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Collaboration Between Parents of Children with Autism Spectrum Disorders and Mental Health Professionals

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Additional information is available at the end of the chapter

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1. Introduction

When mental health professionals and parents of children with autism spectrum disorders start working together, they bring into this relationship their own personal needs, concerns, priorities and responsibilities, which must be taken into consideration in order to create a mutually satisfactory and functional partnership. A partner is a person that one works with in order to achieve a common goal through shared decision-making and risk-taking. Some partnerships last for a short period of time and include casual encounters, while others last long and evolve through numerous official and unofficial encounters [1]. For a partnership model to work, all involved parties must understand how they feel about each other [2] and to recognize that family operates as a system. When parents and mental health professionals disagree, it is essential to resolve any conflict timely in order to avoid serious confrontations or even legal litigations [3].

Minuchin [4] was the first who introduced the theory of family systems and stated that individuals affect the context where they live and are in turn affected by it through a series of repeated interactions. So, whatever affects one family member affects the whole family in direct or indirect ways. Elman [5] describes families as the mobile that hangs over a baby's crib, with the pressure exerted on one end causing movement throughout. The relationships between family subsystems (spouses, parents and children, and siblings) determine the balance of the entire family [6] and interventions at any subsystem must aim to preserve this balance. For example, an intervention aiming at fostering the mother-child bond could affect the mother's relationship with her husband or her other children if the necessary actions are not taken. Family subsystems describe the interac-

tions within the family context, whereas cohesion and adaptability describe the way in which family members interact.

Cohesion is inherent to the notions of engagement and disengagement. Some families with high levels of engagement do not have clear boundaries between the subsystems, are overly engaged in the therapeutic process and overprotective [4] and as a result do not allow the individual with autism spectrum disorders to develop a sense of autonomy. On the other hand, families with extremely low levels of engagement adopt rigid boundaries and do not interact with the child sufficiently. So, the child with autism spectrum disorders is left free, but without experiencing the necessary love and support. The degree to which a family adjusts to the diagnosis of autism spectrum disorders depends to a large extent on the pre-existing family cohesion and stability, while the disruption of family cohesion due to the birth of a child with autism spectrum disorders can lead to increased stress [7]. In order to deal with stress, families employ either internal coping strategies that include passive evaluation or active reframing or external coping strategies through social and spiritual support [8].

Adaptability refers to the family's ability to change its functioning when a stressful event occurs [9]. Family adaptability depends on the severity of autism spectrum disorders, as well as on the accumulation of the demands made on parents [10]. Rigid families do not change to face the stress, while chaotic families become unstable and face changes inconsistently. The families that do not manage to adapt successfully are at risk of becoming isolated and dysfunctional [11]. According to family systems theory the disruption of communication among family members is a sign of dysfunction of the whole system and not of a specific individual. Therefore, mental health professionals should aim at changing interaction patterns and not just individuals, without incriminating anyone. Many family members tend to blame the individual with autism spectrum disorders for the difficulties that they experience, but with the appropriate guidance they perceive that miscommunication is often to blame [12].

Most studies conducted with families of individuals with disabilities are based on the assumption that families are homogeneous [13], but there are many features that differentiate families between them. For example, unemployed parents of a child with autism spectrum disorders have access to different resources than high-income parents [1]. Moreover, single mothers of children with autism spectrum disorders experience heightened stress, since they lack the practical, financial and moral support of their partner [14]. Cultural and contextual factors can also affect the ways that families cope with disabilities. First generation Americans with Chinese origin are afraid that their children with autism spectrum disorders will be stigmatized if they use sign language or other alternative forms of communication [15]. Parental reactions to their child's disorders must be viewed and interpreted within the social, historical, and ecosystemic context of every family [16]. Parents initially experience a stage of shock [17], which is followed by a range of reactions that could eventually lead through consecutive reorganizations to adjustment to reality [18]. However, many parents regress to previous stages when they realize that their children with autism spectrum disorders face difficulties that will not disappear and that they need constant care. In order to support parents of children with autism spectrum disorders, mental health professionals

must know the characteristics of the disorder and set realistic goals both for children with autism spectrum disorders and their families [19].

Many researchers have established that parents of children with disabilities and mental health professionals must cooperate in order to design and implement an effective therapeutic process [20-23]. Therefore, parental involvement in the planning of proper therapeutic intervention for children with autism spectrum disorders was the primary target of many programs since the beginning of the 1980s [24]. Parents have been treated as partners, consultants, advocates, and supporters by the mental health professionals who offer these services. Parents often seek to work together with mental health professionals as they try to help their children overcome the difficulties that they face [25-26]. So, empowering the cooperation between parents and mental health professionals has been a cornerstone for many contemporary care systems for individuals with disabilities [27]. In order to achieve this empowerment, it is important to increase parental autonomy and engagement in decision-making regarding the therapeutic goals [28].

It is expected that the cooperation between parents and mental health professionals will result to better services for the children with disabilities, since the knowledge and the experience that each person brings into this relationship are unique [29]. The problem is that many mental health professionals cannot treat parents as equal partners in this process [30]. Through their training, mental health professionals develop an area of expertise that places them almost automatically at the role of the expert. Sharing responsibility with parents, without having a clear hierarchy, creates a new structure that is opposite to the traditional nature of the relationship between parents and mental health professionals. However, the position and the authority of the mental health professionals have been challenged and transformed according to contemporary political and theoretical models, as can be seen below:

1.1. Professional as experts

This is the traditional cooperation model that is prominent in doctor-patient relationships, where the professionals use their position and their knowledge to decide what will happen. Parental participation is of secondary importance and compliance with the professionals' suggestions is self-evident. Parents are informed about the decisions that were taken without being allowed to express their opinions, feelings, needs, or wishes. Children are treated as the passive recipients of a therapy, while parents are thought not to have the time, the disposition, the skill or the knowledge to help their children. This relationship is very bureaucratic and rigid, because it disadvantages parents by making them dependent on the professional [31]. Moreover, when mental health professionals do not engage parents actively in their child's treatment there may be a disagreement between the therapeutic goals they set [31-32]. The exclusion of parents from the therapeutic process has been highly criticized since the beginning of the 1970s, since the relationship between parents and mental health professionals becomes impersonal and the sense of trust is lost [33]. Therefore, parents started gradually being involved in the therapeutic process [34] and a lot of emphasis was placed on this involvement [35]. It

should be pointed out, that even though this kind of relationship is outdated, there are still mental health professionals who impose themselves on parents.

1.2. The transitional relationship

Mental health professionals started treating parents as co-therapists and realizing that the house can be used as a learning setting. They shared and transferred their skills to parents to help them become more able, more confident, and more skilled. Parents participate as «co-teachers» or «co-trainers» or «co-therapists» [18]. Mental health professionals have to adapt their methods in order to incorporate and to support their cooperation with parents. So, they have to discover ways to communicate with parents and to engage them in the therapeutic process. Parents who cooperate with mental health professionals become more able, more knowledgeable and more assertive [36]. The main drawback of this model is the underlying assumption that all parents have the motive (and are able) to use this professional knowledge to help their child. It ignores the differences that exist in parenting styles, family relationships, family resources, family values and cultural contexts. For example, some parents may not feel comfortable acting as «teachers» of their children [37]. Many interventions have focused solely on mothers and have left out fathers creating disruption to the family system. This relationship is not truly cooperative, since mental health professionals make the basic decisions and are still in control [31].

1.3. Parent as consumers

The consumer model [31] stated that parents should have new rights and be given part of the control. Parents are viewed as consumers, who have the right to choose the appropriate services and interventions for their children. It is the first time that mental health professionals recognize that parents possess specialized knowledge that they lack. Parents use their knowledge to decide what they want and what they need for their child. Mental health professionals guide parents to make more effective and appropriate decisions. Parents may choose not to attend some of the suggested services that they do not consider suitable. Decision-making is reached after mutual exchange of ideas and with mutual respect. The objective is to reach a mutual agreement on the treatment that the child will follow. This model can be quite effective in various intervention settings [38]. The cooperation is very important, since parents have a greater sense of control. The services that adopt this model must be very flexible to provide individualized support [39]. This model presupposes that parents are capable to express and to assert their needs and the needs of their children. However, some parents cannot prioritize their needs or assume the responsibility of making important decisions. The concept of parents as consumers who share resources may not be very realistic in a restrictive financial context that offers minimal services. In this case the consumers do not necessarily buy the best services and many parents cannot afford the increased financial demands of the most effective therapies. This model is similar to counseling that is offered to parents to help them resolve some personal issues.

1.4. The empowerment model

This model has added a social and systemic dimension to the consumer model [39], since parents have the right to choose the services that they will offer to their child and mental health professionals realize that family is a system and a social network. Every family comprises of interconnected social relations within the context of the family itself as well as within the wider social groups (extended family, friends, associates, cultural groups). The system and the network affect the ways in which the family members view the individual with disabilities. Given that each family has different advantages, parents have a unique adjustment method and mental health professionals need to understand and respect that. Mental health professionals should also help parents realize that they can monitor their child's progress and interfere when they identify a problem.

1.5. The negotiation model

Partners use negotiation to reach common decisions and to resolve any disagreements that may arise. Negotiation can lead either to a common decision or to disagreement. Disagreements can come up for various reasons, such as the priorities that are set by each interested party [40]. The negotiation model states that the ways that parents and mental health professionals view a situation or a problem, the options that they have to resolve it, and the extent to which they can face it, are affected by their roles – as well as the social, financial, and structural frames where they function. Therefore, according to this model, cooperation may be dysfunctional under the three following conditions:

1. Either parents or mental health professionals do not have the intention or the skill to work with each other and to enter a cooperative relationship. Personal experiences may decrease the likelihood to cooperate [1].
2. Either parents or mental health professionals make all decisions and are not willing to share responsibility [41].
3. If the interests, the views, the priorities and the values of parents and mental health professionals are contradictory, then their relationship may become competitive – even if they apply various conflict resolution strategies.

Some organizations are eager to engage parents in the therapeutic process not because they recognize parental rights but because of staff shortage or scarce financial resources [36]. Parents should be involved in decision-making regarding their children because mental health professionals need their cooperation to do their job properly. Parents will also have a chance to establish and generalize at home the skills that their children have mastered [38]. In order for parents – and especially mothers – to function as therapists, they must devote a lot of time to meeting with mental health professionals to receive the proper training [42]. Parents of children with disabilities need guidance and support to be effective in their role [43-45]; otherwise, they will lose their self-esteem and become ineffective [46].

For the negotiation model to work, it has to operate at five different levels: personal, interpersonal, organizational, institutional, and ideological [40]. The sense of cooperation

encourages the productive combination of knowledge, skills, and sensitivities from both parents and mental health professionals. The six elements that characterize a cooperative relationship and differentiate it from other types of relationships are [47]: a) cooperation is optional; b) cooperation demands equity among the participants; c) cooperation is based on mutual goals; d) cooperation depends on shared responsibility and decision-making; e) people who cooperate share their resources; and f) people who cooperate are equally responsible for the outcome.

Within this model, mental health professionals should have a clearly defined relationship with parents that has four predetermined goals [48]: a) include parents in decision-making about their child; b) train parents to participate in decision-making about their child; c) help parents therapeutically to deal with some issues that stop them from functioning more effectively; and d) render parents capable to work effectively and meaningfully with their child through empowerment.

The negotiation model has many functioning aspects that facilitate the development of a cooperative relationship between parents and mental health professionals, since it is developmental and parents are not viewed as static agents. They are encouraged to develop and improve their skills to become more effective and to work on their personal issues. In order to meet with the demands of this new role, mental health professionals are often called to take on multiple roles and to become more flexible. They may need to act as mediators between the parents and other agents, as well as to fight for the rights of the parents and their children with disabilities – especially in times of financial and moral crisis.

1.6. How do parents feel about mental health professionals?

Individuals with autism spectrum disorders depend on their families for daily care and support that are essential for the successful implementation of any therapeutic intervention [49]. Therefore, it has been acknowledged that the needs of all the family members should be taken into consideration when designing an intervention [50]. Many highly recommended treatments for autism spectrum disorders [see 49, for more information] – such as Applied Behavioral Analysis [51], TEACCH [52] and Portage [53] – stress the importance of active parental participation in the therapeutic process, which results from the proper cooperation with mental health professionals. However, many parents claim that their participation in their children's therapy is minimal and restrained to six-monthly briefing meetings, while they are not informed that they could be more actively involved in the treatment process [54]. Parents must be treated as partners during the planning, implementation, and evaluation of the therapeutic approach and not just as observers or clients [55].

Many parents complain because they have to wait a long time to diagnose their children with autism spectrum disorders and they need to visit up to four different mental health professionals [54]. In a small scale study where parents of 25 children with autism spectrum disorders were interviewed, it was found that these parents have to take their children to different therapeutic settings, which is extremely time consuming. They work together with an average of six mental health professionals for a total of approximately 37 hours per week [56]. Since parents are often exposed to many diverse opinions and suggestions expressed

by mental health professionals, they end up being confused and they need guidance to make the right choices and decisions [1]. Therefore, mental health professionals who work therapeutically with the parents of children with autism spectrum disorders should assume also a counseling role [57].

Parents need to be extremely persistent in order to ensure the services and the provisions that are necessary for their children with autism spectrum disorders [58-59]. Parents started questioning the power of mental health professionals when they formed groups to fight for their rights. An extreme example of disappointment with mental health professionals was the creation of a centre of counseling and support for the parents of children with special needs that was created by parents and to which mental health professionals had no access [2]. The parents who founded this centre stressed that it provided them with the opportunity to talk and to share their experiences – giving them, thus, the strength to deal with their daily problems.

Despite the fact that parents were overall satisfied with the mental health professionals they had worked with in the past, they generally felt that they had to fight in order to access the services that their children needed. They reported that many mental health professionals failed to communicate with each other and with the parents and this created a heightened sense of dissatisfaction. This was due to the fact that most children were monitored simultaneously by several mental health professionals who seemed to work in isolation without sharing information and common therapeutic goals. Furthermore, many parents supported that the services they received did not suffice to address their children's multiple and complex needs [3]. Moreover, some parents claim that they are tired of being accused for the problems that their children face [60] and that constant criticism does not help them become better and more effective parents. Paradoxically, although some mental health professionals view mothers as guilty, they involve them at the same time in their children's therapy [61].

Crawford and Simonoff [62] studied the attitudes of parents of children attending schools for emotional and behavioral disorders. Many parents believed that they felt stigmatized and isolated because of the problems that their children were facing. Although the stigma accompanying mental health problems or other disorders, such as autism spectrum disorders is well recognized, there is limited research on the topic. Parents feel lonely and without any support, but they hesitate to share their concerns with others, because they are afraid that they will be further stigmatized and held responsible for their children's problems. So, it is not surprising that parents were excited to meet with other parents who face similar problems and can offer them valuable support.

Parents of children with special needs are often dissatisfied with the way that mental health professionals behave and with the attitudes that they express. However, most relevant research has not studied the actual interaction between parents and mental health professionals, but they are based on parental anecdotal evidence that is usually negative [63-64]. If the behaviors that parents report are accurate, then they constitute a breach of the professional code of ethics [65] and should be seriously taken into consideration. On the other hand, many parents appreciate that mental health professionals try to understand the family dynamics and to address the individual needs of every family member [66] and there are also

quite a few parents who mention that mental health professionals have done their best to help them and their children with autism spectrum disorders [54].

The mental health professionals who interact with children with autism spectrum disorders and their families come from different educational and theoretical backgrounds, as well as from different disciplines: specialized professionals (such as psychologists, speech therapists, and social workers), doctors, teachers or students. Despite the fact that the contribution of mental health professionals to the planning and effectiveness of the treatment has been widely acknowledged, more research is needed on identifying how they deal with practical problems that arise during the course of their interactions with parents of children with autism spectrum disorders. The role of mental health professionals and therapists has been approached primarily by the psychoanalytic perspective and most studies have focused only on the role of the teacher of children with autism spectrum disorders.

1.7. How do mental health professionals feel about parents?

The beliefs and the assumptions that mental health professionals hold regarding parental contribution to the appearance and maintenance of their children's problematic behaviors and disorders greatly affect their choice of offered therapies and the intervention strategies that they use when interacting with the specific families [67]. Even the term «professional» has been controversial, since some refer to the traditional definition of professional (e.g., doctors, lawyers, architects, university professors), while others use this term to refer to most working people (e.g., nurses, social workers, and teachers) [68]. The term «mental health professionals» is now used to include all the educated people who have received the appropriate training to work with individuals with disabilities. It is used to make the distinction between trained staff and volunteers, carers, or untrained helping staff who work with individuals with disabilities.

There are different sources of «socially acceptable» power for mental health professionals [69]: physical power, power to provide resources, power of profession, power of specialization and personal power. For many years now, the role of mental health professionals is predetermined to provide them with the power and the right to use their knowledge and their experience as they wish. They have resources at their disposal that they can share with children with disabilities and their families, as well as the specialized knowledge that they have acquired through their training. Mental health professionals are usually considered experts, since they are knowledgeable about an area or a topic. In case that some parents disagree or refuse to cooperate with mental health professionals, the latter have the right to stop providing their services. Mental health professionals can have considerable power and so many parents treat them with respect.

The attitudes and perceptions of mental health professionals regarding their relation with the parents of children with disabilities have not been adequately researched [70]. Smets [71] explored staff attitudes regarding parental involvement in a service for individuals with intellectual disabilities and found that staff believed that parents were either unaware or indifferent to their children's problems. Staff believed that parents were limited to the role of the external observer and they were happy to defer the responsibility of caring for their child to

another person. However, the researcher stressed that the perception of the staff did not correspond to reality and to the actual needs of the families of the service users.

Some mental health professionals recognize the importance of working together with the parents, but they claim that they are not adequately trained or prepared to do so and they receive no support from their services [72-74]. To address this issue, it is important to better understand the skills and the behaviors that mental health professionals need in order to learn how to cooperate with parents [75-76]. Interpersonal skills, such as sensitivity towards the parents, clarity and respect are usually highly appreciated by parents who work together with mental health professionals in early intervention settings [77].

1.8. Cooperation between parents and mental health professionals

Cooperation is a term that was recently introduced to literature looking at the relationship between parents and mental health professionals, but is quite difficult to accomplish in practice given that it means different things to different people. Cooperation can be viewed as basic principle or theoretical viewpoint that is based on fundamental power exchange [78]. However, there are many organizational, geographical or financial obstacles in the cooperation between different groups of mental health professionals or between mental health professionals and service users – that is, parents of children with disabilities [79-81]. The potential cooperation between mental health professionals and parents is based mainly on the anticipation that there will be an increase in the number and quality of offered services. However, many mental health professionals feel threatened when they have to choose who will have access to each service, especially when the choices are limited [82].

The cooperation between parents and mental health professionals is not just desirable but also mandatory, since it is enforced by law in many countries [20, 83]. It has been widely accepted that a healthy cooperative relationship between parents and mental health professionals can lead to timely conflict resolution and benefit children with disabilities [84-85]. This cooperation is even more vital in early intervention programs, which are family-centered [86] and through parental empowerment [87] there is a greater sense of parental accomplishment [88].

Most relevant studies show that parents and mental health professionals are familiar with cooperative relationships through their interpersonal experiences [89-90]. Functional cooperative relationships are characterized by trust, respect, communication and shared vision that are essential to make decisions that will lead to increased communication [91], inclusion [92], and appropriate service provision for children with disabilities [93]. Some research also shows that teachers prefer to have a closer and more meaningful relationship with parents of children with disabilities [94]. The existence of supportive relationships among parents and mental health professionals is the most important determinant of a successful cooperative relationship [75].

Despite the existing legislations in some European countries and the wishes of both parents and mental health professionals, it is often extremely difficult to create successful and functional cooperative relationships [95-96]. For example, in the context of family-

centered early intervention cooperation remains an utopia [86]. Although mental health professionals seem to favor cooperative relationships with parents, research shows that there is a big gap between theory and practice [97]. Relevant studies [98] that were conducted using either focus groups or interviews and questionnaires showed that the basic problem is that mental health professionals do not treat parents as equal partners and continue to maintain control. So, the failure to establish cooperative relationships is due to the fact that there are no trusting and empowering relationships between parents and mental health professionals [11, 99].

This failure to create cooperative relationships could also be caused by the inadequate definition of cooperation [100] that hinders the quest for a common goal through functional interactions [101-103]. There are six factors that are essential for the establishment of a cooperative relationship between parents of children with disabilities and mental health professionals and form the basis of the partnership protocol that will be presented later on in the chapter [104]. These factors are:

- a. communication: parents stressed that communication with mental health professionals must be honest, frequent and open, with no hidden agendas. Mental health professionals should inform parents also about unpleasant developments in the therapeutic process but without becoming rude or aggressive and without using jargon. Parents want to have access to information regarding other services that are available for their children. Communication should be a two-way process, with both parents and mental health professionals listening to each other without being critical. Mental health professionals seem to agree about the necessity of open and honest communication with the parents that can form the basis of a trusting relationship.
- b. commitment: mental health professionals should not view what they do as a simple job that pays for their expenses and treat children with disabilities just as another client or case that is filed. They must value the individual and pay attention to the relationship with the whole family of the child with disabilities. It is noteworthy that some parents thought that mental health professionals should greet them if they meet somewhere in public as a sign of respect and professional commitment. Many mental health professionals recognized the importance of commitment and argued that they often have to deal with parents who do not want to be involved with the therapeutic process or get involved in decision-making regarding their child. However, this should not stop them from making the effort to work closely with the parents.
- c. equity: mental health professionals must make conscious efforts to empower the families that they work with, recognizing the importance of parental knowledge instead of devaluing it. Parents should be encouraged to express their opinions and to be fully engaged in decision-making in the context of a constructive exchange of ideas. Attention is needed to keep the very thin line between empowering the parents and giving them too much independence that could jeopardize the therapeutic process.
- d. skills: parents tend to admire the mental health professionals who make the difference by offering practical help both to them and to their children with disabilities and who

are skilled and well trained. Mental health professionals should have high expectations from the children that they work with if they are going to try hard to make some progress and reach the goals that they have set. Parents appreciate the mental health professionals who have the strength and the will to be constantly updated about the new developments in their areas of expertise. Most mental health professionals referred to the skills that they expect from their colleagues but not from parents (this partly reflects their lack of trust in a cooperative relationship with the parents).

- e. trust: this term has three different meanings according to the context where it is used. It means reliability in the sense that mental health professionals should honor their promises any way they can. It is equal to security, in the sense that parents need to feel that their children with disabilities are safe both physically and emotionally when in the company of mental health professionals. The third dimension of trust is the discretion that mental health professionals should possess regarding the information that they share with colleagues about a child.
- f. respect: a sign of respect is that mental health professionals treat the child with disabilities as a human being and not as a label or a diagnosis, that they are polite, considerate, punctual, and up-to-date with recent developments in the field. Several parents mentioned that these simple rules of courtesy and proper behavior are often overlooked in daily encounters. Many mental health professionals admit that the lack of respect to parents can cause severe damage to the therapeutic relationship.

It is interesting to note that parents and mental health professionals seem to agree on what they think constitutes a desirable and proper cooperative relationship. They may differ in the importance that they place on each factor and in whether they identify it as essential or not for the success of the cooperation. Both sides recognize that for a cooperative relationship to work, both parents and mental health professionals should do their best keeping in mind the interests of the child with disabilities. This study [104] emphasizes that it is imperative to conduct further research to create guidelines to delineate the relationship between parents and mental health professionals, rendering it thus more satisfactory and more effective. This is the aim of the present study that aspires through the use of a partnership protocol to delineate the relationship between parents of children with autism spectrum disorders and mental health professionals – a need that was identified also by other researchers [16, 105].

Because of the heterogeneity of the symptoms and characteristics of autism spectrum disorders, the diagnosis usually does not provide useful suggestions for the appropriate treatment [106]. Successful therapeutic interventions develop when parents and mental health professionals work together as a coordinated and cooperative team [107]. In order to deal with the needs of children with autism spectrum disorders and their families the program COMPASS was created [54], which aims at the cooperation between staff and parents to design the most appropriate therapeutic intervention for each child. The greatest challenge that mental health professionals who work with the families of children with autism spectrum disorders have to face is to ensure that these children attend the therapeutic interventions that best suit their unique and complicated needs [108]. Parental attitudes and parental

satisfaction are widely used as indications of the success of early intervention programs [109]. Since parents are the ones caring for their children with autism spectrum disorders, their views should be seriously taken into consideration by mental health professionals. Parental concerns and preferences can be used to improve offered services, while parental satisfaction can be translated into a measure of success of a therapeutic intervention [110].

The interaction between parents of children with autism spectrum disorders and mental health professionals is crucial in special needs education because of the high incidence of autism spectrum disorders in the school population and the lack of resources [111-112]. However, this interaction is often fragmentary and characterized by confusion, disappointment, and tension that result to low levels of cooperation and decreased quality of service provision to the child with autism spectrum disorders [111].

The relationship between parents of children with autism spectrum disorders and teachers is also worth exploring [113-114], especially given that many children with autism spectrum disorders have communication deficits and cannot express themselves and their needs [115-116]. Research so far suggests that trust is built almost exclusively on personal interactions, encounters, and exchanges. Every encounter between parents and teachers turns into an opportunity to expand and to strengthen the bonds of trust between the interested parties. Of course, if parents suspect that teachers are not worthy of their trust, then the bonds that are created are very fragile. Many parents seek to create a strong bond with their child's teachers, because they believe that this will benefit their child [11, 117]. In order to build up their trust, both parents and teachers should state clearly and openly their expectations from this relationship in an effort to minimize misunderstandings [118].

Mental health professionals often have to announce bad news to parents regarding their child's diagnosis and prognosis, which cause drastic and often negative changes in their lives [119-120]. Since parents have the unquestionable right to know the truth about their child's condition, the question is not whether the mental health professionals will share the news but how they will do it [120]. Many mental health professionals have been criticized for the abrupt way in which they communicate upsetting news to the parents [46] and the detrimental effects this can have on the parents is a matter of great concern [121]. However, if the briefing is done properly, then this can be extremely useful for them, since they will be able to understand their child's needs and design the appropriate treatment plan [122].

Despite the significant increase in knowledge about the causes and course of autism spectrum disorders [123] and the appreciation of the importance of early diagnosis [124], there have been no noteworthy changes in the information that parents receive in their first contact with mental health professionals. Some studies [125-126] have looked at the interaction between parents and mental health professionals during the dissemination of the assessment conclusions. It was found that mental health professionals are aware of the dilemma of delivering upsetting news and seek the active participation of the parents in a joint articulation of the problem. Some mental health professionals ask parents first to express their opinions about their child's problems and then they share the diagnosis to corroborate the parents' perspective [127]. Other mental health professionals present a series of related general and specific symptoms that lead to a specific diagnosis and then allow parents to state

the final diagnosis [126]. Usually, mental health professionals try to bridge the gap between their views and parental views by modifying the diagnostic label, so as to comply with parental wishes and to balance the levels of optimism and pessimism [125].

Parental satisfaction is an important element for the evaluation of the services that are offered to children with disabilities and their families [128] and can be related to other family variables, such as stress or depression [129], increased empowerment [130] or increased school involvement [131]. Some qualitative studies have shown that parents who are not satisfied with their relationship with mental health professionals experience stress and do not feel welcome in the decision-making process regarding their children [59]. There are also some documented cases of parents who were so unsatisfied with the early intervention programs their children attended that they removed them from the program [132]. On the other hand, there are many qualitative studies of families that come from different cultural backgrounds and report that parents who are satisfied with the services provided to their children tend to engage more in their training [133].

Research on parental satisfaction asks parents to evaluate the quantity or the quality of the services that their children receive, as well as the nature of their relationship with mental health professionals [128, 131]. However, there is still a basic gap in identifying a widely accepted definition of parental satisfaction and which intervention model can be implemented to increase this satisfaction [77]. In a survey of satisfaction among 290 parents of children with autism spectrum disorders [134], it was found that most individualized educational plans were not developed in cooperation with mental health professionals, they did not reflect the views and the concerns of the family and they were not successfully coordinated by the many different people who run the services. In another similar study [108] it was reported that most of the 539 parents had difficulty finding about the available services and accessing them. They also claimed that they were not given any choice, that they had to fight for what they wanted and that ultimately the received services differed greatly from what they had originally asked for. Finally, more than half of the parents who participated in another study [135] complained that they were not fully informed about the available services or the structural changes that were taking place in different agencies and that they were unhappy with their cooperation with mental health professionals. All these problems seem to be even more prominent for the families of children with autism spectrum disorders who have to interact with various mental health professionals, such as pediatricians, psychologists, speech therapists and many others [136].

1.9. The present study

The concept of boundaries is inherent in human relations and cooperation and represents the rules and limitations that can create a sense of safety [137]. In strictly professional relationships the involved parties have a clearly defined role that they hesitate to deviate from. However, in many mental health services professionals may fulfill various practical, informative, and emotional needs of the individuals who use these services and their families [105]. Despite the fact that the codes of ethics of different professional bodies offer guidelines for the behaviors that protect mental health professionals against extreme cases of con-

flict of interest or client exploitation for own purposes, there are no guidelines for the delineation of daily interactions between mental health professionals and service users [138]. The code of ethics in special needs education does not address sufficiently the boundaries in relationships between mental health professionals and parents of children with disabilities [105] and this can hinder the establishment of a cooperative relationship between them [11]. So, it is imperative to create a form for the negotiation of the boundaries in daily interactions between parents and mental health professionals in order to make decisions about how, when and why the involved parties will interact [105]. This is how the partnership protocol that will be presented in this chapter was created on the basis of the codes of ethics of the British Psychological Society [139], the American Psychological Association [140], and the Health and Care Practitioners Council [141]. The aim of this study was to explore whether this partnership protocol could change the perceptions of parents of children with autism spectrum disorders and mental health professionals about their relationship. More specifically, it was hypothesized that parents of children with autism spectrum disorders would hold more positive attitudes about mental health professionals after the implementation of the partnership protocol. Mental health professionals would also express more positive attitudes towards the parents of autism spectrum disorders after the implementation of the partnership protocol.

2. Methods

2.1. Participants

The participants of this study were 40 mental health professionals working in the private sector with children with autism spectrum disorders and their families (18 men and 22 women): 5 psychiatrists, 10 speech therapists, 12 occupational therapists, 7 psychologists and 6 special educators. Their age ranged from 26 to 55 years old (mean age = 42 years and 2 months) and they have been working with children with disabilities from 3 to 30 years (mean years of professional experience = 17 years). The mean time that they have been working therapeutically with a child with autism spectrum disorders was 2 hours per week. Forty mothers and fathers of children with autism spectrum disorders from Northern Greece also took part in the study. There were 33 mothers and 7 fathers, aged 29 to 42 years old (mean age = 34 years and 7 months). Ten mothers were housewives, 17 were private employees, 9 were public employees, and 4 were self-employed. One quarter of the parents had one child, 24 had two children and 6 had three children. Most parents lived with their spouses, while 4 mothers were divorced and raised their children alone. All the parents had a child diagnosed with autism spectrum disorders from a public child psychiatric or child developmental clinic. The mean age of their child's diagnosis was 4 years and 8 months. Out of the 40 children with autism spectrum disorders there were 7 girls and 33 boys and their age ranged from 3.5 to 14 years old. Ten children attended special schools, 22 attended inclusion classes and the remaining 8 were in mainstream schools. The parents were in contact with more than 5 mental health professionals from the time they started seeking for a diagnosis and visited someone to help their children with autism spectrum disorders for an average of 5 years and 3.5 hours per week.

2.2. Measures

2.2.1. *Partnership protocol*

The partnership protocol (please see Appendix) is a document that aims to delineate the relationship between mental health professionals and the parents of children with autism spectrum disorders. It defines partnership as a «functional relationship characterized by a common goal, mutual respect and desire for negotiation». The protocol is two pages long in order to be handy and to offer condensed information in the 11 following areas: 1) cooperation between parents and professionals, 2) negotiation of boundaries in parent-professional relationship, 3) parental expectations/feelings/needs, 4) parental accuracy and reporting of knowledge, 5) parental understanding of their child's condition, 6) parental participation in decision-making, 7) parents as therapists, 8) parental briefing, 9) disclosure of information to parents or third parties, 10) family discord and 11) negotiation of parent-professional disagreement. The partnership protocol was piloted with five parents and seven mental health professionals.

2.2.2. *Parent measures*

The parents completed a brief questionnaire at baseline, which included the following information: gender, age, educational level, profession, number of children, age of child with autism spectrum disorders, gender of child with autism spectrum disorders, age of diagnosis of child with autism spectrum disorders, agency of diagnosis of the child with autism spectrum disorders, years of cooperation with mental health professionals, weekly contact frequency with mental health professionals and number of mental health professionals with whom they have cooperated so far. Then, parents were asked to define the relationship between parents and mental health professionals; to specify what they expect from cooperative mental health professionals; to mention the problems that they face from uncooperative mental health professionals; to describe what they do in case of disagreement with mental health professionals; to define negotiation and to judge if it is necessary for a successful therapeutic relationship; and to document the three advantages and the three disadvantages of their relationship with mental health professionals.

Parents were asked after the intervention to state whether the protocol was useful or not justifying their answers; whether any points needed further clarification; which were the most important points of the protocol; how often they used it; if it helped them define the nature of the relationship that they had with the mental health professionals; what happened in case of disagreement with mental health professionals; whether the protocol helped them resolve any disagreement with mental health professionals; and whether anything had changed in their relationship with mental health professionals.

In order to measure parental views about mental health professionals, the *Helping Behavior Checklist – (CBCL)* [142] was used, since it was based on the codes of ethics of six international organizations of mental health professionals. The first part, which was used in this study, consists of 16 statements that parents have to rate on a 4-point scale (where 1 = almost always true and 4 = almost never true), such as «the mental health professional clearly ex-

plained to me what I had to do to help my child», «the mental health professional did not involve me in any decision-making regarding my child's therapy» and «the mental health professional held me responsible for my child's problems». Scores are reversed in some items and the total score for the scale varies from 16 to 64. This questionnaire is highly correlated to parental satisfaction about their child's progress since they started working with the specific mental health professional. Test-retest reliability varies from 0.48 to 0.89 for a period of 2-3 weeks [142]. The Cronbach α of the scale for this study was high $\alpha = 0.89$ and deemed satisfactory.

2.2.3. Mental health professionals measures

The mental health professionals filled in a brief questionnaire at baseline with demographic information: age, gender, profession, years of professional experience, as well as weekly frequency of sessions with children with autism spectrum disorders. Then they were asked to define the relationship between parents and mental health professionals and what they expect from cooperative parents; to mention the problems that they face from uncooperative parents; to state whether their cooperation with parents is necessary for successful intervention; to describe what they do in case of disagreement with parents; to define the concept of negotiation and to judge if it is necessary for a successful therapeutic relationship; and to document the three advantages and the three disadvantages of their relationship with parents.

Mental health professionals were asked after the intervention to state whether the protocol was useful or not justifying their answers; whether any points needed further clarification; which were the most important points of the protocol; how often they used it; if it helped them define the nature of the relationship that they had with parents; what happened in case of disagreement with parents; whether the protocol helped them resolve any disagreement with parents; and whether anything had changed in their relationship with parents.

The views of mental health professionals about the parents of children with autism spectrum disorders they worked with were measured using *Providers' Beliefs About Parents Questionnaire (PBAP)* [143], which is based on some concerns that parents expressed about the attitudes or the behaviors of some mental health professionals who worked with their children with disabilities. It consists of 37 statements that mental health professionals have to rate on a 4-point scale (where 1 = completely disagree and 4 = completely agree). There are 5 subscales: a) «parental incrimination», which consists of nine statements, such as «the most common cause of severe emotional disorder in children is their parents' behavior» or «the most common cause of emotional problems in children is their parents' emotional inadequacy»; b) «necessity of informing parents», which consists of ten statements, such as «it is usually advisable to offer parent unlimited access to their child's files» or «all parents must be informed on how exactly a therapy is expected to help their child»; c) «recognition of parental status», which consists of seven statements, such as «parents of children in need of mental health services are usually emotionally involved to such an extent, that they do not accurately report their child's behavior» or «parents possess special knowledge that mental health professionals lack»; d) «attitudes towards drug use», which consists of six statements, such as «drugs usually help to deal with autism» or «the possible merit of drug therapy

should be taken into consideration in most cases of autism»; and e) «providing guidance to parents», which consists of four statements, such as «it is not usually recommended to inform parents about what they can do exactly to help their child» or «it is therapeutically acceptable to brief parents directly about what they should do to help their child with autism». Scoring is reversed for some statements and the total score varies from 37 to 148. External validity ranges from 0.60 to 0.87 for each subscale [143] and test-retest reliability for the whole scale is 0.89 for a period of 2-3 weeks. Cronbach α for this study was very high for the whole scale ($\alpha = 0.93$) and is deemed extremely satisfactory.

2.3. Procedure

The researcher approached mental health professionals who were working privately with children with autism spectrum disorders in Northern Greece and briefed them about the study. She identified potential participants from the professional phone book and the lists of professional bodies in the area and then randomly pulled 100 papers with names from a container. She contacted them and 68 expressed an initial interest in the study, while 45 ended up agreeing to participate. The next step was to ask these mental health professionals to draw a list with the children with autism spectrum disorders they were working with at that time and the researcher randomly selected one family. The mental health professionals were given the task to brief the families and in case the parents expressed an interest the researcher met with them as well. There were some families who did not want to participate in the study, so another family was selected in their place until every mental health professional was matched to a family of a child with autism spectrum disorders. The parent from each family who participated was the one who was more in charge of the child's therapy and was in more frequent and direct contact with the mental health professional. This was deemed essential in order to follow the partnership protocol and to explore its effectiveness.

Before the beginning of the intervention the researcher informed the participants that they could withdraw at any time without penalty and that all the information that they provided would be confidential. Then, she gave out the baseline questionnaires that were filled out individually in the office of the mental health professionals and in the presence of the researcher. The next step was to present the partnership protocol to the participants in detail, to go through it with them and to answer any questions they might have. The intervention started when all participants reassured the researcher that they had fully understood the content of the partnership protocol and it lasted for six months. During this time the researcher called the participants monthly to check the progress of the data collection and to ask if there were any issues that needed to be addressed. Meanwhile, five parents discontinued the intervention at different points due to time restraints (one parent), health problems (two parents), or because they stopped taking their child to the particular mental health professional. So, the researcher asked the corresponding mental health professionals to stop using the protocol and the final number of participants was decreased to 40 parents of children with autism spectrum disorders and 40 mental health professionals.

Data collection was completed after a series of face-to-face meetings with every participant, who was asked after the intervention to fill in the same questionnaire as in baseline and to

answer some additional questions about the protocol. The answers of the participants in the open-ended questions were explored with thematic analysis, which led to the categories that are presented. A second rater with experience with this type of analysis looked at approximately half of the data and the interrater reliability was extremely satisfactory (95.7%).

3. Results

Data analysis revealed that after the intervention parents of children with autism spectrum disorders were more satisfied with their cooperation with mental health professionals. Following the implementation of the partnership protocol mental health professionals tended to blame parents less for their children's problems, gave them more information about their children's situation and directions on how they should behave, while they also recognized more their parental status.

3.1. Parents of children with autism spectrum disorders

3.1.1. Baseline data

The characteristics of a satisfactory cooperative relationship between parents and mental health professionals according to parents were: honesty, mutual briefing, mutual trust and setting common goals. Parents believed that cooperative mental health professionals provide constant briefing on the child's progress (90%); implement the therapy with consistency (68%); are honest with parents (49%); recognize parental skills (40%); understand parental wishes and problems (35%); and really want to help (10%). Uncooperative mental health professionals, on the other hand, do not brief parents about their child's progress (88%); do not implement the therapy consistently (73%); are dishonest with parents (50%); do not understand parental wishes and aspirations (43%); withhold information related to the therapy (23%); and are not knowledgeable about autism spectrum disorders (20%).

The vast majority of the parents (88%) thought that it is essential to cooperate with mental health professionals in order for the therapy to succeed and approximately 75% reported that they should actively participate in their child's therapy. The rest of the parents considered that nothing can be done to alter the predetermined course that their children with autism spectrum disorders will follow. When a disagreement occurred with mental health professionals, most parents insisted and discussed with them when they believe that they were right, while they backed down when they were not certain. Parents defined negotiation as: clear expression of views from both sides; understanding with the child's progress as a common goal; arrangement of a time frame for the accomplishment of some results; and expression of realistic expectation from both parties. Indeed, almost 2/3 of parents (68%) reported that negotiation is essential for a successful therapeutic relationship. The advantages and the disadvantages that parents identified in their relationships with mental health professionals are presented in Tables 1 and 2 respectively.

	N	%
1. Encouragement about the child's progress	14	35
2. Genuine interest in the child and the family	10	25
3. Cooperation between parents and mental health professionals	7	17.5
4. Provision of practical advise to parents	5	12.5
5. Regular verbal communication with parents	3	7.5
6. Provision of support in all the areas of the child's development	1	2.5

Table 1. Advantages of Working with Mental Health Professionals According to the Parents of Children with Autism Spectrum Disorders

	N	%
1. Dishonesty about the child's progress	12	30
2. Lack of genuine interest in the child and the family	9	22.5
3. No understanding of parental needs	7	17.5
4. Inability to realize what is promised	5	12.5
5. Insensitivity to family's needs	4	10
6. Overcharging for the therapy	3	7.5

Table 2. Disadvantages of Working with Mental Health Professionals According to the Parents of Children with Autism Spectrum Disorders

3.1.2. Post-intervention data

Most parents (87%) stated that the partnership protocol was useful, because it provides a clear context for the relationships between parents and mental health professionals, it defines the roles of both parties, it promotes the positive cooperation that contributes to the child's progress and it familiarizes parents with their rights. The remaining 13% claimed that the protocol is not useful because it is binding and difficult to adhere to. Some parents said that the protocol should also clarify which qualifications mental health professionals should hold in order to work with children with autism spectrum disorders and what parents can do if mental health professionals do not follow the protocol.

The most important points of the partnership protocol were: ensured cooperation, honest relationships, understanding of parental limitations, parental participation in decision-making, and recognition of parental needs and emotions. Parents referred to the protocol every time that something changed in their child's therapy or a problem came up, as well as in case of disagreement with mental health professionals. The changes that parents observed in their relationship with mental health professionals after the implementation of the protocol were: parents and mental health professionals cooperated more effectively (32%); mental health professionals offered psychological support to parents (25%); mental health profes-

sionals took parental needs and expectations into account (19%); parents learned how to act as therapists for their children at home (13%); a time frame was set for the therapy (9%); and mental health professionals did not treat parents just as an income source (3%).

3.1.3. The attitudes of parents of children with autism spectrum disorders towards mental health professionals

Paired-samples t-test was used to compare differences in parental attitudes towards mental health professionals before and after the implementation of the partnership protocol. Before the intervention ($M = 31.95$, $SD = 8.64$) parents expressed statistically significant less positive attitudes towards mental health professionals ($t_{(1, 39)} = 107.25$, $p < 0.001$, $\eta^2 = 0.73$) than after the intervention ($M = 28.65$, $SD = 7.67$).

3.2. Mental health professionals

3.2.1. Baseline data

The characteristics of a satisfactory cooperative relationship between parents and mental health professionals according to mental health professionals were: the exchange of ideas about the child, shared decision-making, mutual trust and respect, will to negotiate, and frequent contact. Mental health professionals believed that cooperative parents provide accurate information about their children (78%); follow their advice (68%); are honest about their child's condition (50%); are interested to learn more about their child (43%); do not have unreasonable expectations for their child's progress (42%); and actively participate in their child's treatment. Uncooperative parents, on the other hand, provide inaccurate information about their children (80%); question the mental health professional (60%); do not understand their child's condition (53%); do not keep certain agreements (45%); have irrational demands for their child's progress (38%); do not participate in their child's therapy (25%); and do not behave consistently (20%).

The vast majority of mental health professionals (93%) claimed that it is necessary to cooperate with parents for the success of the therapeutic intervention, since parents: possess valuable knowledge about their child that can be used in therapy, can complement the therapist's work and spend a lot of time with the child. In order to ensure parental cooperation, mental health professionals make parents feel more comfortable; brief them regularly about their child's progress; show sensitivity to the child's problems; express positive attitudes towards the child and the parents; promote parental beliefs that their child can improve with the proper therapy and support; take parental needs and wishes into account; engage parents in decision-making; gain parental trust; and try to specialize in autism spectrum disorders.

When mental health professionals disagree with parents, they tend usually to have an open and honest discussion with them, to engage them in decision-making, to be discrete, and to present their arguments. They may even resort to another mental health professional and in the end they make the final decisions if they cannot reach an agreement with the parents. Mental health professionals defined negotiation as exchange of ideas with the child's interest in mind, defining the boundaries of the cooperation, determining the expectations from

the therapy, setting mutual goals, discussing new possibilities, and compromising, if necessary. The advantages and the disadvantages that mental health professionals identified in their relationships with parents are presented in Tables 3 and 4 respectively.

	N	%
1. Interest in their child's therapy	38	95
2. Willing to devote time to their child	35	88
3. Realistic expectations about their child's progress	27	68
4. Active participation in their child's therapy at home	22	55
5. Source of important information for the child	19	48
6. Willing to cooperate with mental health professionals	14	35
7. Trust mental health professionals	10	25
8. Wish a better future for their child	9	23
9. Encourage other family members to participate in therapy	6	15

Table 3. Advantages of Working with Parents of Children with Autism Spectrum Disorders According to Mental Health Professionals

	N	%
1. No understanding of the child's condition	33	83
2. Emotional overload	30	75
3. Provision of inaccurate information	29	73
4. Refusal to engage actively in therapy	25	63
5. Exaggerated and unrealistic expectations	25	63
6. Unwillingness to cooperate	20	50
7. Lack of trust in mental health professionals	18	45
8. Feelings of parenting inadequacy	16	40
9. Insecurity for their child's future	15	38
10. Parental disagreements about their child	13	33
11. Rejection of the diagnosis of autism spectrum disorders	10	25
12. Experience of guilt over the child's condition	8	20
13. Crossing the boundaries (e.g., calling in the middle of the night)	6	15
14. Insisting on their views, even when they are wrong	10	4

Table 4. Disadvantages of Working with Parents of Children with Autism Spectrum Disorders According to Mental Health Professionals

3.2.2. *Post-intervention data*

Most mental health professionals (80%) claimed that the partnership was useful, because it sets the boundaries of the cooperation, it promotes negotiation, it emphasizes mutual respect, it clarifies the need for parental involvement in the therapeutic process and mental health professionals have a reference point in case of disagreement. The remaining 20% stat-

ed that the protocol is not useful because it is binding and parents who are not educated cannot understand it. Some mental health professionals said that the protocol should clarify how much time mental health professionals should devote to parents, what happens when parents do not follow the protocol, and for which third parties mental health professionals should get the consent of the parents before they disclose information about their children.

The most important points of the partnership protocol were: the negotiation of the boundaries of the relationship between parents and mental health professionals, the clarification of the roles of both sides, and the emphasis placed on active parental involvement in their child’s therapy. Mental health professionals referred to the protocol every time there was a disagreement with parents. The changes that mental health professionals observed in their relationship with parents after the implementation of the protocol were: parental expectations became more relevant to the child’s condition (93%); parents realized that the whole family should be part of the therapy (80%); initial tensions were normalized (75%); parents felt that their expectations and emotions were taken into account (65%); parents were more committed to the therapy (58%); parents were more open to new suggestions and treatments for their child (35%); parents made less calls of hypothetical crises (23%).

3.2.3. *The attitudes of mental health professionals towards parents of children with autism spectrum disorders*

Analysis with MANOVA revealed that there was a statistically significant change in four out of the five subscales that measured the attitudes of mental health professionals towards the parents of children with autism spectrum disorders, even after being controlled for age, gender, and years of professional experience. More specifically, there were statistically significant changes in parental incrimination ($F_{(1, 39)} = 5.56, p < 0.05, \eta^2 = 0.12$); necessity of informing parents ($F_{(1, 39)} = 5.03, p < 0.05, \eta^2 = 0.11$); recognition of parental status ($F_{(1, 39)} = 4.83, p < 0.05, \eta^2 = 0.10$); and providing guidance to parents ($F_{(1, 39)} = 5.35, p < 0.05, \eta^2 = 0.12$). There was no statistically significant difference in the attitudes that mental health professionals expressed towards drug use before and after the intervention ($F_{(1, 39)} = 0.96, p > 0.05, \eta^2 = 0.02$). Means and standard deviations are presented in Table 5.

	Baseline	Post-intervention	F
	M (SD)	M (SD)	
Parental incrimination	26.69 (3.54)	22.24 (3.44)	5.56*
Necessity of informing parents	14.15 (3.24)	17.93 (2.74)	5.03*
Recognition of parental status	14.06 (2.52)	19 (2.04)	4.83*
Attitudes towards drug use	6.11 (2.18)	8.41 (1.54)	0.96
Providing guidance to parents	3.25 (1.07)	8.17 (2.34)	5.35*

* $p < 0.05$

Table 5. Means and Standard Deviations of the Attitudes of Mental Health Professionals Towards Parents of Children with Autism Spectrum Disorders Before and After the Intervention

4. Discussion

The research hypotheses were confirmed, since both parents of children with autism spectrum disorders and mental health professionals expressed more positive attitudes about each other after the implementation of the partnership protocol. Most participants felt that the partnership protocol was particularly useful and they also identified some points that could be further clarified, while they also pointed out the exact nature of the changes that they have observed in their interactions.

4.1. The attitudes of parents of children with autism spectrum disorders towards mental health professionals

Most parents of children with autism spectrum disorders believed from the beginning that it was imperative to work together with mental health professionals in order to enhance their child's progress, while the rest believed that their child's progress was predetermined and there was nothing they could do to change that. Parents define a cooperative relationship as a relationship that is characterized by honesty, mutual briefing, mutual trust, and setting common goals [27]. The information that parents receive from mental health professionals is more important to them than sympathy or psychological support [144-145].

Parents describe cooperative mental health professionals as constant providers of update regarding their child's progress, consistent, honest, understanding, willing to help, and aware that parents possess certain skills. So, the parents in this study have identified essentially the defining characteristics of cooperative relationships [77]. Parents cannot cooperate with mental health professionals who do not brief them, are inconsistent and insincere, ignore them, withhold information and are not well trained – in agreement with other research [24, 28, 117].

The implementation of the partnership protocol helped the parents of children with autism spectrum disorders to redefine their cooperative relationship with mental health professionals. They learned to function as therapists at home, facilitating thus the therapeutic process [25-26]. They received emotional support from mental health professionals and they set a time frame for some therapeutic goals, which could help them feel less stressed [146]. Most parents reported that after the intervention mental health professionals treated them as more equals, briefed them about their child's progress, engaged them more actively in the therapeutic process, and took their feelings and opinions into consideration. This change may be due to the fact that a trusting relationship was created through the protocol, which helped the parents express themselves more freely and become more assertive. Trust is imperative for the creation of a constructive cooperative relationship between mental health professionals and parents of children with disabilities [104]. Many parents actively seek to create this bond of trust, since they feel that it will benefit their child [11, 117].

An additional change that was reported by the parents of children with autism spectrum disorders was that the mental health professionals started briefing them more about the ways in which the proposed therapy will help their child and encouraged them to get ac-

tively involved in decision-making regarding their child's treatment. Active participation in their child's therapy can help parents develop a sense of efficacy and personal control that can help them become even more effective parents [87] and less stressed and concerned [147]. When parents feel heard and respected, then they can cooperate better with mental health professionals to do what is best for their child and this is something that mental health professionals should aim at [66].

4.2. The attitudes of mental health professionals towards parents of children with autism spectrum disorders

Mental health professionals tended to incriminate parents of children with autism spectrum disorders less after the implementation of the protocol. This is very important, since it affects greatly the choice of suggested therapies and strategies that mental health professionals employ when interacting with the parents of children with autism spectrum disorders [67]. Since parents of children with autism spectrum disorders have been repeatedly blamed for the problems that their children face [148], the partnership protocol encourages the creation of a relationship that frees parents from guilt and treats them as equal partners. After the implementation of the partnership protocol, mental health professionals realized that it is essential to inform parents about their child's condition and the course of the therapy. The needs of all family members are taken into consideration [50] and, therefore, frictions are decreased [3, 11, 99]. So, it is possible to create a strong cooperative relationship that can benefit both parties [40, 47], while children with autism spectrum disorders can also benefit from parental empowerment [149].

The mental health professionals who adopted the protocol said that they recognized more the validity of parental knowledge and information regarding their child with autism spectrum disorders. This change is very positive, since parents of children with autism spectrum disorders know a lot of things about their children that are useful when planning the appropriate intervention [61]. The acknowledgement of the usefulness of parental knowledge by mental health professionals is essential to the cooperative process [60] and is, thus, emphasized in the partnership protocol.

Moreover, mental health professionals understood that they need to provide more clear and more detailed information to parents about the management and upbringing of their children with autism spectrum disorders. The partnership protocol stressed that parents can be trained to satisfy the needs that arise from their parenting role and this is instrumental for various therapeutic approaches [16]. Parents who receive specific guidance on how to deal with challenging and unwanted behaviors believe that they can control them better [150] and so they feel less stressed [146]. However, it is worth pointing out that some parents cannot or do not want to fulfill their instructional role [151] and this is something that mental health professionals should respect.

The statistical analysis revealed that the perceptions that mental health professionals hold about the parents of children with autism spectrum disorders were not affected by their age, gender, or years of professional experience. Therefore, it is likely that they are affected by

their training and by the «social representations» that they hold about parents of children with autism spectrum disorders [152], as well as by cultural and social factors [18].

Almost all the mental health professionals believed that their cooperation with the parents of children with autism spectrum disorders was essential to the successful course of the therapy [86, 128], since they bring their own knowledge and experience into the therapeutic process [29]. Therefore, they claimed that in order to ensure this cooperation they try to earn parental trust and to make them feel comfortable, while taking into account their needs and wishes. By briefing parents about their child's progress, they engage them more actively in decision-making regarding the treatment course [93]. However, it is worth mentioning that at the beginning of the study parents complained that mental health professionals do not try enough to cooperate with them. This could be due to a wider communication problem that has been documented also in other studies, since good intentions alone are not enough to establish cooperation [86, 94]. Finally, mental health professionals claimed that they tried to increase their knowledge through training in order to be able to better deal with the problems of children with autism spectrum disorders. This needs to be done if mental health professionals are to design an intervention that is based on the child's needs and skills and is more likely to be successful [49].

Mental health professionals define cooperation as a relationship that is characterized by exchange of views about the child, shared decision-making, mutual trust and respect, desire to resolve disagreement, frequent contact and discussion on equal terms (there is no expert) [15, 59, 89, 93]. This definition that they provided includes some of the key characteristics of the negotiation model [40].

Parents should provide accurate information about their child that is essential for the establishment of a cooperative relationship with mental health professionals [77]. Otherwise, mental health professionals have to waste a lot of valuable time and resources to find out what they need to design an effective intervention [1]. Parents who are unaware of their child's actual condition may place irrational demands on both their child and mental health professionals and fail to keep agreements and deadlines, jeopardizing their child's progress [111]. Finally, there are some parents who question the training of mental health professionals and their suitability to work with their child, but may continue to cooperate because they have no other options or because they believe they can motivate the mental health professional [11, 99].

Mental health professionals noted that after the implementation of the partnership protocol parents started to have more realistic expectations that made them realize the importance of engaging the whole family in the therapeutic process [54]. Parents understood that they have to follow the advice of mental health professionals to help their children and became more open to new treatment suggestions [104]. These behaviors are indicative of greater trust for the mental health professionals, who need initially to recognize the shock that parents experience [17] and to help them reach the stage of full acceptance [16]. Parents also seemed to have responded positively to the efforts made by mental health professionals to take their feelings and views into account when designing the intervention [75]. Finally, mental health professionals reported that the parents were better able to judge when they

needed to communicate in order to resolve an actual crisis, probably as a result of their active therapeutic engagement [98].

4.3. Evaluation of the partnership protocol

Most parents of children with autism spectrum disorders and mental health professionals who used the partnership protocol said that it was useful, because: a) it clarifies the relationship between the two parties; b) it defines the roles of both parties; c) it promotes effective cooperation; d) it advances negotiation; and e) it values mutual respect. All these elements were rated by many studies [28, 101, 103] as essential for the creation of a functional and effective cooperative relationship among parents and mental health professionals. It is extremely important to point out that both parents and mental health professionals recognize similar benefits from the implementation of the protocol, corroborating the finding that the needs of parents and mental health professionals are closer than one would think, but they need to be clearly defined in order to be satisfied [100].

The parents of children with autism spectrum disorders reported that the partnership protocol informs them of their rights and helps them fight for provisions and services. Parental participation is instrumental in reassuring the existence of options for adults with autism spectrum disorders [153]. Parents become empowered [39, 86] and thus able to negotiate with mental health professionals [40]. Mental health professionals said that they could use this protocol to resolve conflicts or disagreements with parents. This is important, since some mental health professionals do not know how to resolve interpersonal conflicts [3] and they become increasingly stressed [147].

The four parents who thought that the partnership protocol is not useful justified their opinion by saying that it is binding and difficult to adhere to. It is a fact that the implementation of a protocol or any form of agreement requires commitment from all involved parties. Therefore, it is likely that some parents of children with autism spectrum disorders are exhausted from the constant care of a child with multiple and complex needs and do not possess the required strength to enter this process [146]. Moreover, it is plausible that some parents prefer to hold a more distant role from the therapeutic process [54]. The eight mental health professionals who considered the partnership protocol not to be that useful thought as well that it is binding and that parents who are not educated cannot understand it. It seems that they do not want to be committed to a predetermined cooperative relationship with the parents because they have adopted the expert model. Even if some parents are not educated or able to understand some points, it is the role of mental health professionals to explain everything to them in simple and understandable language [56].

Approximately 20% of the parents of children with autism spectrum disorders identified two things that needed further clarification in the partnership protocol: a) which qualifications mental health professionals should hold in order to work with children with autism spectrum disorders and b) what parents can do if mental health professionals do not follow the protocol. The first point partly reflects the insecurity that results from insufficient briefing regarding the options that parents have to choose the suitable mental health professional after the diagnosis [55]. They could also result from limited options due to place of residence

or financial restraints [99]. The second clarification is indicative of feelings of inferiority or intimidation. This partnership protocol has no legal power and it is not a contract with legal ratifications. The whole point of the protocol is to introduce parents to the concept that they can discuss any conflict or disagreement with mental health professionals on equal terms.

Mental health professionals also wanted to know what will happen in case that parents of children with autism spectrum disorders do not follow the protocol. This is something that should be discussed and agreed upon from the beginning between the two parties. Most disagreements are peacefully resolved, while very few have ended up in court [3]. Moreover, it is important that some mental health professionals realize that some parents will not want to cooperate with them [76]. The second question was how much time mental health professionals should spend with parents of children with autism spectrum disorders and this is again to be negotiated between them from the beginning.

The most important positive outcomes of the partnership protocol are: ensured cooperation, honest relationships, understanding of parental limitations, parental participation in decision-making, and recognition of parental needs and emotions. It seems that what parents really need is to feel like equal partners in the therapeutic process and this is something that the partnership protocol offers. Parents who are involved in decision-making about their child and are supported by mental health professionals feel happier [2, 33, 154]. The most important positive outcomes of the partnership protocol are: the negotiation of the boundaries of the relationship between parents and mental health professionals, the clarification of the roles of both sides, and the emphasis placed on active parental involvement in their child's therapy. Mental health professionals need to define their relationships with parents as much as parents do [28, 77-78] and they use the protocol to do so.

4.4. Limitations

The aim of this study was to create a partnership protocol to delineate the relationship between parents of children with autism spectrum disorders and mental health professionals with the ultimate goal to improve the child's condition [84]. The need for this protocol derived from personal experience and from meticulous literature search [16, 105]. Although the findings were positive and encouraging, there are some limitations that should be taken into consideration:

1. The mental health professionals were working in the private sector and so they might be more willing to follow the protocol in order to keep their clients – things could be different if they worked in a public setting.
2. The mental health professionals who agreed to participate in the study might have been the ones who work better with parents, and the parents who participated might have been the ones who were happy with mental health professionals to begin with. However, analysis showed that all the participants identified some problems at baseline.
3. Some confounding variables, such as the training of mental health professionals or the educational level of the parents were not taken into consideration when analyzing the findings. For example, it was found that single mothers of children with autism spectrum disorders experience more stress than married mothers [14].

4. Despite the fact that the participants were reassured that data would be kept confidential, they might be skeptical about expressing very negative attitudes [155].
5. There was no official follow-up, although the researcher had informal contacts with the participants and was informed that many of them continued to follow the partnership protocol after the six-month period.
6. There are many other factors that could have affected the collaboration between parents of children with autism spectrum disorders and mental health professionals that are related to external factors (e.g., financial crisis), internal factors (e.g., depressive mood) or child-specific factors (e.g., severity of the autism spectrum disorders) that were not examined in the present study and could inform further research.

4.5. Practical implementation and future research

This research confirmed the findings of previous studies [77, 104, 147] that the relationship between parents of children with autism spectrum disorders and mental health professionals is quite challenging. However, the aim was not just to identify the existing problems, but to propose also some possible solutions. It seems that the implementation of the partnership protocol had a positive effect on the delineation of the relationship of the involved parties and helped them overcome some the existing obstacles by becoming more cooperative and willing to negotiate for the child's benefit.

As mentioned in the introduction, mental health professionals and parents of children with disabilities hold their personal beliefs regarding the kind of relationship that they should have. The partnership protocol helped them understand their rights and obligations, since they might hesitate to discuss them openly. There are many mental health professionals who do not know how to set limits to their relationships with parents and many parents who do not know how to express their opinions or their questions regarding their child to mental health professionals. Therefore, the partnership protocol may be suggested by mental health professionals as a means to negotiate their relationship with parents, while it serves also as an opportunity to discuss further and to resolve any conflicts. However, it should be stressed that the partnership protocol is not a legally binding document and so parents and mental health professionals should follow it because they believe in its value. It can be implemented in any therapeutic framework, where it is essential for parents of children with disabilities and mental health professionals to work together. It could also be used to train mental health professionals who will work with children and adolescents with disabilities and their families [156].

This is the first study in Greece, and worldwide, that introduced the use of a partnership protocol to resolve possible conflicts that arise between mental health professionals and parents of children with autism spectrum disorders. Therefore, future studies should be conducted with parents of children with other disabilities, as well as with parents of children with chronic illnesses and with other mental health professionals, such as doctors, nurses, or teachers.

5. Conclusion

This study confirmed the findings of previous international research regarding the problematic relationships between mental health professionals and the parents of children with disabilities. It was found that Greek mental health professionals are troubled by the parents' demands and their unwillingness to actively engage in their child's treatment. Greek parents of children with autism spectrum disorders claim that mental health professionals are not interested in involving them in decision-making regarding their child's therapy. Similar complaints have been expressed in other studies that have explored the relationship between mental health professionals and parents of children with autism spectrum disorders [77, 104, 147].

Despite the fact that the difficulties that were documented in this study have been identified a long time ago and in several contexts, there has been no published coordinated effort to resolve them. This partnership protocol was based on the codes of ethics of international organizations of mental health professionals, it is written in simple language and it was considered to be useful by most participants. The implementation of the partnership protocol helped mental health professionals and parents of children with autism spectrum disorders to define their interpersonal relationship and to overcome many of the difficulties and the problems that they had identified at the beginning of their cooperation. They started to communicate more honestly, to respect each other more and to resolve their conflicts more effectively. Even though these findings are encouraging, more longitudinal studies with varied participants are needed to explore further the effectiveness of the partnership protocol.

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Appendix

Parent-Professional Partnership Protocol

When professionals and parents of children with autism come together for the first time, they bring with them their own worries, concerns, priorities, and responsibilities, which must be woven together into a relationship that could be characterized as a partnership. The roles of the parent and the professional impose certain rights and duties, obligations and anticipated behaviours, as well as expectations. It is extremely difficult to define the exact nature of this partnership, since every parent and every family has its own idiosyncrasies and

each professional possesses unique characteristics and ways of working and relating. The aim of the present document is to provide some guidelines that could be adopted and implemented by both interested parties in an attempt to define their partnership and it is based on the principles of the negotiating model. The negotiating model defines partnership as “a working relationship that is characterized by a shared sense of purpose, mutual respect and the willingness to negotiate”.

Cooperation between parents and professionals

Professionals need parental cooperation in order to be able to do their job effectively. Parents should recognize that professionals have specialist knowledge and abilities, but they cannot substitute the role of the caregiver. Since both parents and professionals are interested in the child’s progress, they need to cooperate to achieve the best results.

Negotiation of boundaries in parent-professional relationship

Parents and professionals should clarify and negotiate the nature and the limits of their partnership. It would be advisable to make a contract that is not formal or legally binding. It just sets out mutual expectations and intended behaviours. Depending on the situation it may be appropriate to put this in writing and each party should retain their own copy. It is advisable to repeat this process at later stages according to the progress of the child. Parents should refrain from contacting the professional on a regular basis about things that do not concern the child with autism and professionals should be punctual and fulfil their obligations towards the family and the child.

Parental expectations/feelings/needs

Professionals should identify and evaluate the needs of the family, which cannot be separated from the needs of the child. The child has a relationship with all the other family members and the relationships within the family have an interactive effect with each other. Parents should verbalise and express their urging needs to professionals so that a solution can be sought. These expectations, feelings, and needs should be incorporated into the treatment when the professional believes that is plausible and suitable.

Parental accuracy and reporting of knowledge

Parents possess a unique and special knowledge and understanding about their child that is valuable for the design of a better intervention. The home is the best available place to consolidate the knowledge that the child acquires and it can also offer multiple opportunities for learning. Parents should be honest with professionals and try to overcome the difficulty they may experience to talk publicly about the condition and the difficulties of their child. If the professional is misled or told half the truth, it is very likely that the suggested treatment will not be the appropriate one.

Parental understanding of their child’s condition

Professionals should use simple language when talking to parents, since they do not have expert knowledge that allows them to familiarise themselves with terms used among professionals. Parents should also express their queries and seek to clarify any misconceptions or

worries they might have. If parents believe that they are not being listened to, they should make sure that the attitude of the professional changes. Professionals must not focus on the child alone, but they should advise parents on how to care for their child with autism. Even if parents have other children, they may need some practical assistance and tips on how to overcome some of the issues that arise due to the difficulties faced by their child. It is the parents' responsibility to inform professionals on the areas where they believe they need more help and support.

Parental participation in decision-making

Professionals should allow parents to be more involved in activities and decisions regarding the education and care of their child. For example, professionals should not make drastic changes in the treatment that they follow before consulting with the parents. This is a good way to ensure cooperation and to minimise conflicts in parent-professional relationship. Parents will be able to make an informed choice regarding the future of their own child. Therefore, a common purpose or shared concern or mutual interest should be established in order for the relationship between the interested parties to be productive. Both parents and professionals should be involved in brainstorming regarding potential ideas, plans, or actions that could enhance the development of the child. Parents should make an effort to follow and understand the progress of their child in order to be able to make a decision. This could include reading books, notes, or reports regarding the condition of their child and the treatment that is implemented.

Parents as therapists

Professionals may train parents to use some behavioral techniques that will allow them to teach their child, complementing thus and supporting the work of professionals. If parents feel confident enough, they may want to assume an active role in furthering their child's learning. However, professionals should be aware that parents may not have enough time to be actively involved in the education of their child if they have a full-time job or other children to look after. Therefore, at the beginning of the partnership professionals and parents should reach an agreement on the amount of time that parents can spend with their child on a weekly basis. Professionals should encourage each member of the family to contribute to the treatment of the child with autism, which may need special assistance to participate in family outings and activities. This can be achieved by encouraging parents to communicate with each other and express openly their concerns and needs.

Parental briefing

Professionals should inform parents from the beginning about the cost of the treatment, seek their consent when contemplating the acquisition of new material, and brief them about the progress of their child, even if the news are not particularly encouraging or reassuring. It would be a good idea for professionals to keep notes of the meeting with the parents, so that they can refer to them in the future and keep track of the progress of their child.

Disclosure of information to parents or third parties

Professionals could verbally inform parents about the progress of their child but access to records may be prohibited due to legal issues related to their confidentiality – professionals are called to make individual decisions according to each situation. Parents who advocate their right to have access to the records should be equally responsible in their own record keeping. Professionals should inform parents of any other professionals with whom they discuss the case of their child and elicit their consent before doing so.

Family discord

In case of disagreement between the parents regarding the treatment of their child, professionals should stay neutral and avoid making alliances with one parent or colluding consistently with one parent's preferences. If professionals believe that there are many pressing issues among the family members, they should encourage them to see a counsellor. Parents should realize that professionals working with their child may not have the necessary knowledge and training to deal with these issues.

Negotiation of parent-professional disagreement

When a disagreement arises, both parents and professionals should try to resolve it. They must express their opinions and feelings openly, keeping in mind that they have the child's best interest in mind. If it is impossible to resolve the disagreement, it might be advisable to discontinue the partnership.

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