ftiaka, 2008). Parents collectively may have more power to fight the existing system and demand change if they appeal to the ministries and policy member as a united and organized front. The present study revealed that parents believe in their own powers and expertise, and that they have confidence in their knowledge and in their children capabilities. Hence, if they form united associations and use this expertise collectively, they could also change the attitudes that claim that parents of children with severe disabilities are a minority and as a minority their rights can be disregarded. Unfortunately from the present study and as it has been mentioned in various parts of the thesis, parents associations have assumed the role of filling in the gaps of the state provision. From their answers concerning the needs that led to the foundation of the associations it becomes clear that the claim of rights and equal participation in all social activities, the foundation of independent living structures and the promotion of demands to the appropriate ministries were their priority. But as the state funding decreases and the educational and care provision reality remains stable or in some cases deteriorates, parent associations limit their actions concerning the provision of a better quality of life for children with severe and multiple disabilities to

the construction of care structures, accommodation facilities, special schools and day care centres. Even though one of the main demands of the disability movement worldwide was to provide even to those with the most severe and multiple needs, the opportunity to escape institutionalism and live within their community, Grunewald (2005) still maintains that the success of this effort lays entirely on the flexibility and aims of the political system, regardless of the intentions of the disability movement. It is also alarming that the parents of multiple disabled children and adults during the individual interviews never referred to the support from the disability movement and the parent associations, or showed an awareness of the existence of such associations, a fact that is problematic in terms of the proportion of the parents that have access to parent associations, and whether the associations actually represent and fight for the demands for all parents and disabled children (Ftiaka, 2008). Perhaps it is time for the Greek disability movement and parents association to go back and remember their initial objectives and their ideology for social inclusion for all and their fights against the oppressive social reality (Campbell & Oliver, 1996), elements that are still present in the narrations and the statements of parents in the study, but that are being consumed by the existing reality and the continuous needs of families with disabled children that cannot be put on hold.

## **6.9 Strengths**

A variety of methods was used to collect data from different research participants. In the first phase of the research, the method of semi structured interviews was employed to investigate in detail the views and experiences of parents of multiple disabled children and adults about their efforts to include their children in the education system and to secure an appropriate educational placement. This exploratory phase provided

a first picture of the situation in Greece concerning the education of MD children and young adults through the lived experiences of parents. In the second phase of the research a questionnaire was distributed to all the parent associations in Greece for people with severe and multiple disabilities and were addressed to the board members of each association. The survey provided a considerable amount of data that were used in order to validate the findings of the first phase; to provide a broader picture of the existing situation by examining rural and urban geographical areas, and to enrich the study with a more collective perspective concerning the promotion of the rights in education for MD students and the actions of PAs in ensuring equal opportunities and quality of life within the community for multiple disabled people. The data were analysed with both the use of qualitative (content analysis method) and quantitative (statistical process of the data) methods in order to achieve a more spherical view of the information provided.

The study aimed to raise the voice of parents and to include their views in the research design by applying the suggestions and comments generated by parents during the piloting of the interview and the questionnaire. The involvement of parents in the research design was also attempted – indirectly – with the use of semi-structured interviews, which allowed the flexibility to the participants to add topics of their own personal interest concerning the subject under investigation, even if these were not included in the interview guide prepared by the researcher. Furthermore, effort was made to construct the questionnaire, which by its nature is closed and restricted, in more open way for the participants, by adding open-ended questions and providing multiple spaces for personal comments and additions.

To conclude, the thesis included various quotations and passages from the interviews and the open sections of the questionnaire, in order to provide an inside look to the reader and promote the voice of parents through their testimonies of their lived experiences during the educational course of their children. Parents as both individuals and as members of the Greek disability movement hold valuable information and experience in disability issues; it would be an asset for researchers, policy makers, educationalists and other stakeholders to involve them in all discussions concerning educational issues.

#### **6.10 Limitations**

The questions, both in the interviews and the questionnaire, were intentionally designed to elicit information about the educational course of MD children and adults, the quality of education provided to them, the educational programs and curricula followed and the barriers and opportunities in education, as presented through the parents' experiences. However, along with this information, the parents in our study shared more information concerning the general frame of care, the health and provision policies in Greece, the financial situation of the families with md children and the cultural issues of prejudices and stereotypes. This information enriched the study and provided a more spherical view of the situation, as it was made clear that the barriers in educational access are not the only challenges faced by parents of MD children and adults and that all the above issues are interconnected and affect the educational course of the child. The limitation lies on the fact that parents had many personal experiences concerning these wider and systemic issues, but had little

information to share concerning for example a day in the classroom, the content of their child's individual program, or the aims set by the educationalists.

In terms of sampling, two limitations can be noted. In the first phase of the research the participants were contacted from a single geographical area, that of Attica. Even though Attica is a geographical area with high levels of population concentration, almost half of the total Greek population is located within it, nonetheless it remains an urban area and includes Athens, the capital of Greece, where most ministries, schools and organisations are based. This means that access to services and schools may be more available for parents in this area in comparison to others geographical areas of the country. Therefore, the voices of parents from more rural and remote areas of Greece were not included in the first phase. This decision was made mainly due to the fact that it was not feasible within the frame of the research to invite participants to travel long distances in order to participate in the study, and due to the fact that the study was conducted by one researcher alone and the transportation to different areas of Greece would have been time consuming and relatively expensive. The distribution of questionnaires in the second phase of the study was addressed to all the parent associations in Greece in an attempt for the participants to reflect the geographical diversity of all areas and to include different experiences and realities. Another possible limitation is that nearly all participants in the first phase of the study were women; however this is not significantly limiting for the findings of the research since mothers are typically the primary care providers for MD children and young people. Nevertheless, in the second phase of the study fathers of MD children and adults also participated in the survey and the participation was almost equal for both sexes.

The second limitation of the sampling process lies in the fact that the parents who participated in the first phase of the study were located through schools; therefore they are parents who in some way have succeeded in securing an educational placement. Thus this phase does not account for families with MD children and young people who remain excluded from the official education system, home schooled or not officially documented as existing. In the same frame, the second phase of the study included representatives of parent associations and thus parents who are possibly more active and involved in educational issues and aware of the debate concerning inclusion and the social perspective of disability. Most importantly this research could not include the voices of MD children and young people in the study but this was due to considerable investment of time, resources and expertise needed (Lewis et al, 2007) and that was not feasible to implement in a research conducted by one person.

For all the above mentioned limitations and due to the fact that this research was based on the hermeneutic approach, thus accepting that the researcher is an integral part of the study and that personal bias and views cannot be totally eliminated, caution was taken not to attempt to make inferential or conclusive statements based on the interviews of the study. Instead, the focus was on the education of MD students, the reinforcement of the role of parents in the educational procedure as a valuable source of information and the provision of the ground for further discussion.

Another limitation of the study is based on a personal ethical consideration. Parents participated in the study voluntarily, and when they accepted to do so it was because they felt that through their experiences they might help other parents in similar situations to anticipate barriers but also to be aware that there is a way to overcome them. They agreed to be a part of the study believing in a higher aim that the dissemination of the information provided by them will bring change and open the dialogue concerning the education of their MD children, an issue that is rarely addressed on a source of interest in the wider society. It is the researcher's faith that this study may provide an incentive for the initiation of this dialogue and that it did not raise false hopes amongst the participants that cannot be fulfilled.

### **6.11 Implications for policy and practice**

The focus of this study was primarily on the education of MD children and adults by addressing issues of inequality, educational exclusion and school withdrawal as presented by the experiences of their parents, and on reinforcing the role of parents in the educational process. It is worth considering the findings from this study in the light of recent policy developments relating to the education of disabled children and young people and with emphasis on students with multiple disabilities.

Within the context of the Convention on the rights of persons with disabilities (UNESCO, 2006), the lines of the Lisbon Strategy and building on the UNESCO Policy Guidelines on Inclusion in Education (2009), it has been increasingly recognised that a high level of education and provision of skills is a prerequisite for the establishment of active and equal citizens. It has also been recognized that



inclusion and quality are reciprocal, the adoption of more inclusive practices in education can contribute significantly to the quality of education for all learners. In Greece the recent law on special education (3699/2008) and the Developmental Strategy during the period 2007-2013 (Ministry of Education, 2007) also advocate inclusive education, equal access and opportunities in education for all students.

The aim therefore is to develop more equal, democratic and inclusive systems where diversity is accepted and celebrated. To ensure the above conditions are met, there is an increasing need to create educational systems and services based on non-discrimination and the provision of equal opportunities and access to all students and to take into account the individual needs of those students who are at risk of social exclusion and marginalisation. Multiple disabled students have been identified by relevant researches and through this specific study as students at risk.

Within this frame, policies should ensure that early childhood education is available to all students, that parents are involved in the education of their children and are supported in their efforts, and that an interdisciplinary approach is employed by integrating the expertise of different professionals in order to provide a more holistic support to students with disabilities, even those with the most severe disabilities. These efforts will require the collaboration across different policy sectors, namely education, health, care, social provision.

Educational policy should be viewed as a dynamic negotiation and should move away from the notion that quality education is defined within a positivist framework of depicting the degree of compliance to or deviation from the formal institutional line of all those involved in the educational process (Slee, 2001; Ozga, 2000). With regard to

current trends of evidence based policy-making, it has also been suggested that the perspective of educational policy as a product ready to be implemented, and not as a dynamic process, is limited and restrictive (Ozga, 2000).

With regards to the Greek educational context more specifically, and based on the findings of this study, the following points concerning policy emerge and need further discussion and action from policy makers:

A critical consideration of the hierarchical structure of the Greek educational system structure is needed. The inflexibility of the hierarchy and the existing competitive relationships can't constitute the base of equal opportunities in education for MD students and cannot support parents in becoming equal partners in the education of their children.

The revision of the legislative framework for the education of disabled students is considered crucial; and it should take into account the students with more severe and multiple disabilities. The proposed revision of the current law on special and inclusive education should de-medicalise the educational structures for disabled students by changing the existing terminology which is anachronistic and medically centered, namely *differentiated diagnosis, examination, and percentage of disability* (Law 2699/2008). In addition, it should include the pedagogical assessment of students, discontinue the categorisation of students based on their severity and nature of disability, and revise the role, responsibilities and function of CEDDAS. The legislation should promote and reinforce the inclusive orientation of education, the

differentiation of curriculum to meet the interests and motivate all students and to promote cooperative practices amongst educationalists. It also needs to introduce early childhood intervention programs and structures that will act proactively and will provide support to parents and MD children. Additionally, through the legislation and relevant policies the notion of life long education should be promoted and linked to programs of independent or semi-independent living and life skills training.

The involvement and participation of MD children's parents should be promoted in all stages of planning, decision making and monitoring of the progress of their children. Parents should be educated, further trained and legally provided with the right to choose the appropriate educational placement for their child.

## **6.12 Conclusion**

The current educational reality for MD students has been presented by their parents through their personal lived experiences. Parents described the educational course of their MD children and adults and shared their personal stories. On the other hand representatives of Parent Associations for people with severe and multiple disabilities, shared their aims, demands and actions for the promotion of MD children's and young people's rights for full and equal participation in the social and educational life of their community and as citizens of their country.

These experiences drew up incidents of exclusion, barriers in education, lack of opportunities and in plain words the denial to MD students to access the existing

educational system. The inclusion of MD children and adults within the Greek educational system, not merely as presence but, as equal participators requires the total change and reform of the social, and by extension the educational system. The idea of inclusion in the existing educational system appears utopic because it cannot be supported ideologically or practically.

Inclusion is linked to MD children and adults in a basic and straightforward way, as parents and PAs representatives have repeatedly highlighted in various narrations that MD children and young people have been denied access in education. Quality and meaningful education for MD children and adults, according to the literature review and the participants' accounts, must include educational programs for the development of daily living skills and social skills and it must promote and develop the level of their autonomy and the idea of lifelong learning. By providing skills, training and education MD children and adults will have better opportunities of self-development and progress. MD children should be educated from a very young age and be provided with choices. Without choices even the idea of independent living as proposed by the disability movement and promoted by parent associations will remain in the notion of care, protection and institutionalisation.

The parents in this study linger between the theory of personal tragedy and the social perspective of disability. Depending on the barriers and challenges faced, parents either return to a state of confinement within the family and try to cope with difficulties alone, based on the conception that all problems emerging and concerning their MD child should be their personal case and responsibility to solve; or they

realise that these emerging ‘problems’ are not always caused by their children’s disabilities but also due to the unchanging and inflexible system. When parents realise that they and their children have rights and they are entitled to claim them then they make demands from the state, from the policies and from schools. The participants of this study were very dynamic and made great efforts to support their children and advocate on their behalf, they proved to be a valuable source of information concerning the existing reality, provided ideas for reforms, possible solutions and suggestions.

Parents - members of the associations also appeared dynamic and empowered. They were very well aware of the legislation, policies and informed with regard to the idea of inclusion and the social aspect of disability. Even though in practice parent associations deal with discovering quick and practical solutions to meet the needs of MD children and adults we should keep in mind that they try to fill the gaps of the political system and the holes in the care, provision and education system. For this reason they focus on providing special structures for providing care, protection and health care provision to children and families in need.

The most critical part of the study proved to be the fact that participants had a lot of information to share that went beyond the issue of education. Participants shared personal stories concerning issues of bureaucracy, health care and provision, communication and also structural and cultural matters. The way that parents elaborated on the above their interconnected nature raises a bigger question of inclusion and exclusion for MD children and adults in society and reinforces the idea

that multiple disability is not one dimensional and cannot be examined as so. Multiple factors, as the ones that the participants underlined, interact and lead to the existing reality.

By examining the educational reality of severely and multiple disabled children and adults, the study yield the conclusion that maybe we need to return and remember the fundamental principles of education and inclusion and take under consideration that in between all the current debates concerning education internationally, there is an additional group of students, multiple disabled students, who are placed on the margin of policies, of the educational and social life and more than often of our thoughts and consideration. As it was briefly mentioned in the introduction, because of our rare encounters with MD students maybe we have forgotten that they have the right be a part of the educational and social system.

The aim at this point is not to produce generalisations and determine conclusions but provide the opportunity and the foundation for the initiation of a dialogue between multiple disabled people, educational researchers, policy makers, teachers, professional and parents concerning the steps towards ensuring the rights of multiple disabled students in education and the planning of specific pedagogical practices not within isolated settings but near their non-disabled peers, close to their neighbourhood and their parents.

During all stages of the study, new research themes and questions emerged that could support the topic under investigation. Firstly it would be interesting to investigate in detail the educational reality for multiple disabled students within their school environment and thus collect more details about the pedagogical methods used, their individual educational programs, the aims set by the educationalists, the monitoring of their progress and the methods of assessment.

Furthermore, an in-depth study of the Greek disability movement and parental associations in terms of history, current positions and future plans will be valuable.

Another thought-provoking issue is the investigation of the attitudes and views of parents with typically developing children towards severely and multiple disabled children and young people, since in this study their stereotypical behaviour, as experienced by parents of MD children and adults, had cause an additional barrier in education. It is important to understand how these stereotypes were constructed and rooted, since parents with negative attitudes towards disability may transfer these attitudes to their children.

Some parents also mentioned that discrimination against MD people is not encountered only in the case of non-disabled people, it can also be encountered between disabled people; this aspect was only presented briefly and it will be noteworthy to look deeper into that issue and all further implications and projections that might emerge.

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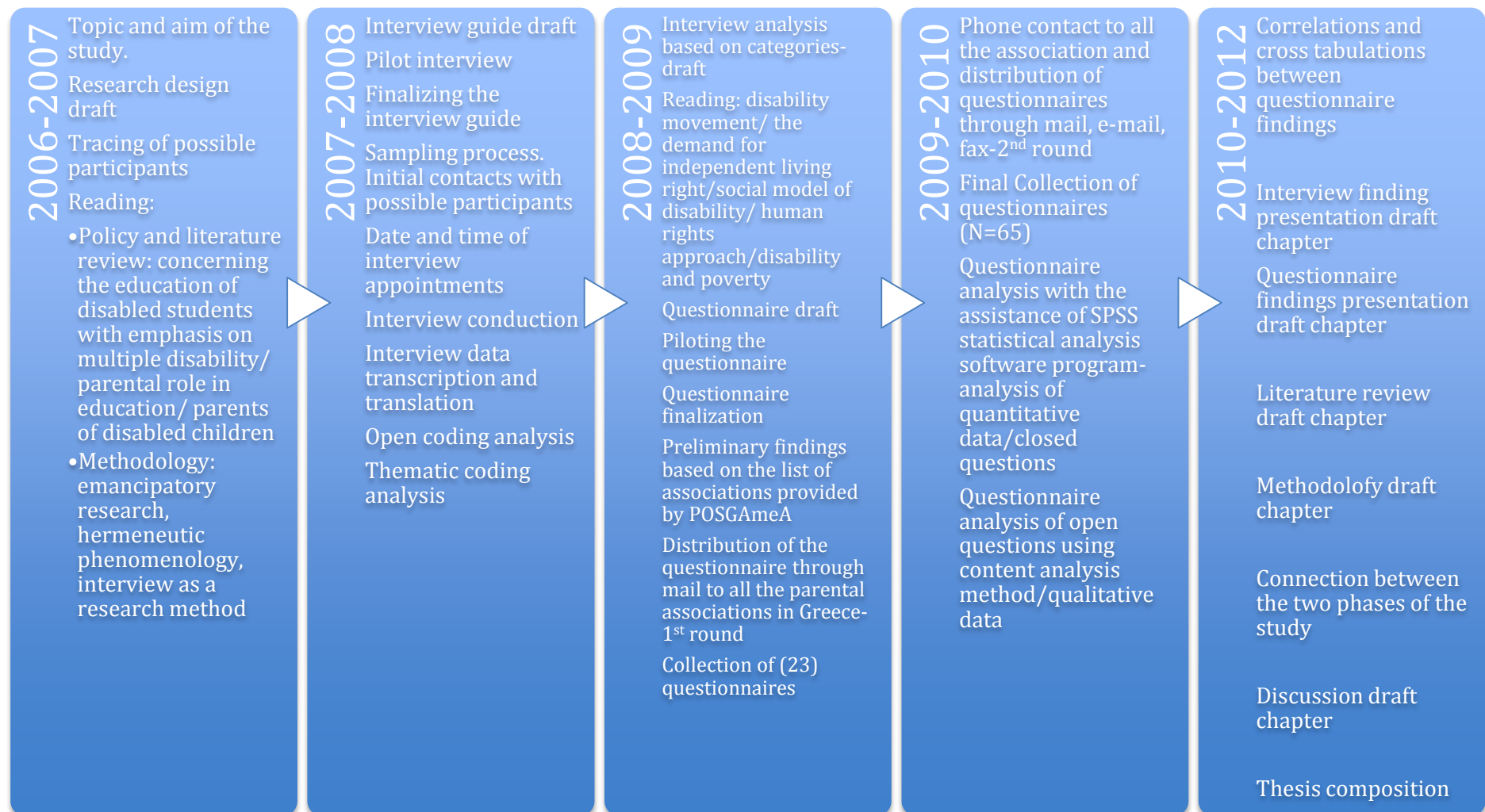
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# List of Appendices

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## **Appendix 1: Timeline of the study**



## **Appendix 2: Interview guide**

## **Interview guide:**

### **Thematic Area 1: Family composition.**

(Could be used at the beginning of the interview):

Could you describe me your family?

How many children do you have?

What age are they?

Does the grandmother, the grandfather or any other member of the extended family live with you/ or near you?

(To be introduced at a later stage of the interview):

Do you work outside of the house?

Is your wife/husband employed?

How do you balance your time and responsibility between home and work?

Who is usually the main responsible of the house care and children's' care?

Could you tell me a bit more about your daughter/son (with multiple disabilities)?

How old is he/she?

Does she/he have a hobby?

Something he/she enjoys doing during the day?

How he/she spends his/hers day?

Who is his/hers best friend?

Does she/he spend time with hers/his siblings-with the parents?

What does she/ he enjoys doing with all the family?

What does the family enjoy doing with him/her?

**Thematic area 2: Centres of Differentiated Diagnosis, Assessment and Support  
for Children with Special needs (KEDDY):**

Have you ever cooperated with KEDDY?

It was your own initiative to seek for an educational diagnosis and assessment?

Who referred you to KEDDY?

Could you describe me your experience of the assessment process?

How old was your child when you first visited KEDDY?

It was easy to make an appointment?

How long did the whole process last from the moment you decided to make an appointment since the day that you received the final assessment?

How often do you need to visit KEDDY for an assessment?

It was the first time that you obtained a professional diagnostic assessment?

What was the diagnostic assessment, could you tell me a bit more?

How did you use the diagnosis, for what purpose?

The assessment was based on the recommendation of one person? Was there a team of professionals?

Did KEDDY representatives propose an appropriate school placement?

Did you agree with the assessment/school placement? Did you try to contest it? What steps did you follow?

Was your opinion taken into account? Were you asked for information concerning your child?

How would you describe your cooperation with the KEDDY representatives? Were they helpful/supportive?

**Thematic area 3: Educational course, educators and special education staff:**

What kind of school does your child attend today (Primary, secondary, state, private, mainstream, special, day care center)?

How was his/hers day at the school? Could you describe a day?

In what kind of activities is he/she mostly involved in school?

Is she/he a part of a classroom/group of students?

Who is his/hers best friend from school?

How would you comment your child's progress/personal development in school?

Could you describe me the educational course of your child? (Changes of schools, transitions, etc.)

Could you tell me some of the good experiences you have had during the educational course of your child (prompts to help the parents elaborate on their answers: When was this? What happened? How was that enjoyable? How was it helpful? How did it affect the child and the family?).

Could you tell me some of the bad experiences you have had during the educational course of your child (Prompts to help the parents elaborate on their answers: How was that a problem? How was it overcome? Could you have done anything differently? What were the more difficult issues/challenges/barriers?).

When did you first start considering about an educational placement for your child/made plans/took action to enroll your child in school?



Did your child attend an early intervention program? (If yes) Who advised to you to do so? Could you describe me your experience? Was it helpful? What did the educational program include? Were you a part of the program?

How did you decide the appropriate school placement of your child?

Were you/are you satisfied with your child's school placement?

(If it was a decision not made by them/or if they were not satisfied with the placement proposal):

Did you try to contest this proposal/decision? What steps did you follow? Were you successful in promoting your point of view? Were your concerns addressed by the professionals?

How was the relationship between your child and the teachers?

How was the relationship between you and the teachers?

Did they know of your child's multiple disabilities? How did they know (asked information from you/consulted the diagnosis)?

How have any disability issues affected your child's education?

Were the school, head teacher, teacher, and educational counselor open in discussing support that might help?

Were they open in discussing changes in the existing teaching/learning methods, curricula that could help meet your child's needs?

Where you involved in your child's education?

Were you informed regularly about his progress and his involvement in learning activities?

Did you help the teacher set the educational aims for your child?

Has the school asked you how you would like to be involved in your child's education and what help they can be in assisting with this? And if so, do you have any suggestions on this?

Was any additional support provided to your child? What kind of support? (additional teacher, special education staff, health care staff, specialized equipment, etc.)

Were you informed about the educators' expectations and aims set for your child?  
Was there an individual program?

What kind of changes would you like to see in the educational provision for your child?

(In case the parents stated a disagreement/disapproval of the child's current school placement): Are you considering changing schools next year? Based on your experience so far what kind of school will be most appropriate for your child? Have you considered mainstream education?

#### **Thematic area 4: Legislation, Education Policy and Provision:**

Which pieces of legislation have been/are helpful during the educational course of your child?

How are you informed of new legislation pieces?

How does the current education policy promote and ensure your child's right in education in your opinion?

Financially how do you manage to cope with the expenses?

State welfare is available to assist you?

#### **Thematic area 5: Hopes, expectations and concerns:**

Which were your first expectations concerning his/her school placement and learning?

Did these expectations change during the educational course of your child? How so?

Which were your expectations concerning the education you would like for him/her to receive?

What are your expectations concerning your child's educational progress now and in the future?

In your opinion, what kind of use will your child have of the education provided in his/hers future life?

In which level do you believe that being included in school will lead to being and feeling included in the community?

Have you considered future steps concerning your child's education?

Do you still have concerns about his educational and personal development?

**At the end of the interview:**

Is there anything that you would like to ask me?

Is there anything else you would like to comment on?

Will it be ok for me to phone you in the future concerning this specific research?

### **Appendix 3: Families' composition table**

Parents	Mother's Profession	Father's Profession	Age of the child	Gender of the child	Siblings	Duration of the Interview	Place of the interview
Mother 1	House hold	Private Sector/businessman	14	Girl	Younger sister without disability	50 minutes	School area
Mother 2	Educationalist	Private Sector	28	Boy	Older brother without	1 hour and a half	School area
Mother 3	House hold	Public Sector	12	Boy	None	1 hour	School area
Mother 4	House hold	Doctor	9	Girl	None	50 minutes	Family house
Mother 5	Educationalist	Doctor	20	Girl	None	55 minutes	Family house
Mother 6	Shop owner	Construction Worker	12	Boy	None	45 minutes	School area
Mother 7	House hold	Public Sector	8	Girl	Older sister without	50 minutes	Family house
Mother 8	House hold	Private Sector	9	Girl	None	45 minutes	School area
Mother 9	House hold	Bank employee	10	Boy	None	55 minutes	Family house
Mother 10	Shop owner	Public Sector	12	Boy	Younger sister without	45 minutes	Family house
Mother 11	House hold	Bank employee	14	Girl	Younger brother without	45 minutes	Family house
Mother 12	House hold	Public Sector	10	Girl	None	50 minutes	Family house
Mother 13	House hold	Public Sector	14	Girl	None	55 minutes	Family house
Mother 14	Bank employee	Public Sector	12	Boy	One younger brother and one	50 minutes	Family house
Mother 15	House hold	Private Sector	14	Girl	None	45 minutes	Family house

#### **Appendix 4: Letter of participation in Interviews (in English and in Greek)**

## **Participation in research letter**

Konstantina Lampropoulou  
PhD student  
School of Education  
University of Birmingham

Dear Sir/Madame

You are invited to participate in a research study conducted by Konstantina Lampropoulou, PhD student, School of Education, University of Birmingham and the purpose of this letter is to provide information to help you make an informed decision.

The purpose of this study is to learn more about the education of children with multiple disabilities in Greece. Your participation in the study will contribute to a better understanding of the education of children with multiple disabilities as you will be asked to provide your personal experiences and insight on the matter during an interview with the researcher. Your participation will be a rich and valuable source of information for this research and it will require an hour of your time. This study will contribute to the researcher's completion of her thesis dissertation. The material of the interview will be used for the completion of the researcher's thesis dissertation and part of the research findings may be included in scientific magazines with the aim to contribute to the dialogue concerning disability.

With your consent the interview will be audiotaped and any information obtained will be anonymous and kept in the strictest confidence. No identifiable information will be collected and no identifiable responses will be presented in the final form of this study. With the guarantee of anonymity and confidentiality and with your consent quotations from the interview will be included in the findings presentation of the thesis.

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind and any information provided by you will be destroyed and not included in the thesis.

If you have questions or concerns during the time of the interview, or after its completion or you would like to receive a copy of the interview transcription and research findings of this study, please don't hesitate to contact me.

Thank you for your participation,

Yours sincerely,

*Konstantina Lampropoulou*

*Ph D Student in Special Education, University of Birmingham*

Telephone:

E-mail address:

**I have read this letter and I fully understand the contents of this document and voluntarily consent to participate. All of my questions concerning this research have been answered. If I have any questions in the future about this study they will be answered by the researcher listed above.**

Participant's signature

If you need any further information before, during or after the end of the interview please don't hesitate to ask me or contact me.



## Πρόσκληση συμμετοχής σε έρευνα

Κωνσταντίνα Λαμπροπούλου  
Διδακτορική φοιτήτρια  
Τμήμα Εκπαίδευσης  
Πανεπιστήμιο του Birmingham

Αγαπητέ κύριε/Αγαπητή κυρία

Η παρούσα επιστολή αποτελεί πρόσκληση συμμετοχής σε έρευνα η οποία διεξάγεται από την Κωνσταντίνα Λαμπροπούλου, Διδακτορική φοιτήτρια του Πανεπιστημίου του Birmingham. Σκοπός της επιστολής είναι να σας ενημερώσει σχετικά με την διεξαγωγή και τον σκοπό της έρευνας πριν την απόφασή σας να συμμετάσχετε ή όχι.

Σκοπός της έρευνας είναι να διερευνήσει την παρεχόμενη εκπαίδευση για παιδιά με πολλαπλές αναπηρίες στην Ελλάδα. Η συμμετοχή σας στην έρευνα κρίνεται ιδιαίτερος σημαντική καθώς θα σας ζητηθεί να μοιραστείτε τις προσωπικές σας εμπειρίες και απόψεις σχετικά με το θέμα κατά την διάρκεια μίας συνέντευξης διάρκειας περίπου μίας ώρας και θα αποτελέσει μία αυθεντική και πλούσια πηγή πληροφοριών. Το υλικό της συνέντευξης θα συμπεριληφθεί στην διδακτορική διατριβή της ερευνήτριας και τα ευρήματα της έρευνας πιθανόν να δημοσιευθούν σε επιστημονικά περιοδικά με σκοπό να συνεισφέρουν στον διάλογο σχετικά με ζητήματα αναπηρίας.

Με τη συγκατάθεσή σας η συνέντευξη θα μαγνητοφωνηθεί και θα εξασφαλιστεί η ανωνυμία σας σχετικά με οποιαδήποτε πληροφορία καθώς και η απόλυτη εχεμύθεια. Καμία αναγνωρίσιμη πληροφορία δεν θα συμπεριληφθεί στην τελική μορφή της διατριβής. Με την εγγύηση της τήρησης ανωνυμίας και εχεμύθειας και ύστερα από δική σας συγκατάθεση αποσπάσματα της συνέντευξης θα συμπεριληφθούν κατά την παρουσίαση ευρημάτων στη διατριβή.

Η συμμετοχή σας είναι εθελοντική και ασφαλώς έχετε το δικαίωμα να μην συμμετάσχετε. Εφόσον επιθυμείτε να συμμετάσχετε, διατηρείτε το δικαίωμα να

αποχωρήσετε οποιαδήποτε στιγμή χωρίς καμία συνέπεια. Οποιαδήποτε πληροφορία έχετε μοιραστεί με τον ερευνητή θα καταστραφεί και δε θα συμπεριληφθεί στην έρευνα.

Σε περίπτωση που έχετε οποιαδήποτε απορία πριν, κατά τη διάρκεια ή μετά την ολοκλήρωση της συνέντευξης ή σε περίπτωση που επιθυμείτε να παραλάβετε αντίγραφο της απομαγνητοφώνησης της συνέντευξης και των ευρημάτων της έρευνας σας παρακαλώ μη διστάσετε να επικοινωνήσετε μαζί μου.

Σας ευχαριστώ για τη συμμετοχή σας,

*Κωνσταντίνα Λαμπρόπουλου*

*Υποψήφια διδάκτωρ Ειδική Αγωγής, Πανεπιστήμιο του Birmingham*

Τηλέφωνο:

Διεύθυνση ηλεκτρονικού ταχυδρομείου:

**Έχω διαβάσει την επιστολή συμμετοχής σε έρευνα και κατανοώ απόλυτα το περιεχόμενο του κειμένου και εθελοντικά δίνω τη συγκατάθεση μου να συμμετέχω. Όλες οι απορίες μου σχετικά με την έρευνα έχουν απαντηθεί. Σε περίπτωση που έχω σχετικές με την έρευνα ερωτήσεις στο μέλλον θα απαντηθούν από τον συγκεκριμένο ερευνητή.**

Υπογραφή συμμετέχοντα

Για οποιαδήποτε διευκρίνιση πριν, κατά τη διάρκεια η και μετά το τέλος της συνέντευξης σας παρακαλώ να μην διστάσετε να με ρωτήσετε η και ν επικοινωνήσετε μαζί μου.

## **Appendix 5: Map of Greece and specific geographical regions**



**Appendix 6: Invitation of participation in survey and Questionnaire  
(in English and in Greek)**



**School of Education  
Edgbaston  
Birmingham B15 2TT  
United Kingdom  
Telephone [REDACTED]**

Dear parents and guardians,

Thank you for taking the time to read this. The questionnaire that you hold in your hands has been composed as part of my PhD thesis research at the University of Birmingham, UK.

Its purpose is to investigate the operation of unions/associations of parents and guardians of people with disabilities, with emphasis on multiple disabilities.

The questionnaire is anonymous and will be used solely for the purpose of this study. Your contribution is essential and crucial in order to help develop practice in Greece.

I would like to ask you to answer all the questions, so that a complete picture will be formed.

Thank you for your taking the time to fill in this questionnaire. Please do not hesitate to contact me on ... and ..., if you have any queries.

Yours sincerely,

Konstantina Lampropoulou

Ph D Student in Special Education, University of Birmingham

## ***QUESTIONNAIRE***

### **1. Gender:**

Male ☐

Female ☐

### **2. Age:**

25-29 ☐

30-39 ☐

40-49 ☐

50-59 ☐

60-69 ☐

### **3. What is your profession?**

.....

### **4. Are you a parent/guardian of a disabled child?**

Yes ☐

No ☐

If yes, please specify:

α) the child's age .....

β) the child's diagnosis .....

### **5. What is your position in the union/association?**

.....

### **6. Select the geographical area in which your union/association is located:**

Attica ☐

Dodecanese Islands ☐

Ionian Islands ☐

Epirus ☐

Thessaly ☐

Thrace ☐

Crete ☐

Cyclades ☐

Macedonia ☐

North Aegean Islands ☐

Peloponnesus ☐

Central Greece ☐

**7. Date of the foundation of the union/association**

**(Approximately, please leave blank if not known):**

.....

**8. Number of union/association members**

**(Approximately, please leave blank if not known):**

.....

**9. Members of your union/association are parents/guardians of children with**

**(Please, tick all that apply):**

- ⇒ Multiple disabilities ☐
- ⇒ Learning difficulties ☐
- ⇒ Mental Retardation ☐
- ⇒ Autism ☐
- ⇒ Deafness/Hearing Problems ☐
- ⇒ Blindness/Partially Sighted ☐
- ⇒ AD/HD ☐
- ⇒ Physical disability ☐
- ⇒ Speech and language difficulties ☐
- ⇒ Behavioral Problems ☐
- ⇒ Psychological Problems ☐
- ⇒ Environmental/ Social Problems ☐
- ⇒ Epilepsy ☐
- ⇒ Mental disorders ☐
- ⇒ Health problems ☐
- ⇒ Other.....

.....

**10. Informing parents/guardians about the existence and operation of your union/association is realised through**

**(Please, tick all that apply):**

- ⇒ Hospital Units ☐
- ⇒ Diagnostic Centers ☐
- ⇒ Local authorities/Municipalities ☐
- ⇒ Media ☐
- ⇒ Internet ☐
- ⇒ Leaflets ☐
- ⇒ Family environment/ Friends ☐
- ⇒ Other .....



**11. Do you consider the means of informing parents, described above, effective?**

Not at all ☐    A little ☐    Fair ☐    Quite a lot ☐    Very much ☐

**If you selected 'not at all' what would you propose as an effective way of informing parents?**

.....

.....

.....

**12. Is a form of financial subscription required in order to become a member of your union/association?**

Yes ☐    No ☐

**If yes, the amount of this financial subscription is:** .....

**13. What do you think is the basic need that led to the foundation of your union/association?**

**(Please, tick all that apply)**

- ⇒ Highlighting problems ☐
- ⇒ The demand of solutions from the Ministry of Education ☐
- ⇒ The demand of solutions from the Ministry of Health and Social Welfare ☐
- ⇒ Informing parents ☐
- ⇒ Representation of parents ☐
- ⇒ Care ☐
- ⇒ Promoting the right to access in mainstream education ☐
- ⇒ Other.....

**14. The main activities of your union/association focus on matters concerning:**

**(Please, number in order of priority)**

- ⇒ Legislation ☐
- ⇒ Education ☐
- ⇒ Vocational rehabilitation ☐
- ⇒ Welfare/provision ☐
- ⇒ Medical ☐
- ⇒ Social ☐
- ⇒ Autonomy ☐
- ⇒ Financial support of families ☐
- ⇒ Support between parents ☐
- ⇒ Other.....☐

**15. The Panhellenic Federation of Parents of Persons with Disabilities (P.O.S.G.K.A.meA)**

**record a total of 187 unions/associations of parents/guardian of children with disabilities in Greece. Do you believe these unions/associations are sufficient to meet the needs and to help families of people with special needs / disabilities?**

Yes ☐ No ☐

**16. Do you believe that these unions/associations are sufficient to meet the needs and to help families of people with multiple disabilities?**

Yes ☐ No ☐

**Please explain your answer:**

.....

.....

.....

.....

**17. Are there link, contact and cooperation between the unions/associations?**

Not at all ☐ A little ☐ Fair ☐ Quite a lot ☐ Very much ☐

**Please explain your answer:**

.....

.....

.....

.....

**18. Unions/associations of parents and guardians of people with special needs / disabilities mostly represent a particular category of special needs / disabilities. In your opinion, such a division is useful?**

Yes ☐ No ☐

**Please explain your answer:**

.....

.....

.....

.....

**19. To what extent has the action of parents' and guardians' unions/associations of people with disabilities affected issues concerning:**

**a) the legislative framework of the country**

Not at all ☐   A little ☐   Fair ☐   Quite a lot ☐   Very much ☐

**b) education**

Not at all ☐   A little ☐   Fair ☐   Quite a lot ☐   Very much ☐

**c) the social context of the country**

Not at all ☐   A little ☐   Fair ☐   Quite a lot ☐   Very much ☐

**d) care**

Not at all ☐   A little ☐   Fair ☐   Quite a lot ☐   Very much ☐

**e) welfare/provision**

Not at all ☐   A little ☐   Fair ☐   Quite a lot ☐   Very much ☐

**f) employment**

Not at all ☐   A little ☐   Fair ☐   Quite a lot ☐   Very much ☐

**g) independent/semi- independent living**

Not at all ☐   A little ☐   Fair ☐   Quite a lot ☐   Very much ☐

**20. Which, in your opinion, groups with special needs / disabilities claim their rights?**

**α) to a greater extent**

.....

**β) to a lesser extent**

.....

**Why do you think there is this differentiation?**

.....

**21. Which cases of pupils do you think can attend mainstream education? Pupils with:**

- ⇒ Multiple disabilities ☐
- ⇒ Learning difficulties ☐
- ⇒ Mental Retardation ☐
- ⇒ Autism ☐
- ⇒ Deafness/Hearing Problems ☐
- ⇒ Blindness/Partially Sighted ☐
- ⇒ AD/HD ☐
- ⇒ Physical disability ☐
- ⇒ Speech and language difficulties ☐
- ⇒ Behavioral Problems ☐
- ⇒ Psychological Problems ☐
- ⇒ Environmental/ Social Problems ☐
- ⇒ Epilepsy ☐
- ⇒ Mental disorders ☐
- ⇒ Health problems ☐
- ⇒ Other.....

.....

**22. In your union/association are there parents and guardians of children with multiple disabilities;**

Yes ☐      No ☐

**If yes:**

**Number of members:**

.....

**What kind of cases of multiple disabilities (children):**

.....

**If no:**

**What is your opinion on why there aren't parents of children with multiple disabilities in your union/association?**

.....

.....

.....

**23. Which do you think is the more appropriate union/association for parents of children with multiple disabilities to address?**

.....

.....

.....

.....

**24. What are the main challenges for children with multiple disabilities?**

**(Please, number in order of priority)**

- ⇒ Legislative ☐
  - ⇒ Educational ☐
  - ⇒ Vocational Rehabilitation ☐
  - ⇒ Welfare/Provision ☐
  - ⇒ Medical/Health ☐
  - ⇒ Social ☐
  - ⇒ Autonomy ☐
  - ⇒ Independent/ Semi- independent services ☐
  - ⇒ Other.....
- ..... ☐

**25. To what degree are the following rights of children with multiple disabilities promoted in our country:**

	Not at all satisfactory	A little satisfactory	Fairly satisfactory	Quite a lot satisfactory	Very much satisfactory
Medical and psychological follow-up					
Education / Training					
Employment					
Inclusion to the community					
Access to information					
Autonomy					
Developing skills of daily living					

**26. Which do you think is the appropriate educational setting for children with multiple disabilities?**

.....

.....

.....

.....

**27. Is your union/association concerned with issues related to the promotion of rights of children with multiple disabilities?**

Yes ☐      No ☐

**If yes, with which specific issues?**

- ⇒ Legislation ☐
- ⇒ Education ☐
- ⇒ Vocational Rehabilitation ☐
- ⇒ Welfare/Provision ☐
- ⇒ Medical/health ☐
- ⇒ Social ☐
- ⇒ Autonomy ☐
- ⇒ Independent living structures ☐
- ⇒ Other ☐

**28. Which is, in your view, the main action of your union/association towards the promotion of rights of children with multiple disabilities and the improvement of their quality of life?**

.....

.....

.....

.....

**29. With which of the following definitions of multiple disabilities would you agree with more?**

**(Select one of the following definitions)**

- a) Multiple disabled people experience more than one disability, including physical, intellectual, communicative, sensory, and/or emotional. ☐
- b) People with multiple disabilities need constant medical care and need ongoing support to more than one sector of life in order to participate in social activities and enjoy life with their fellow human beings. ☐
- c) A person with multiple disability is defined as someone whose additional disabilities, physical, intellectual sensory, behavioural is so severe that each one individually affects the normal development or education. ☐
- d) Children and adults with multiple disabilities are children who do not fit into another category of disability. ☐
- e) The term multiple disabilities describes students who have severe intellectual disabilities and more than one additional disability (visual impairment, hearing impairment, epilepsy, physical disability, chronic illness). ☐

**30. In your view is the formation of a concrete, functional definition of multiple disabilities essential?**

Not at all ☐    A little ☐    Fair ☐    Quite a lot ☐    Very much ☐

**31. The formation of a precise definition of multiple disabilities can act as an:**

- ⇒ useful for people with multiple disabilities ☐
- ⇒ an inhibitor for people with multiple disabilities ☐

**Please explain your answer:**

.....

.....

.....

## GENERAL OBSERVATIONS AND COMMENTS

.....

.....

.....

.....

Thank you very much for sharing your views.

If you are interested in finding out more about the research you can contact me at any time

<b><i>Contact Details:</i></b>	
<b>Tel</b>	
<b>E-mail</b>	
<b>Fax</b>	
<b>Address</b>	

In case you might be interested in participating in a follow up interview please provide some contact details information so that I would be able to reach you



## ΕΡΩΤΗΜΑΤΟΛΟΓΙΟ

Αγαπητοί γονείς και κηδεμόνες,

το ερωτηματολόγιο που κρατάτε στα χέρια σας έχει δημιουργηθεί στο πλαίσιο εκπόνησης της διδακτορικής μου διατριβής, στο πανεπιστήμιο του Birmingham.

Σκοπός του είναι η διερεύνηση του τρόπου λειτουργίας των σωματείων γονέων και κηδεμόνων ατόμων με αναπηρίες, με έμφαση στις πολλαπλές αναπηρίες.

Το ερωτηματολόγιο είναι ανώνυμο και θα χρησιμοποιηθεί αποκλειστικά για τους σκοπούς της διατριβής. Η συμβολή σας είναι απαραίτητη και καθοριστική για την ολοκλήρωση της εργασίας μου.

Θα σας παρακαλούσα να απαντήσετε σε όλες τις ερωτήσεις, ώστε να υπάρχει μια ολοκληρωμένη εικόνα των δεδομένων.

*Σας ευχαριστώ πολύ για την συνεργασία σας!*

*Κωνσταντίνα Λαμπροπούλου*

*Υποψήφια διδάκτωρ Ειδικής Αγωγής, Πανεπιστήμιο του Birmingham*

# ΕΡΩΤΗΜΑΤΟΛΟΓΙΟ

## 1. Φύλο:

Ανδρας ☐

Γυναίκα ☐

## 2. Ηλικία:

Κάτω των 25 ☐

25-29 ☐

30-39 ☐

40-49 ☐

50-59 ☐

60-69 ☐

70 και άνω ☐

## 3. Ποια είναι η επαγγελματική σας ιδιότητα;

.....

## 4. Είστε γονέας παιδιού με αναπηρίες;

Ναι ☐

Όχι ☐

αν ναι, προσδιορίστε:

α) την ηλικία του παιδιού .....

β) τη διάγνωση του παιδιού .....

## 5. Ποια είναι η θέση σας στο σωματείο;

.....

## 6. Επιλέξτε σε ποια περιφέρεια ανήκει το σωματείο σας:

Αττική ☐

Δωδεκάνησα ☐

Επάνησα ☐

Ήπειρος ☐

Θεσσαλία ☐

Θράκη ☐

Κρήτη ☐

Κυκλάδες ☐

Μακεδονία ☐

Νησιά Βορείου Αιγαίου ☐

Πελοπόννησος ☐

Στερεά Ελλάδα ☐

**7. Έτος Ίδρυσης του σωματείου σας:**

.....

**8. Αριθμός μελών του σωματείου σας:**

.....

**9. Εγγεγραμμένα μέλη στο σωματείο σας είναι γονείς/κηδεμόνες παιδιών με:**

- ⇒ Πολλαπλές αναπηρίες ☐
- ⇒ Μαθησιακές δυσκολίες ☐
- ⇒ Νοητική καθυστέρηση ☐
- ⇒ Αυτισμό ☐
- ⇒ Κώφωση – Βαρηκοΐα ☐
- ⇒ Τύφλωση – Αμβλυωπία ☐
- ⇒ Σύνδρομο υπερκινητικότητας ☐
- ⇒ Κινητικά προβλήματα ☐
- ⇒ Διαταραχές λόγου και ομιλίας ☐
- ⇒ Προβλήματα συμπεριφοράς ☐
- ⇒ Συναισθηματικά προβλήματα ☐
- ⇒ Περιβαλλοντικά – κοινωνικά προβλήματα ☐
- ⇒ Επιληψία ☐
- ⇒ Ψυχικές διαταραχές ☐
- ⇒ Προβλήματα υγείας ☐
- ⇒ Άλλες περιπτώσεις.....

.....

**10. Η ενημέρωση των γονέων για την ύπαρξη και τη λειτουργία του σωματείου σας γίνεται μέσω:**

- ⇒ Νοσοκομειακών Μονάδων ☐
- ⇒ Διαγνωστικών Ιατροπαιδαγωγικών Κέντρων ☐
- ⇒ Σχολείων ☐
- ⇒ Δήμων ☐
- ⇒ Μ.Μ.Ε. ☐
- ⇒ Διαδικτύου ☐
- ⇒ Ενημερωτικών φυλλαδίων ☐
- ⇒ Φιλικού/Οικογενειακού περιβάλλοντος ☐
- ⇒ Άλλο .....

**11. Πιστεύετε ότι οι τρόποι ενημέρωσης που περιγράψατε παραπάνω είναι αποτελεσματικοί;**

Καθόλου ☐      Λίγο ☐      Αρκετά ☐      Πολύ ☐      Πάρα πολύ ☐

**αν επιλέξατε καθόλου, ποιους τρόπους ενημέρωσης θα προτείνατε εσείς;**

.....

.....

.....

**12. Για να γίνει ένας γονέας/κηδεμόνας μέλος του σωματείου σας είναι απαραίτητη κάποια μορφή οικονομικής εγγραφής;**

Ναι ☐      Όχι ☐

**εάν ναι, ποιο είναι το ποσό της οικονομικής εγγραφής; .....**

**13. Ποια κατά τη γνώμη σας είναι η βασική ανάγκη που οδήγησε στην ίδρυση του σωματείου σας;**

- ⇒ Ανάδειξη προβλημάτων ☐
- ⇒ Διεκδίκηση λύσεων από την πολιτεία (ΥΠΕΠΘ, Υπ. Υγείας, Υπ. Απασχόλησης) ☐
- ⇒ Ενημέρωση γονέων ☐
- ⇒ Εκπροσώπηση γονέων ☐
- ⇒ Περίθαλψη ☐
- ⇒ Προώθηση του δικαιώματος για πρόσβαση στην εκπαίδευση ☐
- ⇒ Άλλο.....

**14. Οι βασικές δραστηριότητες του σωματείου σας επικεντρώνονται σε ζητήματα:**

**(επιλέξτε με σειρά προτεραιότητας)**

- ⇒ Νομοθετικά ☐
- ⇒ Εκπαιδευτικά ☐
- ⇒ Ζητήματα επαγγελματικής αποκατάστασης ☐
- ⇒ Πρόνοιας ☐
- ⇒ Ιατρικά ☐
- ⇒ Κοινωνικά ☐
- ⇒ Αυτονομίας ☐
- ⇒ Οικονομική ενίσχυση οικογενειών ☐
- ⇒ Στήριξη γονέων από γονείς ☐
- ⇒ Άλλο.....☐

**15. Η Πανελλήνια Ομοσπονδία Σωματείων Γονέων και Κηδεμόνων Ατόμων με Αναπηρία (Π.Ο.Σ.Γ.Κ.Α.μεΑ) καταγράφει συνολικά τη λειτουργία 187 σωματείων ανά την Ελλάδα. Πιστεύετε ότι τα σωματεία αυτά επαρκούν για τη κάλυψη των αναγκών και την ενίσχυση των οικογενειών ατόμων με αναπηρίες;**

Ναι ☐ Όχι ☐

**16. Πιστεύετε ότι τα σωματεία αυτά επαρκούν για τη κάλυψη των αναγκών και την ενίσχυση των οικογενειών ατόμων με πολλαπλές αναπηρίες;**

Ναι ☐ Όχι ☐

**Παρακαλώ αιτιολογήστε:**

.....

.....

.....

.....

**17. Υπάρχει σύνδεση, επικοινωνία και συνεργασία μεταξύ των σωματείων;**

Καθόλου ☐ Λίγο ☐ Αρκετά ☐ Πολύ ☐ Πάρα πολύ ☐

**Παρακαλώ αιτιολογήστε:**

.....

.....

.....

.....

**18. Τα σωματεία γονέων και κηδεμόνων ατόμων με αναπηρίες στην πλειοψηφία τους εκπροσωπούν μια συγκεκριμένη κατηγορία αναπηριών. Κατά τη γνώμη σας ένας τέτοιος καταμερισμός είναι βοηθητικός;**

Ναι ☐ Όχι ☐

**Παρακαλώ αιτιολογήστε:**

.....

.....

.....

.....

**19. Η δράση των σωματείων γονέων και κηδεμόνων ατόμων με αναπηρία σε ποιο βαθμό έχει επηρεάσει θέματα που αφορούν:**

**α) το νομοθετικό πλαίσιο της χώρας**

Καθόλου ☐      Λίγο ☐      Αρκετά ☐      Πολύ ☐      Πάρα πολύ ☐

**β) το εκπαιδευτικό πλαίσιο της χώρας**

Καθόλου ☐      Λίγο ☐      Αρκετά ☐      Πολύ ☐      Πάρα πολύ ☐

**γ) το κοινωνικό πλαίσιο της χώρας**

Καθόλου ☐      Λίγο ☐      Αρκετά ☐      Πολύ ☐      Πάρα πολύ ☐

**δ) την περίθαλψη**

Καθόλου ☐      Λίγο ☐      Αρκετά ☐      Πολύ ☐      Πάρα πολύ ☐

**ε) την πρόνοια**

Καθόλου ☐      Λίγο ☐      Αρκετά ☐      Πολύ ☐      Πάρα πολύ ☐

**στ) την απασχόληση**

Καθόλου ☐      Λίγο ☐      Αρκετά ☐      Πολύ ☐      Πάρα πολύ ☐

**ζ) την υποστηριζόμενη διαβίωση**

Καθόλου ☐      Λίγο ☐      Αρκετά ☐      Πολύ ☐      Πάρα πολύ ☐

**20. Ποια, κατά τη γνώμη σας, ομάδα ατόμων με αναπηρίες διεκδικεί τα δικαιώματά τους;**

**α) στο μεγαλύτερο βαθμό**

.....

**β) στο μικρότερο βαθμό**

.....

**Γιατί πιστεύετε ότι υπάρχει αυτή η διαφοροποίηση;**

.....

**21. Ποιες περιπτώσεις μαθητών από τις παρακάτω πιστεύετε ότι μπορούν να φοιτούν στο πλαίσιο της γενικής εκπαίδευσης:**

- ⇒ Πολλαπλές αναπηρίες ☐
- ⇒ Μαθησιακές δυσκολίες ☐
- ⇒ Νοητική καθυστέρηση ☐
- ⇒ Αυτισμό ☐
- ⇒ Κώφωση – Βαρηκοΐα ☐
- ⇒ Τύφλωση – Αμβλυωπία ☐
- ⇒ Σύνδρομο υπερκινητικότητας ☐
- ⇒ Κινητικά προβλήματα ☐
- ⇒ Διαταραχές λόγου και ομιλίας ☐
- ⇒ Προβλήματα συμπεριφοράς ☐
- ⇒ Συναισθηματικά προβλήματα ☐
- ⇒ Περιβαλλοντικά – κοινωνικά προβλήματα ☐
- ⇒ Επιληψία ☐
- ⇒ Ψυχικές διαταραχές ☐
- ⇒ Προβλήματα υγείας ☐
- ⇒ Άλλες περιπτώσεις .....
- .....

**22. Στο σωματείο σας ανήκουν γονείς και κηδεμόνες παιδιών με πολλαπλές αναπηρίες;**

Ναι ☐ Όχι ☐

**εάν ναι:**

**Αριθμός μελών:**

.....

**Τι είδους περιπτώσεις πολλαπλών αναπηριών έχουν τα παιδιά των μελών του σωματείου σας;**

.....

**εάν όχι:**

**Ποιος είναι, κατά τη γνώμη σας, ο λόγος που δεν υπάρχουν στο σωματείο σας γονείς παιδιών με πολλαπλές αναπηρίες;**

.....

.....

.....

**23. Ποιο κατά τη γνώμη σας είναι το καταλληλότερο σωματείο στο οποίο θα πρέπει να απευθύνονται γονείς παιδιών με πολλαπλές αναπηρίες;**

.....

.....

.....

.....

**24. Ποιες είναι οι κυριότερες προκλήσεις για τα παιδιά με πολλαπλές αναπηρίες (βάλτε σε σειρά προτεραιότητας):**

- ⇒ Νομοθετικά ☐
- ⇒ Εκπαιδευτικά ☐
- ⇒ Ζητήματα επαγγελματικής αποκατάστασης ☐
- ⇒ Πρόνοιας ☐
- ⇒ Ιατρικά ☐
- ⇒ Κοινωνικά ☐
- ⇒ Αυτονομίας ☐
- ⇒ Υπηρεσίες για μελλοντική αυτόνομη/υποστηριζόμενη διαβίωση ☐
- ⇒ Άλλο ..... ☐

**25. Θεωρείτε ότι τα παρακάτω δικαιώματα των παιδιών με πολλαπλές αναπηρίες προωθούνται στην χώρα μας;**

	Καθόλου ικανοποιητικά	Λίγο ικανοποιητικά	Αρκετά ικανοποιητικά	Πολύ ικανοποιητικά	Πάρα πολύ ικανοποιητικά
Ιατρική και ψυχολογική παρακολούθηση					
Εκπαίδευση/ κατάρτιση					
Απασχόληση					
Υπηρεσίες ένταξης στο κοινωνικό σύνολο					



Πρόσβαση στην πληροφόρηση					
Αυτονομία					
Ανάπτυξη δεξιοτήτων καθημερινής διαβίωσης					

**26. Ποιο κατά τη γνώμη σας είναι το καταλληλότερο πλαίσιο εκπαίδευσης για τα παιδιά με πολλαπλές αναπηρίες:**

.....

.....

.....

.....

**27. Το σωματείο σας έχει ασχοληθεί με ζητήματα που αφορούν την προώθηση των δικαιωμάτων παιδιών με πολλαπλές αναπηρίες;**

Ναι ☐ Όχι ☐

**Αν ναι, με ποια συγκεκριμένα ζητήματα;**

- ⇒ Νομοθετικά ☐
- ⇒ Εκπαιδευτικά ☐
- ⇒ Ζητήματα επαγγελματικής αποκατάστασης ☐
- ⇒ Πρόνοιας ☐
- ⇒ Ιατρικά ☐
- ⇒ Κοινωνικά ☐
- ⇒ Αυτονομίας ☐
- ⇒ Υπηρεσίες για μελλοντική αυτόνομη/υποστηριζόμενη διαβίωση ☐
- ⇒ Άλλο ☐

**28. Ποια είναι, κατά τη προσωπική σας γνώμη, η ουσιαστικότερη δράση του σωματείου σας με σκοπό την προώθηση των δικαιωμάτων των παιδιών με πολλαπλές αναπηρίες και την βελτίωση της ποιότητας ζωής τους;**

.....

.....

.....

.....

**29. Με ποιον από τους παρακάτω ορισμούς της πολλαπλής αναπηρίας όπως καταγράφονται από τον ελληνικό και διεθνή επιστημονικό χώρο συμφωνείτε; (επιλέξτε ένα από τους παρακάτω ορισμούς)**

**α)** Παιδί με πολλαπλές αναπηρίες είναι ένα παιδί που έχει παραπάνω από μια αναπηρία, στις οποίες συμπεριλαμβάνονται οι κινητικές, οι νοητικές, επικοινωνιακές, αισθητηριακές, συναισθηματικές. ☐

**β)** Τα παιδιά με πολλαπλές αναπηρίες χρειάζονται συνεχή ιατρική φροντίδα και έχουν ανάγκη από συνεχή υποστήριξη σε περισσότερους από έναν τομείς της ζωής τους, προκειμένου να μπορούν να συμμετέχουν σε κοινωνικές δραστηριότητες και να χαίρονται τη ζωή μαζί με τους συνανθρώπους τους. ☐

**γ)** Ένα παιδί με πολλαπλές αναπηρίες ορίζεται ως άτομο του οποίου οι επιπρόσθετες αναπηρίες, κινητικές, νοητικές, αισθητηριακές, συμπεριφοράς, είναι τόσο σοβαρές η καθεμία ξεχωριστά ώστε επηρεάζει την φυσιολογική ανάπτυξη ή εκπαίδευση. ☐

**δ)** Παιδιά με πολλαπλές αναπηρίες είναι παιδιά που δεν εντάσσονται σε άλλη οριοθετημένη κατηγορία αναπηρίας. ☐

**στ)** Ο όρος πολλαπλή αναπηρία περιγράφει μαθητές οι οποίοι έχουν βαριά νοητική καθυστέρηση και περισσότερες από μια επιπρόσθετες αναπηρίες (προβλήματα όρασης, προβλήματα ακοής, επιληψία, κινητική αναπηρία, χρόνιες παθήσεις). ☐

**30. Πόσο κατά την γνώμη σας απαραίτητη είναι η κατασκευή ενός συγκεκριμένου και λειτουργικού ορισμού της πολλαπλής αναπηρίας;**

Καθόλου ☐      Λίγο ☐      Αρκετά ☐      Πολύ ☐      Πάρα πολύ ☐

**31. Η δημιουργία ενός συγκεκριμένου ορισμού της πολλαπλής αναπηρίας μπορεί να δράσει:**

⇒ βοηθητικά για τα άτομα με πολλαπλές αναπηρίες ☐

⇒ ανασταλτικά για τα άτομα με πολλαπλές αναπηρίες ☐

**Παρακαλώ αιτιολογήστε την απάντησή σας:**

.....

.....

.....

## ΓΕΝΙΚΕΣ ΠΑΡΑΤΗΡΗΣΕΙΣ ΚΑΙ ΣΧΟΛΙΑ

.....

.....

.....

.....

Σας ευχαριστώ πολύ για τη συμμετοχή σας.

Σε περίπτωση που χρειάζεστε οποιαδήποτε πληροφορία σχετικά με την έρευνα, μην διστάσετε να επικοινωνήσετε μαζί μου.

<b>Στοιχεία επικοινωνίας:</b>	
<b>Τηλ.</b>	
<b>E-mail</b>	
<b>Fax</b>	
<b>Διεύθυνση</b>	

Σε περίπτωση που θα σας ενδιέφερε να συμμετάσχετε σε μελλοντική συνέντευξη στη συνέχεια της έρευνας σας παρακαλώ να μου παραχωρήσετε κάποια στοιχεία ώστε να μπορέσω να επικοινωνήσω μαζί σας.

**Appendix 7: Correlation tables between the age of the participants  
and the age of their children**

**Correlations**

		Age of part.	Age of child
Age	Pearson Correlation	1	.598**
	Sig. (2-tailed)		.000
	N	64	54
Q4a	Pearson Correlation	.598**	1
	Sig. (2-tailed)	.000	
	N	54	54

\*\*, Correlation is significant at the 0.01 level (2-tailed).

**Table 7a****Chi-Square Tests**

	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	52.603 <sup>a</sup>	20	.000
Likelihood Ratio	46.440	20	.001
Linear-by-Linear Association	18.939	1	.000
N of Valid Cases	54		

a. 27 cells (90.0%) have expected count less than 5. The minimum expected count is .06.

**Table 7b**

## Age \* Age of child

Age \* Age of child Crosstabulation

			Age of child						Total
			0-10	11-20	21-30	31-40	41-50	51-60	
Age	30-39	Count	1	2	0	0	0	0	3
		% within Age	33.3%	<b>66.7%</b>	.0%	.0%	.0%	.0%	100.0%
	40-49	Count	0	5	3	0	0	1	9
		% within Age	.0%	<b>55.6%</b>	33.3%	.0%	.0%	11.1%	100.0%
	50-59	Count	0	5	12	4	0	1	22
		% within Age	.0%	22.7%	<b>54.5%</b>	18.2%	.0%	4.5%	100.0%
	60-69	Count	0	0	5	6	1	2	14
		% within Age	.0%	.0%	35.7%	<b>42.9%</b>	7.1%	14.3%	100.0%
	70 and above	Count	0	0	0	3	2	1	6
		% within Age	.0%	.0%	.0%	<b>50.0%</b>	33.3%	16.7%	100.0%
	Total	Count	1	12	20	13	3	5	54
		% within Age	1.9%	22.2%	37.0%	24.1%	5.6%	9.3%	100.0%

Table 7c

**Appendix 8: Correlation tables between the age of the participants and their views on the level of influence that parent associations for disabled children have achieved in educational matters for multiple disabled children.**



Correlations			
		Age	Education
Age	Pearson Correlation	1	-.460**
	Sig. (2-tailed)		.000
	N	64	64
Q19_2	Pearson Correlation	-.460**	1
	Sig. (2-tailed)	.000	
	N	64	65

\*\*. Correlation is significant at the 0.01 level (2-tailed).

**Table 8a**

Chi-Square Tests			
	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	21.317 <sup>a</sup>	12	.046
Likelihood Ratio	22.607	12	.031
Linear-by-Linear Association	13.349	1	.000
N of Valid Cases	64		

a. 16 cells (80.0%) have expected count less than 5. The minimum expected count is .08.

**Table 8b**

Age \* Q19\_2 Crosstabulation

			Education				Total
			A little	Fair	Quite a lot	Very much	
Age	30-39	Count	0	3	2	0	5
		% within Age	.0%	<b>60.0%</b>	40.0%	.0%	100.0%
	40-49	Count	1	6	6	0	13
		% within Age	7.7%	<b>46.2%</b>	46.2%	.0%	100.0%
	50-59	Count	8	15	2	1	26
		% within Age	30.8%	<b>57.7%</b>	7.7%	3.8%	100.0%
	60-69	Count	7	6	1	0	14
		% within Age	<b>50.0%</b>	42.9%	7.1%	.0%	100.0%
	70 and above	Count	4	2	0	0	6
		% within Age	<b>66.7%</b>	33.3%	.0%	.0%	100.0%
	Total	Count	20	32	11	1	64
		% within Age	31.3%	50.0%	17.2%	1.6%	100.0%

Table 8c

**Appendix 9: Correlation tables between the influence of parent associations on multiple disability issues in the Greek context and the associations' main activities**

### Correlations

		Education	Social
Educ.	Pearson Correlation	1	,269*
	Sig. (2-tailed)		,030
	N	65	65
Social	Pearson Correlation	,269*	1
	Sig. (2-tailed)	,030	
	N	65	65

\*. Correlation is significant at the 0.05 level (2-tailed).

**Table 9a**

### Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	5,969 <sup>a</sup>	4	,202
Likelihood Ratio	6,799	4	,147
Linear-by-Linear Association	4,633	1	,031
N of Valid Cases	65		

a. 5 cells (50,0%) have expected count less than 5. The minimum expected count is ,26.

**Table 9b**

Education \* Social Crosstabulation

			Education		Total
			0	1	
Social	Not at all	Count	1	0	1
		% within Social	<b>100,0%</b>	,0%	100,0%
	A little	Count	5	8	13
		% within Social	38,5%	<b>61,5%</b>	100,0%
	Fair	Count	6	15	21
		% within Social	28,6%	<b>71,4%</b>	100,0%
	Quite a lot	Count	5	21	26
		% within Social	19,2%	<b>80,8%</b>	100,0%
	Very much	Count	0	4	4
		% within Social	,0%	<b>100,0%</b>	100,0%
	Total	Count	17	48	65
		% within Social	26,2%	73,8%	100,0%

Table 9c

## **Appendix 10: List of presentations made during the course of the study**

Date	Presentation
<b>20 December 2012</b>	<p>The complexities in the sampling process and issues of access when looking at the work and actions of the Parental Associations for people with severe and multiple disabilities</p> <p>Paper presented at Postgraduate Program of Special Education. National and Kapodistrian University of Athens. Department of Early Childhood Education. Research Forum. University of Athens.</p> <p>20-22 December 2012</p>
<b>12 September 2011</b>	<p>The educational course of multiple disabled students in Greece – Parents’ perspective.</p> <p>Paper presented at the European Conference on Educational Research, Urban Education, EERA-ECER.</p> <p>Berlin, 12-16 September 2011</p>
<b>14 November 2009</b>	<p>Views and experiences of parents of multiple disabled children and adults concerning their educational course within the Greek school system.</p> <p>Paper presented at the International Symposium on ‘Disability and the Politics of Inclusion’. National and Kapodistrian University of Athens in collaboration with the Department of Early Childhood Education and the Centre for Research, Assessment and Implementation of Inclusive Educational Programs.</p> <p>Athens, 13-14 November 2009</p>
<b>10 September 2008</b>	<p>Interviews with parents of multiple disabled children and young adults – Process and outcomes</p> <p>Paper presented at the In-service teachers’ training program. National and Kapodistrian University of Athens. Department of Early Childhood Education.</p> <p>Athens: 10 September 2008</p>
<b>14 June 2012</b>	<p>‘Raising achievements for all learners. Quality in Inclusive Education. Are we certain that we do mean for all learners?’</p> <p>Short presentation in the frame of the conference ‘Raising Achievements for All Learners. Quality in</p>

	<p>Inclusive Education'. European Agency for Special Needs and Inclusive Education with the Danish Ministry of Education and the Odense Municipal Authorities.</p> <p>Odense: 13-15 June 2012</p>
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