

Having a Child with Autistic Spectrum Disorders in Bosnia and Herzegovina

Parents' Experiences with Coping Strategies

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**Having a Child with Autistic Spectrum
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Parents' Experiences with Coping Strategies**

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IV

Abstract

The aim of this study is to investigate how parents of children with autistic spectrum disorders cope in Bosnia and Herzegovina through their personal experiences and perspectives.

As a basic theoretical framework for this study, stress and coping theory was used together with two family resilience models. Within stress and coping theory coping strategies are described which are crucial for better understanding of this study. Hill's ABCX model was described as a prototype for all other resilience models that came afterwards. Double ABCX model is introduced as an updated version of the prior model and is used to better visualize findings in this study.

Qualitative phenomenological study was applied to this research as it seemed to be the most suitable approach for investigating the lived experiences of these parents. Using the purposive sampling 4 parents were chosen for the research. Semi-structured interviews were applied for data collection. In analyzing data thematic analysis was used as a main tool.

The findings have showed that parents of children with autism spectrum disorders cope rather good, although they receive minimum help from the government and mostly depend on non-governmental organizations which are being centralized and not so many in general. It appears that parents are using problem-focused coping strategies which are desirable for better coping in whole. From the very beginning, when they wondered and searched diagnosis being desperate to help their children they employed these type of strategies which are focused on identifying the problem and working on solving it. There was no time for despair, but just think of how to help their children and fight the fight. On the other hand, fear of uncertain future can sometimes be hard to bear for these parents, but they try not to think of it as much and rather focus on the hard work with their children. Parents showed quite resilience regarding all the stressful factors that they are affected by. This means that their coping

process is successful in a way. Although, not employing so much active emotion-focused strategies such as use of support groups, for example to release the stress, can lead to potential burn-out.

Dedication

To all parents and their children with autistic spectrum disorders in Bosnia and Herzegovina whose every day fight is usually being silent for the majority. In hope that in the near future their voices are being heard more and that the system in general changes for the better.

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Table of Contents

Having a Child with Autistic Spectrum Disorders in Bosnia and Herzegovina.....	III
Abstract	V
Dedication	VII
Aknowledgments	VIII
Table of Contents	X
List of Figures	XIII
Acronyms	XIV
1. Introduction.....	1
1.1. Background of the Study	1
1.2. Personal Motivation for the Study.....	5
1.3. Rationale for the Study and Research Problem	6
1.3.1. Rationale for the Study	6
1.3.2. Research Aim and Question	7
2. Theoretical Framework/Literature Review	8
2.1. Introduction	8
2.2. Family Stress and Coping Theory	9
2.2.1. The Concept of Stress, Appraisal and Coping	9
2.2.2. The Concept of Stress	9
2.2.3. Cognitive Appraisal	11
2.2.4. The Concept of Coping	13
2.3. Family Stress Models	16
2.3.1. Hill’s ABCX Model	16
2.3.2. Double ABCX Model	18
2.4. Literature Review	21
3. Methodology	24

3.1.	Research Design	24
3.2.	Sampling procedures and Participants	26
3.2.1.	Sample	26
3.2.2.	Participants	28
3.3.	Instrumentation and data collection	29
3.3.1.	Developing Interview Guide	30
3.3.2.	Pilot Study	31
3.4.	Data Analysis	31
3.5.	Ethical considerations	33
3.6.	Validity and Reliability	34
3.7.	Limitation to the Study	36
4.	Presentation of the Data	37
4.1.	Introduction	37
4.2.	Theme 1 – Dealing with the Diagnosis	37
4.2.1.	Acceptance	39
4.2.2.	Trying Everything to Help a Child	41
4.3.	Theme 2 – Self-help Strategies	42
4.3.1.	Motivation for Moving Forward	43
4.4.	Theme 3 – Financial Security	44
4.5.	Theme 4 – Family Support	45
4.5.1.	Coping Together with the Spouse	46
4.6.	Theme 5 - Support Among Parents	48
4.7.	Theme 6 – Getting Help from Provided Services	49
4.8.	Theme 7 – Coping with Fear and Worries	51
4.9.	Theme 8 – Coping with Social Attitudes	52
5.	Discussion, conclusion and recommendations	54
5.1.	Discussion	54

5.2.	Conclusion	58
5.3.	Recommendations for further research	60
	References	63
	Appendices	68

List of Figures

Figure 1. ABCX Model (Hill, 1949)18

Figure 2. Double ABCX Model (McCubbin & Patterson, 1983)20

Acronyms

B&H - Bosnia and Herzegovina

RS - Republika Srpska

FB&H - Federation of Bosnia and Herzegovina

ASD - Autistic Spectrum Disorder

KM – Convertable Mark

DUGA - “Society of United Actions of Citizens

OHR - Ombudsmen Institution for Human Rights

EDUS - Association for Advancement of Education and Support for Children with and without Developmental Delays

URDAS - Association of Parents of Children and Adults in Autistic Spectrum

URDOSA - Association of Parents of Children and Adults with Autism

DD – Developmental Delays

PSG – Parent Support Groups

NGO – Non-governmental Organization

OSCE - Organization for Security and Co-operation in Europe

NSD - National Social Science Data Service

1. Introduction

1.1. Background of the Study

In general, raising a child without any disorders is an enormous challenge. It requires a lot of responsibilities that sometimes we are not well prepared for. This is often the case when parents have a child with disabilities. One of these disabilities is autistic spectrum disorders (ASD) which is probably one of the most challenging in the disability spectrum.

ASD is neurodevelopmental disorder that affects communication and social aspects of a person's life. Another common characteristic is that they exhibit repetitive and disruptive behaviors. What we take for granted in our daily lives for people with ASD can be every day struggle such as simple thing as smiling to a friend (Durand, 2014, p. 9). Center for Disease Control (2009) estimated the prevalence of autism 1 in 100. This number has increased in past decades and it still in growing. This is probably related to better diagnostics and the successful treatment methods being used (Kirk et al., 2012, pp. 140-141).

During the past twenty years there has been a twist when it comes to approaches to working with parents of children with ASD. It seems that ever since autism was recognized as a developmental disorder and not as an emotional disturbance parents got involved more in the treatment of their children than before. They are no longer seen as a cause of the problem, but as a very important figure in their child's treatment. To be able to succeed in this new role they need functioning coping strategies (Marcus et al., 1997; Sivberg, 2002, p. 37). According to Lazarus and Folkman (1984), coping is:

“[...] constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.141).

Coping becomes even harder for parents who live in developing and deprived societies. One of these societies is also Bosnia and Herzegovina (B&H) which has a very complicated infrastructure that affects negatively many aspects within the existing system. The reason for that is because in order to stop the biggest war after World War II in B&H international community interfered with the imposing a very complex structure for creating the inter-ethnic balance (S. Gavrić, D. Banović & Mariña Barreiro, 2013, p. 11). This resulted in dividing the society into two entities, Federation of Bosnia and Herzegovina (FB&H) , Republika Srpska (RS) and Brčko District (BD). FB&H has 10 cantons and within these cantons municipalities. On the other hand, RS has only municipalities. While BD is a small neutral area.

“The law in both entities prohibits discrimination against persons with physical, sensory, intellectual, and mental disabilities; however, there was discrimination against persons with disabilities in employment, education, and access to health care and other state services”
(U.S. Department of State, 2011, p. 30).

One of the biggest reasons why discrimination still vividly exists in both entities is because different subsystems within the entities (cantons and municipalities) are not being operationalized in accordance to their Framework Law, but rather have their own political systems.

According to Organization for Security and Co-operation in Europe’s (OSCE, 2012) publication “Right to Social Welfare in Bosnia and Herzegovina”, social welfare for persons with disabilities is around 219 Convertible Marks (KM) to 396KM in FB&H which also depends on a degree of a disability. In RS this right practically does not exist, the only social help that is provided is the one that includes assistance of another person which is 41KM monthly (p.39). This describes the discrepancies between the entities when it comes to financial help and how B&H as a country has a chaotic infrastructure.

In Delfos’ report (2010) she points out that when it comes to diagnosis, there are only two centers in the country, one is in RS in Banja Luka which is the Child Psychiatric Ward in Banja Luka together with the Neurology Department of the Clinic of Child Diseases, and the

other one is the Psychiatric Ward in Sarajevo (p. 18). Furthermore she adds, *“There is no general system of diagnose in B&H [...] health care is not well organized and is very costly not everyone has access to Health care”* (p. 18). This means that only wealthy families can afford to secure diagnosis and help and most of the children in the country are not being diagnosed and are living at home in a very hard conditions *“[...]with desperate parents not understanding what is happening with their child”* (p. 18).

All these above mentioned factors contribute to harder living on daily basis for persons with disabilities and their families. It is quite demanding and challenging to raise a child with autism (Delfos, 2010, p.15). Especially, when living in society that imposes a lot of limitation and stigmatization in environment. In B&H society there is almost no public awareness about autism (p.15). This can, for example, make it a lot harder for parents when they are in public. If a child has tantrums in a public place where awareness about autism is very low people can be very judgmental and perceive parents as “bad guys”. Therefore, they are often seen as someone who doesn’t teach their children “good manners”.

The population density in B&H has changed after the war with approximately 1.2 million people leaving the country and half million returning back. Therefore, statistics on how many people with ASD were left in the country is unknown, even though the prevalence is probably smaller since it requires a lot of organizing and knowledge of social interacting for people with autism in order to flee and live somewhere else (Delfos, 2010, p. 13). According to Delfos (2010), *“On a population of 4.5 million people before the war, it would be ranging from 27.000 to 52.200 people with autism (young and old)”* (p. 13).

Disabilities can be seen as a stigma and a reason for unpleasant feelings (Association “Society of United Actions of Citizens” - “DUGA”, 2006, p.13). According to the report of the Ombudsmen Institution for Human Rights of B&H (OHR, 2010), parents are usually left on their own and the government is contributing minimum to their and child’s needs. They mostly go through the process of acceptance by themselves without any support services provided by the government. Further in their report parents stated that after getting the diagnosis they usually have no one to seek for help. They are informing themselves through

the Internet as an often main source of information or disinformation (p.62). This can result in wondering around for quite a while desperately seeking for help which is time consuming and frustrating for a family.

Association for Advancement of Education and Support for Children with and without Developmental Delays (EDUS) among other things every now and then organizes educational workshops for parents. In 2012 their focus was on a healthy environment for children within the families, since there were cases of domestic violence that was increased by the stress related to raising a child with developmental difficulties (p. 6). Influence of the family on the child with disability is determined by the family situation, as well as the severity of disability (“DUGA”, 2006, p.13). It occurs often that one parent cannot work, because he/she has to stay at home and take care of the child which reduces their income. Also, misbalanced differences between realistic and expected possibilities usually results in emotional reactions that are not only stressful for parents, but for siblings and a child himself/herself as well (“DUGA”, 2006, p.13). *“Professionals and parents are looking desperately for methodology, instruments, treatment, models, diagnose models, intervention models in general, and how to come with the strange and often difficult behavior of children with ASD” (Delfos, 2010, p. 15).*

It’s not an easy task to do when beside having a child with ASD and focusing on him/her parents are forced to focus on “fixing the system” in order to find the best possible solutions for their children. This is something that government supposes to ensure in the first place, not parents. In order to feel more secure parents need help in developing positive attitudes when it comes to raising their children. Also, parents need to help and support each other so they don’t come to the point of a burn-out (Delfos, 2010, p. 25). Unfortunately, parents in B&H cannot rely on support services and mostly depend on NGO’s initiatives. This also becomes a big issue for parents who are living in smaller cities where they don’t have that kind of a support either and have to travel to bigger cities which also is financially exhausting and only few can afford that. Therefore, centralization is also one of the biggest problems when it comes to these issues.

1.2. Personal Motivation for the Study

As it was already mentioned in the introduction, B&H has a quite dysfunctional system in general that is affecting families of children with ASD on many levels. The government is not doing much to help these families. Non-governmental organizations (NGO) for autism are probably the biggest resource for managing difficult situations and moving forward. When parents are wondering in the beginning NGO's can be very useful in a way that they can give relevant information on where to go and what to do next. Not only that, many NGO's can offer treatments for children or space for parents to gather together and discuss many important issues. The only problem is that there are no many NGO's for autism and that mostly they are being centralized so people from rural areas have difficulties to reach them. Some of them are: Association of Parents of Children and Adults in Autistic Spectrum (URDAS) in Sarajevo; Association of Parents of Children and Adults with Autism (URDOSA) in Tuzla; and "Djeca Svjetlosti" in Banja Luka. These associations are very important for parents since it is often extremely difficult for them to handle the situation on their own (Delfos, 2010, p. 24).

I worked in association URDAS that has been mentioned above. I worked there for one year as a speech therapist and I had parents coming every day bringing their children for a session hour. During this period they would have time for themselves, where they could go and have a coffee with their friends, have a haircut, do some work they needed to do and some other things that they usually couldn't do when they were taking care of their children. This was really important to them, to have a place where they can bring their children and leave them to someone who will take proper care of them, work with them, love them and be in a secure space without worrying that something might happen while they're gone. Unfortunately, that would last for only 1-2 hours per week and they would have to go back to their reality which in most of the times is not that easy to bear. Sometimes they would stay longer after they came to pick up their children and we would have a coffee. During that time, they used to tell me how hard it is to cope with a daily life and how big the struggle is since there are a lot of holes in the system which makes it harder for them to manage everything on their own. They have to go through many stressful situations every day. Just going to the city for a

coffee can turn into a night mare. If a parent chooses, for example other way than the one they usually go to when they are on their way to the city it can break up a child's routine where he/she starts a tantrum. Since their physical appearance is not different from children without developmental problems people often judge a parent in this case. They usually say to parents to make them stop and how they didn't teach them how to behave "properly". Then besides trying to calm their child they also have to explain to people around that their child actually has autism. This is very exhausting and stressful for them and they have to go through this every day, sometimes even many times a day.

These are some of the main reasons why I was truly motivated to do this research about parents' experiences and coping strategies they use in order to manage stressful situations. I couldn't just do nothing about it when hearing these heartbreaking stories almost every day. I believe it is very important that their stories are heard hoping that it will have at least minor effect to further changes in the system.

1.3. Rationale for the Study and Research problem

1.3.1. Rationale for the Study

There is little attention given to parents who have children with ASD in B&H. What do they experience or how do they cope with daily challenges. Not so many studies were found focusing on these issues in B&H. I believe that this is very important to investigate on so many levels, especially in a country with such a complicated infrastructure and obstacles such as poverty, mind set and so on.

I hope that this study will give a better insight to wider public on how is it to have a child with ASD and how parents are coping with the situation that has so many challenges. On the other

hand, it should give an insight to an actual situation from direct personal stories which can indicate certain changes in the dysfunctional existing system within B&H society.

1.3.2. Research Aim and Question

The aim of this study is to investigate how is it to be a parent of a child with ASD in B&H and what are parents' perspectives when it comes to coping strategies they use.

The main research question is: What kind of coping strategies parents use when having a child with ASD?

In the following sections theory that is relevant for this study will be discussed as well as significant research that has been done on the same topic: stress and coping theory and two family resilience models (Chapter 2); then the methodology part follows (Chapter 3); after which the findings are presented (Chapter 4); and finally discussion of the findings based on the theoretical framework and previous relevant research (Chapter 5).

2. Theoretical Framework/Literature review

2.1. Introduction

This section consists of two parts. First part is theoretical framework which uses stress and coping theory as basis for this study. It also includes Hill's ABCX model of family crisis and Double ABCX model as an upgraded version of aforementioned model. Theory is basis for the study and guide us to further examine the important issues we are studying. "[...] *it is used as a broad explanation for behavior and attitudes [...]*" (Creswell, 2014, p.64).

The second part is based on a literature review. Literature review helps us to place the knowledge on a relevant subjects that we are studying into retrospective. It is a critique of an existing knowledge and it helps reader to get an insight into a study (McMillan & Schumacher, 1997, p. 119). Furthermore, it helps reader see a bigger picture with other studies that are related to ours (Cooper, 2010; Marshall & Rossman, 2011; Creswell, 2014, p.28). It also helps us compare results with other research findings and creates an important basic framework for the study (p.28).

In the process of searching for the relevant literature I mostly used electronic library Oria at the University of Oslo where I found a lot of journals, articles, unpublished papers etc. I started searching with the key words that were connected with my topic. This way I found a lot of research, mostly recent ones that was similar to my topic. I managed to find more than 100 journals, articles and other relevant papers for my research. After that I read through all of them taking notes on the side that were very important for my study. Through the process of taking notes I made a selection of relevant papers in relation to my work and made a visual map which helped me later in the writing process a lot. In this way I could easily find what I needed and I had clearer picture for my study.

2.2. Family Stress and Coping Theory

Family stress and coping theory was chosen as a basis for this study. It explains its core concepts such as stress, appraisal and coping. It continues to discuss about theoretical models regarding family coping and adaptation beginning with the Hill's ABCX model to contemporary revised version of it into a Double ABCX model.

2.2.1. The Concept of Stress, Appraisal and Coping

In the following sections the concepts of stress, appraisal and coping shall be discussed in details. This will help to build a clearer picture for a reader in order to better comprehend the study in whole.

2.2.2. The Concept of Stress

The term "stress" goes all the way back to the 14th century which meant "[...] *hardship, straits, adversity, affliction*" (cf. Lumsden, 1981 as cited in Lazarus & Folkman, 1984, p.2). In late 17th century the "stress" and "strain" were used in physical sciences. "'Load" was defined as an external force; "stress" was the ratio of an internal force (created by load) to the area over which the force acted; and "strain" was the deformation or distortion of the object" (Hinkle, 1977 as cited in Lazarus & Folkman, 1984, p.2). In the 19th century they have started representing basics of the psychological health (p.2).

To further expand the meaning of stress we have to define some of the features that actually define the stress itself. According to Lazarus (1977; 1984), in order to understand stress we

cannot treat it as only one variable, but group of many variables and processes (p. 12). Most of the psychologists agreed that stress is actually a stimulus. Stress stimuli are mostly the events that strike a person. Stimuli can also be certain events that happen within a person such as hunger or the ones that happen on neurological level (p.12). Lazarus and Cohen (1977; 1984) talk about three types of stimuli which are: major changes that effect many people; major changes that effect one or few people; and changes that happen on daily basis (p. 12). Major changes that have a huge stressful effect on one or few people can be, for example, parents who are expecting a baby and due to some complications baby is born with severe complications.

The degree and equality of stress can also vary immensely and it mostly depends on predictability of an event or control that person has over it. For example, the distinction in the degree and equality of stress will vary drastically in a situation where a person loses the loved one in a car accident from the one where person is aware that is going to lose a loved one from an incurable illness (Lazarus & Folkman, 1984, p.13).

In biology, stress is usually defined as a response. If the response, whether of a person or an animal is emphasized it gives a feedback of a stressful acting. Although, we cannot define stress by a simple response, because then we cannot properly know what is stressor or what is not. The reaction is what we must await for. Many responses can be misunderstood as a psychological stress. For example, our heart rate will be a lot higher during a relaxed and pleasant exercise. Therefore, “the response cannot reliably be judged as a psychological stress reaction without reference to the stimulus” (Lazarus & Folkman, 1984, p.15). We can see the analogy between previously mentioned terms “stress” and “strain”, and stress stimuli and response, where “stress” is actually stress stimuli and “strain” is response (Lazarus, 1999, p.32).

We cannot just define stress through stress-response relationship, but we also have to consider person-environment relationship. When we are considering environmental stressful factors that affect people we must not exclude the personal characteristics which are equally important. For example, a person doesn't get sick because of the harmful factors from the environment, but because she/he is being vulnerable to those factors. Therefore, what can be

stressful for someone doesn't necessarily have to be for others (Lazarus & Folkman, 1984, p.17).

According to everything above mentioned we can say that: *“Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being”* (Lazarus & Folkman, 1984, p.19).

2.2.3. Cognitive Appraisal

Cognitive appraisal refers to cognitive evaluative processes that operates either consciously or subconsciously to determine to what extent particular situations between a person and environment are being stressful (Lazarus & Folkman, 1984, p. 19). As a noun “appraisal” usually refers to evaluative process, and as a verb, “appraising” is the action of that evaluation (Lazarus, 1999, p. 75).

There is a whole set of cognitive action that happen when something triggers it and it is *“[...] immediate and in-deliberate [...]”* (Lazarus, 1999, p.25). A good example that describes these chains of cognitive actions is a fire alarm. When we hear the alarm our initial reaction would be fear that is being automatically generated. If there is no need for panic then we have time to think about it and evaluate it more. We assess the situation further from the initial threat that happened in an instant that alarm went on. If we have more time we then engage into a more complex of a cognitive activity in order to finely adapt to new situations (Lazarus & Folkman, 1984, p. 26).

There are two types of appraisal: primary and secondary. Terminologically speaking the distinction is not that one is primary in a way that is more significant than the other, but they are both as important and intertwined (Lazarus & Folkman, 1984, p. 31).

“Primary appraising has to do with whether or not what is happening is relevant to one’s values, goal commitments, beliefs about self and world, situational intentions” (Lazarus, 1999, p. 75). We have three distinguishing types of primary appraisal: irrelevant, benign-positive, and stressful. When something happens in the environment that has no effect on our well-being whatsoever we call it “irrelevant”. For example, if we shout at the dog it will react with opening it’s eyes and moving it’s ears. If we continue doing that and nothing actually happens after we shout, the reaction of a dog will fade away and eventually will no longer react to shouting. It similar applies to people. We can in great dispense discriminate what is being relevant and what not. So the cognitive appraising will appear only when we have interest or necessity for something (Lazarus & Folkman, 1984, p. 32).

Benign-positive appraisals are the ones that occur when a certain event in an environment results in positive emotions such as happiness, joy, love and so on. On the other hand, there are some benign-positive appraisals that lack apprehension, but rarely occurs. This refers to people who think that if they enjoy happy moments will suffer later so the moments turn into anxiety or guilt. Therefore, appraisals are mixed and complex and depend on individual factors as well as environmental context (Lazarus & Folkman, 1984, p. 32).

“Stress appraisals include harm/loss, threat, and challenge” (Lazarus & Folkman, 1984, p. 32). Harm/loss refers to something bad that has already happened. Threat is something bad that potentially could happen in a future. Challenge is when some people put themselves against certain obstacles in order to struggle with what is about to happen (Lazarus & Folkman, 1984, p. 32).

Secondary appraisal is basically *“[...] a cognitive-evaluative process that is focused on what can be done about stressful person-environment relationship, especially when there has been a primary appraisal of harm, threat, or challenge” (Lazarus, 1999, p. 75).* Secondary appraisal naturally follows the primary appraisal and raises the questions such as “what can be done about the stressful situation?”, in other words it searches for adequate coping options. It may seem that secondary appraisal is the same as coping, but they are not. In fact, secondary appraisal triggers and stimulates the coping process. On the other hand, it is hard to distinguish empirically, because both threat and challenge are something that could happen in

the future. Therefore, there is a constant feeling of uncertainty and we actually don't know what will happen (Lazarus, 1999, p. 77).

Sometimes initial appraisals can be changed due to different factors of person-environment relationship. These changes are called reappraisals. For example, if we are having a stressful argument with another person, we cannot always predict how she/he will react to our anger, sorrow or aggression and vice versa. This is when reappraisals occur, when such uncertain situations reappraises new cognitive evaluation of the same situation (Lazarus & Folkman, 1984, p. 38).

Now that we have cleared a little bit about the relevant concepts of the stress theory we can go further in depth with concept of coping which is the crucial factor in directing the later discussion with research findings.

2.2.4. The Concept of Coping

As it was already mentioned in previous texts coping is “[...] *constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person*” (Lazarus & Folkman, 1984, p.141). This definition is derived from a process-oriented approach which was introduced as a transactional model in the late '70s contrasting a trait-oriented approach which was then abandoned (Lazarus, 1993, p.235). The definition implicates that we constantly engage into cognitive processes of appraisals and reappraisals in order to find the best coping options possible for the specific stressful encounter.

The reason that trait-oriented approach was abandoned is because it had so many limitations. One of the most important ones was that it views coping as two completely different opposing styles such as repression versus sensitization. This means that it oversimplifies all those coping thoughts, strategies and action that happen during the stressful encounters (Lazarus,

1999, p. 108). It actually rather puts an accent on stability than a change (Zeidner & Endler, 1996, p.133). Unlike process-oriented approach which actually takes into account both psychological and environmental stressors in specific encounter situations (Folkman et al., 1986, p. 992). Process-oriented approach is more focused on “[...] *what a person actually thinks or does, in contrast what the person usually does, would do or should do, which is the concern of the trait approach*” (Lazarus & Folkman, 1984, p.142). So trait approach is focused on what person usually or automatically does in stressful situations not taking into consideration the process of coping itself and how it unfolds due to different factors in person-environment stressful situations.

There are two main functions of coping: problem-focused coping and emotion-focused coping. Problem-focused coping is basically focused on changing the person-environment relation that is causing the distress. Emotion-focused coping focuses on managing the stressful emotions (Folkman et al., 1986, p. 993). Usually, problem-focused coping is used in stressful encounters that are changeable and emotion-focused coping occur when the stressful encounters cannot be changed such as a loss of a loved one (Lazarus & Folkman, 1984, p.150).

Problem-focused coping uses similar strategies as in problem solving. It focuses on identifying the problem, searching for the best options for solutions, choosing the best ones and finally acting upon the problem. For example, students usually stress before exams. In order to reduce the stress we should organize our time and start preparing ourselves a lot before exams takes place. There are two major groups of problem-focused strategies suggested by Khan et al. (1964). One group of strategies is directed at altering and solving problems related to environmental pressure, obstacles, and resources and so on. The other group is directed to oneself and changes on motivational or cognitive level which can be related to changes in ego, aspiration, behavior, learning new skills etc. The second group that is directed toward the self is not really to be called problem-solving techniques, even though it is focused on solving a problem. These inward-directed strategies suggested by Khan et al. are called “cognitive reappraisals” by Lazarus and Folkman which are problem focused (1984, p.152-153).

Emotion-focused strategies are directed on reducing emotional distress and they include minimization, avoidance, selective attention, distancing, wresting positive value from negative events and positive comparisons. Some of these strategies are actively used to produce a positive change even though they are not changing situation objectively. These are almost the same as reappraisals (Lazarus & Folkman, 1984, p.151). For example, if a person makes a really bad joke that insults us in a way we might act angry at first, but when we reevaluate the situation and reinterpret it we might just think “I have more important things to do then wasting my time on that stupid joke”. *“Some emotion-focused responses involve denial, others involve positive reinterpretation of events, and still others involve the seeking out of social support”* (Carver et al., 1989, p. 268). Some people when they lose loved ones for a quite while deny the situation and the process of grieving and refuse to acknowledge it which results in self-deception or distortion of reality (Lazarus & Folkman, 1984, p.151). On the other hand there are people who in similar situations seek for social help immediately. As long as grieving doesn't last for a very long time and becomes the only thing in our lives it can be good for a person until they feel better to move on.

Both problem and emotion-focused coping strategies can be used for the same stressful situation where they can either help to reduce stress or making a completely opposite effect (Lazarus & Folkman, 1984, p.153). For example, if a student is about to have a public presentation in a very important subject and anxiety grows as he/she knows he/she is next soon, focusing on the presentation itself reduces the emotional distress. On the other hand, if a person has to make a big decision and instead of focusing on the problem that will help him/her decide he/she starts having a selective forgetting, selective inattention, wishful thinking that he hadn't been in that situation and so on. Trying to use emotional directed strategy actually interfered with problem directed coping (p.153-154).

Even though problem-focused approach seems to be more effective and practical when it comes to stressful encounters this is not always the case. If a person is grieving, using problem-focused coping might not be the best idea. We cannot really plan and solve grieving. Therefore, emotion-focused strategy is much better in this case where a person actually expresses his/her loss, acknowledges the situation and go through this process with help of

her/his friends or social support until they feel better. Then, problem-focused strategy can be used to start planning further in life (Bartram & Gardner, 2008, p.229).

2.3. Family Stress Models

2.3.1. Hill's ABCX Model

In 1930, during the Great Depression Reuben Hill started his research on how people coped with the huge economic and other losses that came along within this period. He found out that some adapted much better than others (Boss, 2002; Wilmoth & Smyser, 2009, p. 155). After that he developed a family crisis model that was a product of studying families that were under stress because of the father/husband absence in World War II. This model was named ABCX model (p.155).

ABCX model was a foundation for further research on family stress and family resilience models. It was a bit modified in 1958, but stayed the prototype for all upcoming and upgraded family resilience models in the future (Burr, 1973/1982; McCubbin & Patterson, 1982; VanBreda, 2001, p.64). The model helps to understand why some families are driven into crisis and others successfully cope. The interaction between three variables A,B,C are contributing to a final product X (Boss, 2002; Wilmoth & Smyser, 2009, p. 155 - 156).

According to McCubbin & Patterson (1983b) the A factor refers to a stressor which is a certain life event such as death or having a child that has an impact on the family unit and either produces or had the potential to produce the change within the family (VanBreda, 2001, p.65).

The B factor refers to resources that are available within the family. These resources are important in preventing the stressful event and the crisis in the end (McCubbin & Patterson, 1982; 1983b; VanBreda, 2001, p.67). Resources help families to develop needed coping strategies in order to prevent the crisis. The three main sources of resources that are used are

actual members of the family, wider family and social support (Wilmoth & Smyser, 2009, p.156).

The C factor represents a family definition of an occurring stressful event. This refers to family perceptions of the stressful event and how they define it interacting with each other (Boss, 2002; Patterson & Garwick, 2003; Wilmoth & Smyser, 2009, p.157). The definition that a family comes up with depends on three factors “[...] *the family’s value system, previous definitions used, and previous experiences used in handling the crisis*” (Hill, 1958; Wilmoth & Smyser, 2009, p.157).

The X factor represents family crisis that refers to some kind of a disruption in the family or when the family homeostasis is misbalanced. More misbalance within the family occurs the bigger crisis will occur (VanBreda, 2001, p.67).

In the Figure 1. it is more visual how this model works. If a family defines the existing problem in a manageable way and uses all available resources to reduce or eliminate the problem then the family shall probably avoid the crisis. On contrary, if there is misbalance in the family when making the definitions and using existing resources then the crisis is inevitable.

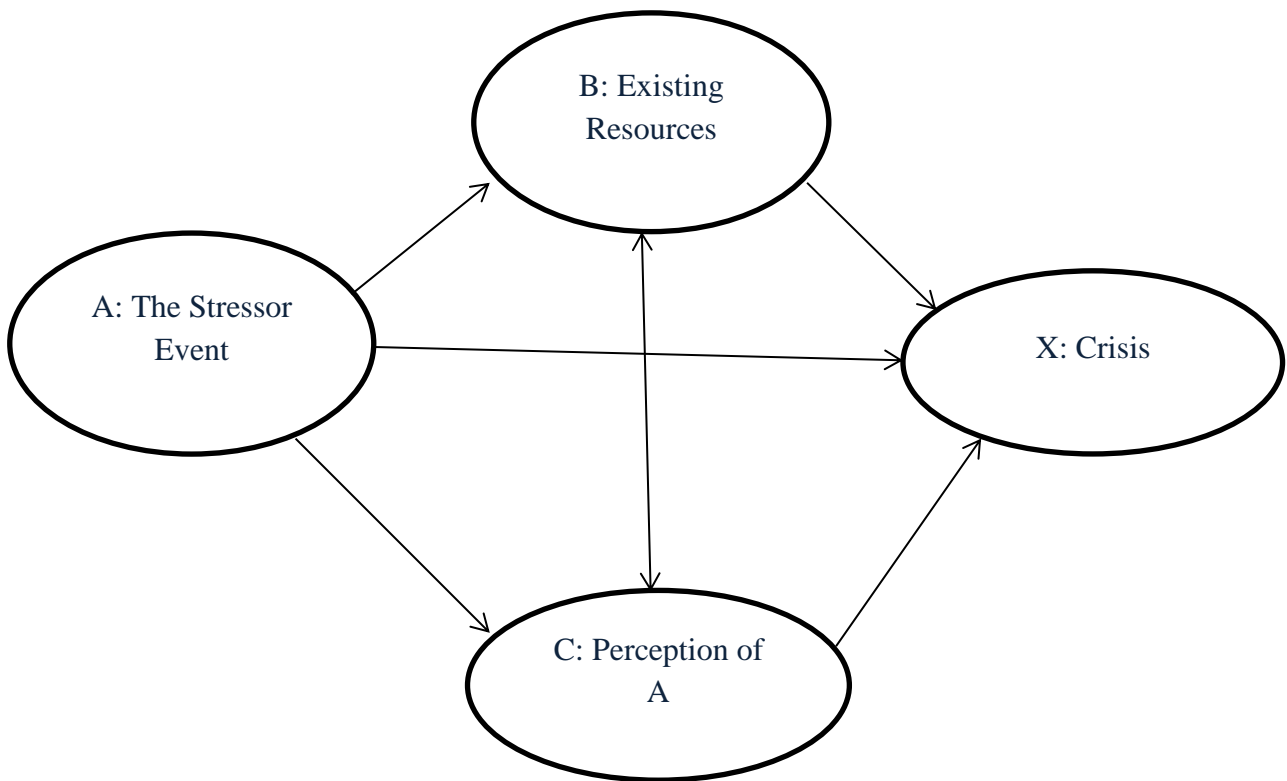


Figure 1. ABCX Model (Hill, 1949).

2.3.2. Double ABCX Model

As it was said in the beginning ABCX model was a basis for further resilience models that were developed later on. In analyzing ABCX model, McCubbin and Patterson found that the existing model had some limitations and had to be revised in order to incorporate new relevant factors. So they developed a new model that was named Double ABCX model (M.A.

McCubbin & McCubbin, 1996, pp. 6-7; VanBreda, 2001, p.95). They added five new factors: aA, bB, cC, xX and coping patterns (M.A. McCubbin & McCubbin, 1996; VanBreda, 2001, p.96).

The reason they incorporated an aA factor was because it is rare that during the crisis families encounter only one stressor, but rather they experience pile up of stressors and demands that come up on a way when coping (McCubin & Patterson, 1983, p.11). For example, initial stressor can be if a wife suddenly lost a husband and apart from trying to cope with this stressful event she has other demands that pile up in the process of coping such as doubling her role as a mother (p.11).

The bB factor refers to adding new resources to the initial use of resources that family used in order to overcome the crisis. These resources can be on individual, family or community level. One of the most important ones that families usually use is social support to prevent potential crisis in the future or prepare to cope successfully (VanBreda, 2001, p.98).

Another factor cC about defining and meaning of crisis was added to Double ABCX model. The reason for that was because it was limiting that family only defines the stressor and the whole situation that stressor is affecting. There is necessity to include new demands as well as new resources into defining the stressful situation in order to come up with a good plan what to do next and how to cope (VanBreda, 2001, p.98).

In Hill's ABCX model X is actually the outcome of the stress which can be distributed on a continuum ranging from maladaptive negative end to bonadaptive positive end. In which direction will outcome go it depends on family demands resources and definitions of an event that family come up with itself as well as the interaction of the event (Wilmoth & Smyser, 2009, p.158). McCubin & Patterson wanted to highlight the balance between the demands regarding member to family fit and family to community fit. This is why they added xX factor (VanBreda, 2001, p.99). Balancing the both levels member to family fit and family to community fit will result in placing a family on the bonadaptive positive end of the continuum and having this imbalance will result in ending on the maladaptive end (McCubbin & Patterson, 1983a; VanBreda, 2001, p.100).

In the Figure 2. Double ABCX model is more visually represented. Compared to the original ABCX model this model is more complexed in the way that includes new stressors and new resources that new stressful situation brought up itself. Having this in mind it helps family plan better to overcome the potential crisis.

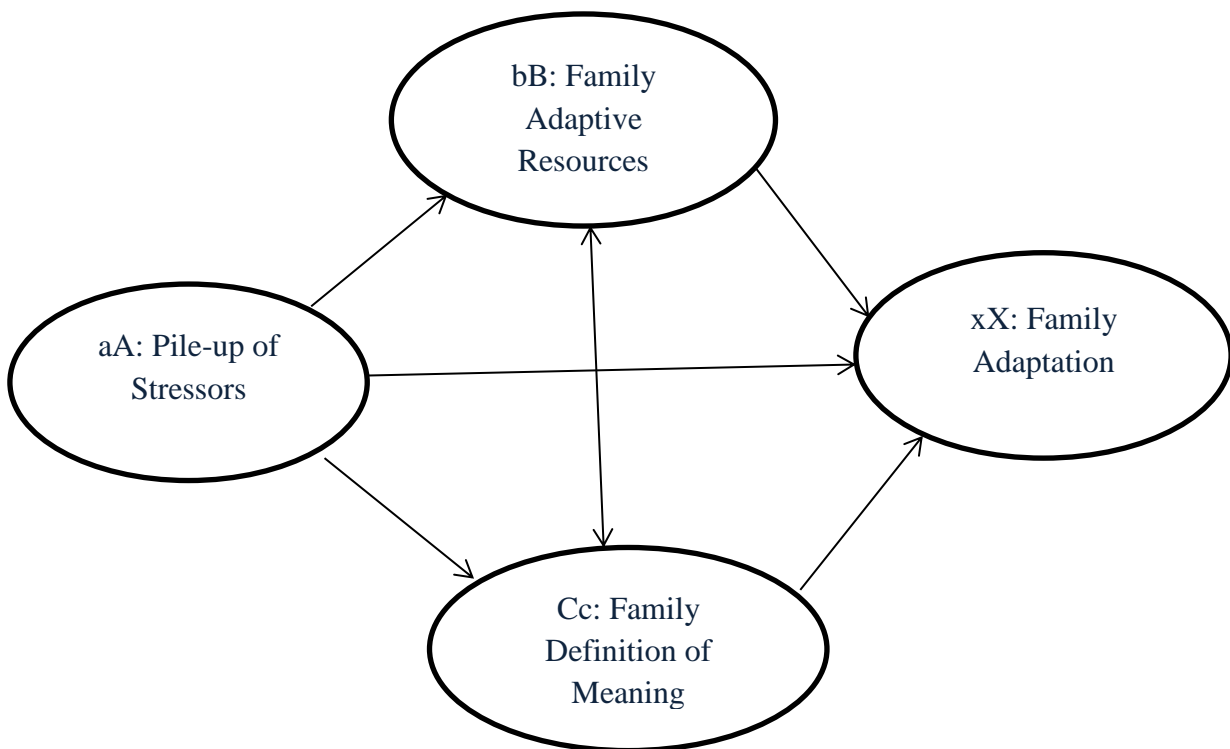


Figure 2. Double ABCX Model (McCubbin & Patterson, 1983).

2.4. Literature Review

It has been widely recognized that parents of children with ASD show high level of family stress (Schieve et al., 2007; Kahana et al., 2015, p. 153). This is due to different internal and external factors that parents face such as getting the diagnosis in the first place, adjusting to a child, getting involved into therapeutic and educational services or using different kinds of resources for therapeutically purposes (McGee, 2001; Twoy et al., 2007, pp.252-253).

When it comes to diagnosis of ASD, it appears that there is a greater uncertainty regarding a child's future for parents of children with ASD than for example, for parents of children with Down syndrome. This is because the diagnosis of Down syndrome is made right after birth and it's based on the genetic test so parents can already start the adaptation process. On the other hand, diagnosis of ASD is usually delayed and procedure is based on behavioral aspects which leaves parents to question it whether is "correct" or not (Lord & Rissi, 2000; Abbeduto et al., 2004, p.239). Furthermore, research regarding autism is relatively new which results in a greater worry for the future of the child compared to parents of children with Down syndrome (Seltzer et al., 2000; Abbeduto et al., 2004, p.239).

A certain amount of research has shown another stressor that increases parental-related stress and is connected to a child's behavior. For example, one research focused on an impact of a child's behavior on parental-related stress and psychological distress in mothers of toddlers with ASD compared with mothers of toddlers with developmental delays (DD). Results showed that mothers of toddlers with ASD expressed higher parental-related stress and psychological distress regarding child's behavior than parents of children with DD which is consistent to prior research. The reason for this is probably because previous findings indicate higher potential of behavioral problems in children with ASD than other groups (Estes et al., 2012, pp.136-137). On the other hand, some research indicated elevated stress in mothers of children with ASD regarding sociability rather than behavioral aspects of a child. This was the case in Allen et al. (2013) research on mothers' and fathers' stress related to parenting a child with ASD. This study showed that mothers perceived stress only for the dimension of

sociability which is inconsistent to previous findings. This might be due to an age of a child where such a behaviors are not perceived as stressful, but might be stressful to parents with older children (p.7).

Among many stressful factors, parents of children with ASD must deal with complex care services which are often slow with diagnostic procedures and have access impediments for treatment. The core problem is insufficient communication among doctors and educators who work in educational system with limited resources (Exkorn, 2005; Shapiro, 1993; Kahana, 2015, p. 154). On the other hand, families of children with ASD often experience social stigma. Even from their own communities as well as from other members of the family who cannot understand and accept a child's behavior (Sicile-Kira, 2004; Kahana, 2015, p. 155). Financial problems are more likely to appear in parents with ASD than in parents with typically developing children. This is due to medical expenses and work loss (Hecimovic & Gregory, 2005; Parish et al., 2004; Brereton, 2009, p.1). Having a child with ASD is demanding and requires a lot more care than for typical children. For this reason, one of the parents is usually not working and is dedicated to the child which effects family income in a negative way (Kahana, 2015, p. 155). For example, in Abbeduto et al. (2004) research was shown that mothers of children with ASD, X Fragile syndrome and Down syndrome tend to be more depressed when they have lower family income (p.248).

Parents support groups (PSG) can be quite useful in a way that help them cope better. According to Clifford&Minnes's (2012) research a group of parents who were participating in PGSs stated that they were beneficial for them and helped them use more adaptive coping strategies, unlike the group of parents who used PGS in the past who claimed that it didn't helped them much. There were another group of parents who was being indiferential in their opinions, because they have never participated in PGS. They claimed that the reason for that was lack of child care and the timing was not good. It was suggested that the group of parents who participated in the past and didn't find them beneficial was because PGSs were focusing on giving information and teaching instead of offering the emotional support (p.183). Apart from social support, studies have shown that informal support can be more effective for parents of children with ASD than formal one (Boyd, 2002; Bristol & Schopler, 1983; Kahana et al., 2015, p.158). In their research, Kahana et al. (2015) emphasizes the important role of other family members in the coping process. One of the extremely valuable human resources

that they found to be very effective in supporting parents of children with ASD are grandparents. They can be of a great help when it comes to balancing the work and family tasks together (p.159). For example, grandparents have more free time that can use on spending time with their grandchild while parents can use that time for work or other things such as participating in trainings that could help them work on improvement on their interaction with a child. Some of these trainings for parents showed to improve the behavioral treatments of a child (Schreibman, 2000; Brereton, 2009, p. 2).

Using avoidant emotion-focused strategies is usually associated with increase of stress (Folkman & Lazarus, 1998; Pisula & Kossakowska, 2010, p.1491). Pisula and Kossakowska's (2010) found in their study on Sense of Coherence (SOC) and coping in parents of children with ASD that relationship between SOC and coping strategy for accepting responsibility was negatively correlated. This coping strategy is characterized similar to distancing, escape-avoidance and self-controlling strategies where cognitive and emotional efforts are made, but situation stays unchanged. This is typical emotion -focused strategy that usually enhances stressful encounter even more and can lead to depression (p.1491). In one research (Abbeduto et al., 2004) on coping of mothers of children with ASD, X Fragile syndrome and Down syndrome was shown that mothers who mostly used emotion-focused coping strategies rather than problem focused ones showed higher levels of pessimism. Also, mothers who mostly used problem-focused strategies usually perceived reciprocal closeness from their daughter or son (p. 248). One of the rare studies (Seymour et al., 2013) that examined maternal fatigue in parents with children with ASD regarding their behavior problems showed association with increased maladaptive coping strategies they use such as self-blame and denial. Generally, this rather gives negative results in managing stress than other coping strategies such as acceptance or planning (Benson, 2010; Hastings et al., 2005; pp.1552-1553).

3. Methodology

The purpose of this study is to examine lived experiences of parents with children with ASD and the coping strategies they use. The focus of this chapter will be on sections which is to (1) describe the research methodology of this study, (2) describe selection of the sample, (3) explain the procedure of designing the instrument and method to collect data, (4) describe how data was analyzed, (5) describe the ethical considerations, (6) discuss validity and reliability, and (7) limitation to the study.

3.1. Research Design

In order to get in-depth information about parents' perspectives and experiences on having a child with ASD in Bosnia and Herzegovina and to find out what are the coping strategies they use in daily life a qualitative research seemed a natural choice for this study.

According to Creswell (1998):

“Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting” (p.15).

Qualitative researchers thus are interested more in the process of the research rather than the outcome itself which is common for quantitative research such as surveys and experiments

which are limiting in this sense. Qualitative researchers are focused on interpreting the meanings that participants give to their experiences (Maxwell, 2013, p.30).

Maxwell (2013) explains the differences between qualitative and quantitative research as “[...] quantitative researchers tend to be interested in whether and to what extent variance in x causes variance in y . Qualitative researchers, on the other hand, tend to ask how x plays a role in causing y , what the process is that connects x and y ” (p.31). What is really good about the qualitative research is that is flexible and open to modification during the research process. It allows a researcher to discover something new (p.30).

Within this qualitative research I also decided that phenomenological approach would be the best to use in my case since the focus is on the lived experiences of parents with children with ASD and the meaning they give to these experiences. Phenomenology is based on philosophical movement from which some research approaches emerged. Husserl was the first who initiated it as a philosophical movement and later on Heidegger moved away from it and started focusing more on existential and hermeneutic elaborations (Finaly, 2009; Kafle, 2011, p.181). In phenomenological research the researcher uses participants’ lived experiences to describe the studied phenomenon that is related to the participants (Giorgi, 2009; Moustakas, 1994 as cited in Creswell, 2014, p. 14). According to Van Manen (1990): “[...] phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world” (p.9).

Since there are two types of phenomenology, both descriptive and interpretative. I chose the interpretative one which is often called “hermeneutics”. According to Kafle (2011): “Hermeneutic phenomenology is focused on subjective experience of individuals and groups. It is an attempt to unveil the world as experienced by the subject through their life world stories” (186).

This approach argues that everything is in a one way interpretive “... *and the description itself is an interpretive process*” (Kafle, 2011, p.187).

3.2. Sampling procedures and Participants

In the following sections the sampling procedures shall be discussed as a very important part of the methodology. Also, reader shall get more insight into participant’s backgrounds. Of course, keeping the anonymity of each participant at the same time.

3.2.1. Sample

Sample means “[...] *to be able to obtain data from a smaller group or subset of the total population in such a way that the knowledge gained is representative of the total population (however defined) under study [...]*” (Cohen et al., 2000, p. 92). The sample that I chose for my study is a non-probability sample which is mostly used in qualitative research. Non-probability samples are used in small researches where a researcher is targeting a specific group knowing that it doesn’t represent the population, but itself and where a researcher’s goal is not to generalize the findings (Cohen et al., 2000, p. 102). “*In non-probability sampling, individuals are not selected by chance, but by some other means*” (Gall et al., 2007, p.174).

Within non-probability samples I used purposive sampling. “*In purposive sampling, researchers handpick the cases to be included in the sample on the basis of their judgement of their typicality. In this way, they build up a sample that is satisfactory to their specific needs*” (Cohen et al., 2000, p.103). The way I picked up my sample was contacting the non-governmental organizations (NGO) for autism. I found them through the internet search. My

goal was to find parents from 4 bigger cities in B&H in order to cover both entities: RS and FB&H. The reason I chose both entities, which I already explained in the introduction, is regarding the legislative differences within these two. Each city that I needed for my research had at least one NGO that was for parents of children with ASD. I contacted them and specified my request for participants. I told them the profile of participants that I needed for

my research which was parents who had a child with autism. Also, it was important for me that there were communicative and willing to participate.

Criteria at first was:

- Geographical – parents from both entities will be interviewed
- Age of the child – 7 to 15 years old
- Child's diagnosis – disharmonic developmental disorder with elements of autism
- Marital status - parents are married and live together

These criteria hasn't changed much during the process of data collection. Geographical area of participants which was to have them from both entities stayed the same. Reason for choosing participants from both entities was because political situation is different even though they are within the same country. Also, the laws are implemented differently in each of them. For example, according to the Organization for Security and Co-operation in Europe - OSCE publication "Right for Social Welfare in Bosnia and Herzegovina", in one of the entities, RS social welfare for children with disabilities is only 41KM. On the other hand, in the other entity, FB&H is much more, around 400KM (2012, p.39).

On the other hand, diagnosis criteria changed a little bit in a way that it only had different names for the same diagnosis practically. The reason for this is because the diagnostic system is not very well developed in Bosnia and Herzegovina.

The criteria for the child has also changed from 7 to 18, since there was difficult to find parents who had younger kids in city of Mostar, because the department for autism they have is mostly with older children.

The criteria for marital status had to be changed, since I managed to find only one parent in city of Mostar that was willing to participate. She is a widowed single mother. All other

participants are married. The reason I set this criteria was the intention to interview both parents and get both perspectives and to compare them, but in the end it turned out it wasn't an easy task to do. For example, even if this mother still had her partner alive it would be hard to interview both parents. Reason for this is that during some interviews participants were stating that they didn't really have enough support from their partners and don't really like to be "exposed" with this label for their children publicly. So, instead of having both of parents I chose one parent from each bigger city in Bosnia and Herzegovina; Mostar, Banja Luka, Sarajevo and Tuzla.

3.2.2. Participants

This study included 4 participants from four bigger cities in B&H. One city, Banja Luka from entity of RS and the other three Mostar, Sarajevo and Tuzla from entity of FB&H. There were 3 mothers and 1 father of children with ASD. 3 of them are married and 1 parent is a widow. All parents are employed. Respondent 1 is a single mother from Mostar and has a 17 years old son with ASD. Respondent 2 is from Banja Luka and has a 7 year old boy with ASD. Respondent 3 is from Sarajevo and has two 7 year old boys who are twins and both with ASD. Respondent 4 is from Tuzla and has a 8 year old son with ASD. During the writing process, the name of parents and children were changed into fictive names. Respondent 1 is Alma; respondent 2 is Aleksandra; respondent 3 is Irma; and respondent 4 is Ibrahim. Alma's

son is Dino; Aleksandra's son is Dejan; Irma's twins are Amir and Sanjin; and Ibrahim's son is Mahir.

3.3. Instrumentation and data collection

Before starting with the study I received the confirmation letter from the University of Oslo that I had a permission to conduct the study. Also, I received a permission from NSD (National Social Science Data Service) for ethical considerations that my study shall not reveal any sensitive information about the participants either directly or indirectly. Informants were giving information both orally and in a written form. As I contacted each participant on the phone first, I explained in details what the study was about and that it was voluntary. After they received the information about the study and agreed for the participation we set up the meeting. Before starting the interview right away I gave them the consent paper to carefully read through and sign it. Our meetings were held in some of the NGO's offices where we could have a peaceful environment without distractions. Only one interview was held in one café bar. The bar was almost empty and we had a quite space for ourselves. A parent suggested to have an interview there, because we didn't really have alternatives in this case.

Instrument that was used for this study was qualitative semi-structured interviews. Since I used phenomenological approach I adapted my interview guide to this method. *"This kind of interview seeks to obtain descriptions of the interviewees' lived world with respect to interpretation of the meaning of the described phenomena"* (Kvale & Brinkman, 2009, p.27). As they describe, interview guide should be focusing on specific themes that might include suggested questions. After being transcribed, material is ready for meaning analysis (p.27).

First, I constructed the interview guide with the themes relevant for my research question and some sub-questions that I thought would be a backup and help get more information. Then after having a pilot study I also developed some new sub-questions. All the interviews were

audio-recorded. Sub-questions I only used if a person wasn't talking too much so to help to get the information I needed. Or if they wondered of the topic so I used these sub-questions to get them "back on the track" and direct them towards the specific theme. Otherwise, I wouldn't use them and let a person talk as much as possible to the relevant topic.

3.3.1. Developing Interview Guide

The questions I used in the interview guide were open-ended questions in order to get as much as information from participants as possible. "*The research interview proceeds rather like a normal conversation but has a specific purpose and structure: It is characterized by a systematic form of questioning*" (Kvale, 1996, p.132). The questions were made as themes related to the main research question. I also develop some sub-questions in case interviewees needed more direction and guidance during the interview sessions.

The interviews were usually conducted in an office of an organization where we had a quiet time without any disturbances. Only one interview was conducted in a café bar which was also very quiet and we were quite isolated from other people.

Before starting the formal part of interview I preferred to get to know parents a bit first, at least for 5 minutes in order to make them feel relaxed and comfortable. This was very important to me so they tell their stories in a non-stressful environment. "*It is normally best for the interviewer to open with a question which the interviewee can answer easily and without potential embarrassment or distress*" (Cassell & Symon, 2004, p. 17).

During the interview we didn't have any difficulties understanding each other. They understood most of the questions smoothly and gave rich full answers. Only one parent from time to time used to wonder off the topic, but I directed him back. This is normal when there is so much to say. The sub-questions in this case were very useful.

3.3.2. Pilot Study

Before starting with the main study I tested the interview guide and some sub-questions I have constructed with one mother whom I knew from before and I worked with her son who has ASD. This was very important to try and see if the interview guide needed to be revised before continuing with the study. The guide gave a lot of information and was satisfactory to a certain level, but after her feedback I also added some more sub-questions that I thought were necessary and relevant for the study. These sub-questions I wrote down and started using them for the actual participants. They helped to gain a lot more information and not just that, but also to motivate some respondents to tell me more information that otherwise wouldn't tell me by just asking the main questions. The reason I didn't use this mother I knew from before nor other parents for that matter is because of the potential bias. *“A pilot study involves small-scale testing of the procedures that you plan to use in the main study, and revising the procedures based on what the testing reveals” (Gall et al., 2007, p.56).*

3.4. Data Analysis

As it was already mentioned in the instrumentation and data collection part that I collected the data by audio-recording the interviews. After I had all data collected I started with the transcription. Since there were Bosnian speaking informants, I transcribed the material in Bosnian. Only the parts that I used in the data analysis were translated in English. I used thematic analysis for making the relevant themes out of the transcript. *“Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data (Braun & Clarke, 2006, p. 6).* I used thematic coding to analyze the data. *“Coding is followed by grouping the initial codes into a smaller number of themes” (Robson, 2011, p.474).* *“In qualitative research, [...], the goal of coding is not to produce the counts of things but “fracture” [...] (Strauss, 1987, p.29) [...]the data and rearrange it into categories that*

facilitate comparison between things in the same category and between categories”
(Maxwell, 2008, p.237).

First we identify the phenomenon which we are studying and then we collect data from the people who are related to this study with their experiences. After we have done that we analyze the data by identifying important segments from the data and forming them into themes. The next step is to develop “[...] *a textural description of the experiences of the persons (what participants experienced), a structural description of their experiences (how they experienced it in terms of the conditions, situations, or context), and a combination of the textural and structural descriptions to convey an overall essence of the experience*” (Creswell, 2007, p. 60).

First, I read the text once. Then I read it for the second time with underlining important words (themes) that were repeated in all four interviews. After that I read through it again and made some notes on the side. This gave me a lot bigger picture than I had it before. After I isolated some codes that were important for the data I started to combine them into themes. Now I could see which were the important themes for the study that were connecting all the participants. I identified 8 themes and 4 sub-themes. Here are the following 8 themes: dealing with the diagnosis; self-help strategies; financial security; family support; support among parents; getting help from provided services; coping with fear and worries; and coping with social attitudes. There are also 4 sub-themes which are: acceptance; trying everything to help a child; motivation for moving forward; and coping together with a spouse. I made the matrix for the themes and sub-themes where I used quotations from the interviews to justify them. After that, I summed up and described each of them separately.

3.5. Ethical considerations

As it was mentioned in instrumentation part, I received a permission from NSD (National Social Science Data Service) for ethical considerations where my study shall not reveal

sensitive information about the participants. Participants in this study were given assurances of anonymity and confidentiality about the study both orally and in the written form. First, they were contacted by the phone where I explained everything about the study: gave them information that study is anonymous and will not reveal their identities at any point; explained what I was expecting of them; asked them what were they expecting from me; what time and place suited them the most to meet; and that they could withdraw from the study at any time if they felt like doing that. All this was also given in the written informed consent which both of us voluntarily signed. According to McMillan & Schumacher (1997):

“Informing participants is done in a manner to encourage free choice of participation. The time required for participation and the non interfering, nonjudgmental research role is explained. Usually interview time and places are selected by the informants. Because researchers attempt to establish trusting relationships, they need to plan how to handle the dialogue. Most participants detect and reject insincerity and manipulation” (pp. 419-420).

In this study, participants were given fictional names as well as their children. In this way the information about the participants is not identifiable to the public.

3.6. Validity and Reliability

Validity and reliability are important components of every research. According to Maxwell (2013), in qualitative research it refers “[...] to the correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account” (p. 122). In order to ensure validity, which is in qualitative research often called “trustworthiness” there are some criteria that must be full-filled. This includes: credibility, transferability, dependability, and confirmability (Lincon & Guba, 1985; Morse et al., 2002, p.5).

Credibility corresponds to internal validity within positivist’s research and is one of the most important measures in qualitative research. In qualitative research it measures how actually findings are matching the reality (Shenton, 2003, p. 64). In order to avoid missing a certain amount of information from participants I recorded the interviews. One of the validity threats in qualitative research is “reactivity”. This refers to influence of a researcher. Even though it is almost impossible to avoid it (Maxwell, 2013, pp. 124-125), I tried to minimize my interference during the interviews. To obtain as realistic as possible perspectives from participants I used open-ended questions without least interference and guiding questions, unless it was necessary which happened not that often. Before beginning with the interviews I used 5-10 minutes to have an informal talk with participants so they can feel more relaxed and comfortable with telling their stories which is important regarding the quality of the information they give. The space we used was a safe space where we could have an interview without any interruptions. In data analysis I went through the transcripts a several times to ensure the accuracy of the given information. There were no bigger challenges when it comes to transparency of the transcript content. As I mentioned I read it through a couple of times where I underlined very important words that all parents repeated through the interviews. In this way I isolated important codes and categories that helped me form themes. The only challenge that might be a validity threat is translation from Bosnian to English. I tried to translate exactly how they said it without losing the original meaning of the content. On the other hand, I used a rich data about the studied phenomenon from various sources. In this way the data was triangulated which means that it used “[...]different data sources of information

by examining evidence from the sources and using it to build up a coherent justification for themes” (Creswell, 2014, p. 201). It helps to reduce the researcher’s bias of a specific method and helps us to understand better what we are actually studying (Maxwell, 2013, p. 102). Besides all above mentioned, I also conducted the pilot study which verified the quality of the instrument to provide more in-depth information.

Within positivists research generalizability refers to applying the results of a certain study to a wider population (Shenton, 2004, p.69). In qualitative research this is called “transferability”. This means that the results within a qualitative research are specific for small groups and situations that are being studied and it’s impossible to generalize them to other populations and situations (p.69). I tried to provide a reader with a thick description about participants’ stories including a detailed description of contextual factors that are relevant to the study. This is very important for the reader to be able to compare the results from the study to those they’ve experienced (p.70).

Dependability correspond to reliability in quantitative inquiry which means that if the same study was repeated with same participants, same situations and same methods the results should be similar (Shenton, 2004, p.70). In order to increase dependability in qualitative research the procedures within a research should be addressed in detail so future researcher can be able to repeat the study (p.71). To secure that, I tried to write this research report in as much as details as possible.

Confirmability or objectivity of the study in qualitative research means that a researcher needs to make sure that the “*[...]findings are the result of the experiences and ideas of informants, rather than the characteristics and preferences of the researcher” (Shenton, 2004, p.72).* As it was mentioned before, I tried to minimize my interference during the interviews in order to avoid the bias in the study. Also, through analyzing the data I was being careful of the personal inference and tried to stay objective as much as possible. The data was also triangulated as mentioned before which maintained the confirmability of the study.

3.7. Limitation to the Study

One of the limitations of the study could be small number of participants. It would probably be more rich full if there were more participants with their stories and perspectives from different areas in B&H. This would give a bigger picture and more in depth data. The reason for not having more participants was because of the time limit and it was not easy to find participants who were willing to participate. Another limitation could be the language. Translating from Bosnian to English when analyzing the data could limit the exact meaning even though I tried to translate it in the best possible way.

Maybe for the future similar research in a wider perspective these limitations can be avoided in order to provide more rich full and in depth report.

4. Presentation of the Data

4.1. Introduction

Following findings contain descriptions of the main themes and sub-themes which were obtained through qualitative semi-structured interviews. Both main and sub-themes are closely connected with the coping theory which is the basic theoretical framework for this particular study. There are 8 themes and 4 sub-themes. 8 themes are: dealing with the diagnosis; self-help strategies; financial security; family support; support among parents; getting help from provided services; coping with fear and worries; and coping with social attitudes. 4 sub-themes are: acceptance; trying everything to help a child; motivation for moving forward; and coping together with the spouse. Each theme and sub-theme are being elaborated for better discussion that follows afterwards.

Real names of both participants and children were not used in this study. Instead, I used the fictional names such as Aleksandra for respondent 2, for example.

4.2. Theme 1 – Dealing with the Diagnosis

Based on the pattern from data-material and analysis this theme was one of the most relevant in the findings. This is mostly because it sets focus on the first steps in search for answers which brings a lot of stress and uncertainty. It also gives an insight to diagnostic procedures in B&H and how parents experienced it. It can be very stressful for parents when the system is dysfunctional regarding diagnostic procedures. When this is the case they often wonder around desperately searching for the answers. According to three of the respondents the

process of getting diagnosis and actually getting adequate one is not that easy. These respondents explained how it takes a quite some time to get the diagnosis.

Irma, a mother of twins with ASD says: *“Diagnostics here takes a long time, so we kind of shortened the way, since we had done everything in private clinics.”*

There is not that much difference in RS. Aleksandra who has a 7 years old boy with ASD says: *“I was trying for so long to get the diagnosis and also to find professional help, but it was going quite hard and slowly.”*

On the other hand, one respondent got the diagnosis while they were living in Germany which was not that slow, but she had similar experience like other parents when it comes to specifying diagnosis. Doctors in Germany gave the diagnosis back then to her now 17 years old son. The diagnosis back then was as she explains: *“[...] suspicion on mental retardation and “Autistische Züge” as it is called in German.”*

Often professionals hesitate to give specific diagnosis as Aleksandra says: *“So, it is not autism, it’s not pervasive, but disharmonic development with elements of pervasive developmental disorders.”*

Irma had similar experience when it comes to giving diagnosis to her children. Doctor who was on top when it comes to these diagnostic procedures approached to this process very non-professionally. As she continues: *“Diagnosis was “they are phenomenon to me” given by Dr. N who was the main character in diagnostic procedures. Later I found out that it referred to their diagnosis for autism, for autistic spectrum.”* After a while she got diagnosis for autistic spectrum disorders as she adds: *“Now, the situation is a bit better and they give diagnosis for autistic spectrum.”*

Ibrahim was also wondering for some time trying to find someone who will help him with founding the diagnosis for his 8 years old son. In the beginning he was desperately looking for help everywhere. He explained how he tried to get the answers from different kind of experts and even went abroad looking for answers. *“I even took him to Turkey to a neuropediatrician who is into hmmm. He was on Tibet and he is also for autism. I also took him to homeopathy in Belgium and the woman confirmed that is autism.”* After all these

searches for confirmation of the diagnosis he adds: *“But for these six years working with him if I didn’t even take him anywhere I read enough literature to know, so nobody needs to tell me anything.”*

As participants state, they wondered for quite a while before getting the diagnosis. This is due to dysfunctional system where we lack many resources in this field such as professionals, adequate and fast procedures, adequate treatment programs and so forth. More parents wonder more stress it brings along. Longer they wait for the diagnosis longer a child will stagnate. Longer a child stagnates more it affects the prognosis in a negative way regarding the treatment. This means that most of the therapies that give results are based on behavioral principals which means that teaches children new behaviors. So if a child has already automatized negative behavior, because he/she is late with the treatment it will be more difficult to change it with the desirable one. This all leads to accumulated stress that can potentially lead to burn-out.

4.2.1. Acceptance

It is not always easy to accept a new situation which brings a lot of stress and uncertainty. Period around getting the diagnosis brought the feeling of being helpless and lost in a way due to dysfunctional system in B&H. This sub-theme explains how parents accepted the situation after they children got the diagnosis. Acceptance is crucial in order to move on and actually work on getting things better. Ignorance of the situation could only make things worse and have long-term negative effects both for a child and a parent.

Alma shares her feelings about this period: *“And believe me, one long period I was helpless. You think how, what...I mean, I can see that this cannot go forever, that he cannot do the same thing all the time, because other things are regressing.”*

Aleksandra was hoping for some time that everything will be ok, that she was maybe exaggerating his problems and that this diagnosis will just disappear one day. “[...] *that one day we all will wake up, Dejan will speak, there will be no more diagnosis nor any problems.*” She continues: *“I think that through all that period I actually knew that my child had a problem and that is something that we must deal for the rest of our lives.”*

Ibrahim also says how he can never know with his son how he will behave and often encounter not that pleasant situations. He explains one of the many situations that he encounters on almost daily basis. *“And then they come and tell you that the flight is delayed, and when he screams you are all in hmm.... When we arrived there I lost my stomach. Luckily, he stops.”*

The most hurting thing for Irma was that her children between them didn't have any communication. She says: *“They didn't have any communication between each other what hurt me the most.”*

Even though this period around diagnosis was hard for all the respondents they accepted the situation quite fast as it is and in a good way. Alma accepted the fact soon as she realized that something was “wrong” although she had her hopes that these problems would just disappear. She says: *“As I have already accepted the fact that something is not right with him. I mean, relatively fast.”*

They said how important is to realize it as soon as possible and to start the fight like Ibrahim says: *“A child is a child. As soon as you have a child, you start a fight.”*

Irma explains how there was no time for being desperate, but fight. As she says: *“No matter what was written, we were aware that they had a problem and we had to work on it [...]. And what to do, I didn't have that phase of despair, crying, and being helpless, that was skipped. There is no time. What they say when parents have a problem with accepting diagnosis. Accept and work on it.”*

These parents realized quite fast that in order to move on they needed to accept the situation as it is and start the fight. There was no time to waste. They show positive attitudes regarding their situation which is very important in order to move in the positive direction. Although,

the fight is hard they show determination and enthusiasm on moving forward with helping their children in any possible way.

4.2.2. Trying Everything to Help a Child

This sub-theme is about the next step when parents already accepted the situation and desperately trying every possible option that is out there to help their children. Finding options to get their children better also brings more positive feelings within themselves which keep them going forward.

As Alma says: *“I even used to take him to some kind of a vitamin therapy...those were the after war years. In B&H everything was boom, everything interesting, everything new and acceptable and people are weak.”*

Aleksandra included Dejan in all possible activities that were offered. She says: *“Then she said: “Why did you even come here, you already have so many activities there? How are you managing? Why would you also have this therapy as well? I told her that I will do anything I can just to get some results. Give me anything possible, I will try everything.”*

Irma even made a classroom in her on home to secure the best possible therapy for her children. She says: *“[...] I have a classroom in my house [...]. I knitted half of the net so they don't lack absolutely anything, so they are settled intensively with everything.”*

Ibrahim's son even goes to a regular school now. As he says: *“Every day he has been included in treatments. Every day for 6 years now. And I included him into a healthy environment, in kindergarten and now he goes to school, a regular school.”*

Parents show a strong will and determination to help their children in every possible way. This strong determination and hard work lead to positive results for their children which in return has positive effect on parents as well. It is not easy to keep it up like that when the

system lacks so many resources they need in order to ensure best possible treatment for their children. This indicates resilience in parents which shows they cope rather good regardless of the difficulty of the situation.

4.3. Theme 2 – Self-help Strategies

This theme explains parents' attitudes toward the whole situation and how that affects their coping process. Usually when we put too much expectation onto a child or onto ourselves can be contra productive and lead to a frustration. The following gives an insight into their thoughts on self-help strategies.

Alma explained how it's not simple, but that she tries everything to help her child. She says: *"Not to expect too much from a child. Not to put too much pressure on him/her. Be realistic."* She continues: *"I would say that I handled all that pretty good. It is not simple for you, you wish it wasn't like that, but you are trying to help your child as much as you can."*

They all mostly have positive thoughts and attitudes. As Irma says: *"You have to learn to have strong nerves and patience, to come to the terms with repeating some things and to enjoy their world...It requires more energy, a lot more energy, more will, but as they take that energy from you they also give it back."*

Aleksandra says: *"I am trying not to think too much about the things that I cannot have influence on and that I cannot change. I am doing what I can in a certain moment to make situation better, to have it under control, because it is really important to me to keep it all together and all other things I just try not to think about. I think acceptance is the most important and then after that determined fight to work .Just work, fight and that's it."*

Ibrahim also has a positive attitude and adds: *“There is nothing to do, except fight [...] you have to work with a child and that is how it is.”*

According to all above mentioned, parents show positive and realistic attitudes about the whole situation which helps them keep it together. What is the most important is that they are very well aware of the situation which makes the coping process more successful.

4.3.1. Motivation for Moving Forward

In this sub-theme parents describe what keeps their motivation for moving forward. In order to be motivated to continue the fight we have to have a progress and things that we can hold on to, otherwise it can be quite frustrating to have a feeling of standing in one place all the time.

Ibrahim explains it so positively. He says: *“The most beautiful experience is that he is able to understand in a way. More you succeed the better you feel.”*

Alma was describing her experience with her child so happily and with enthusiasm. *“I say: “Where is the cat?” and in that moment Denis turned around and looked. So he was looking at the direction where the cat was standing. That was the first time when I realized that my child understood what I asked him. Wow, that was to me...that was the happiest moment in my life. So later on, somehow everything was OK. He understands that now, but that was a trigger. That motivated me so much.”*

Aleksandra says: *“And he really is progressing and developing a speech. And sometimes, really, maybe it is so lame to say, but I get a hope that his life will almost be normal, because sometimes he really communicates in a good way, especially when it comes to his needs.”*

Irma explains with optimism how she is working and progressing with her children. She says: *“Amir’s speech is much better. He already started to pose questions such as: “What are you doing mother?”; “What now?”; “What is happening?” and Sanjin sometimes says “Let me go”. We sit at the table and through real life situations practice looking at each others eyes.”*

As parents state, they find their motivation in some would call them a “little things”, but they are huge for them. It shows them that their fight is worth it and all the effort and dedication actually leads to progress. These “little things” give them hope and motivation to continue their journey in a positive direction and not to give up, but stay persistent and determined in their goals.

4.4. Theme 3 – Financial Security

One of the factors that can be extremely stressful is finances. This can impose so many limitations regarding the treatment, every day expenses, therapy equipment and other additional expenses when it comes to a child with ASD. This theme gives an insight into parents’ finances and how they handle situation from that perspective.

Aleksandra from RS receives a lot less than parents from FB&H. She says about the money she receives from social services: *“De facto we receive it on two grounds [...] assistance and care and mother’s add on. One is 80,80KM and the other one is 90KM.”* She adds: *“My husband and I are both employed so let’s say we have a normal income. Well, there are situations where his financial aid helps in a certain moment, simple because you have to cover from today until tomorrow. No matter if in reality I have a quite good job and regular salary, it simply happens when you have life expenses and loans.”*

On the other hand, Alma from FB&H receives almost 400KM a month for her son. She says: *“He receives almost 400KM a month. In my opinion that is fairly enough if we are looking at*

his needs, because he is not using any medicaments.” She continues: “Income is minimal. Where ever I work it’s minimal and delayed. On the other hand, I cannot say that we don’t have finances to live. We receive pension that was left after my husband, also one part of pension from Germany as well as his monthly financial aid...For today’s circumstances, I think that is enough[...]”.

Irma adds about how much her son receives: *“It is 384KM per person.”*

Ibrahim says: *“My wife doesn’t work. I work [...]. He has been categorized and receives help from a government. He also have a free transport and that’s it.”*

All respondents are employed and receive additional financial aid for their children. The only difference is in amount of money they receive from the social services for them. This depends whether they come from RS or FB&H. This misbalance between two entities indicates the complex infrastructure of the country itself since the Framework Law is unequally distributed in these two. These parents are lucky enough, because they do have a certain financial security, but according to country’s high rate of unemployment and the dysfunctional system this is not always the case.

4.5. Theme 4 – Family Support

Having a family support certainly eases the stressful situations no matter what they were about. Other members of the family can be useful help in different kinds of way such as offering their help with looking after a child or simply having a lot of understanding for the whole situation without judgmental attitudes. In this theme parents describe their relations to other members of the family.

Alma says: *“I am saying that we are lucky that his grandpa is there so he has place to go.”*

As Aleksandra says: *“Anyhow, my father in law and I are maximum committed.”*

Ibrahim also adds about importance of grandparents for a child: *“There is my mother and my wife so... And when we want to go out sometimes he can stay at my mothers.”*

Irma explains about family support they have: *“I really have a great family. Everybody really accepted them, nobody is avoiding us. My children play with the children of my cousins.”*

It seems that all parents have a good family support. They described how they can rely on other members of the family which means a lot to them. It appears that three of the respondents rely a lot on grandparents and emphasize the importance of them for a child. Grandparents often have more free time and can be immensely helpful which these parents confirmed.

4.5.1. Coping Together with the Spouse

Apart from importance of other members of the family support from the spouse is extremely important for the family's balance in a coping process. If one of the spouses, for example doesn't accept the situation and have mostly negative attitudes towards the whole situation that immediately creates the misbalance in the family and the coping process is affected negatively. This can potentially lead to family crisis. The following sub-theme describes a little about the relationship between spouses and how they cope together.

Aleksandra and Ibrahim have a good communication when it comes to a team work with their spouses.

Aleksandra believes that she is more involved than her husband. She says: *“We work as a team work. We cooperate. Maybe I should say...I am not sure if that is really like that to say that I am maybe more committed. I don't know if it's because I am a mother or have less working hours.”*

Ibrahim said that he took a year off the work while his wife was pregnant. As he describes: *“I am currently taking a sick leave from work for a year, because I didn't want to risk while she is pregnant.”*

Also, Alma said that she was more engaged than her husband before he deceased. *“Primary, it was my husband and I. Of course, me more, because he had o work. Although, in his free time he would go out with him and in that way helped me with the house work...because I really dedicated myself, me and my husband and everybody was involved. It wasn't like we were isolated, everybody participated in that in their own way.”*

On the other hand, Irma said that she doesn't really get support from her husband, only lately he got a little bit different.

She explains how he is worried what others will say and that he doesn't show as much as care as she does, which is typical for Bosnian fathers, as she adds : *“Not so much. Everything is on me. Look, for three and a half year we've been having a hard time with him. Only recently he has started to look at it a little bit differently. He wouldn't talk about it. I was the one who was never ashamed to say that our children have autism. For instance, he never searched for professionals [...]. Like most fathers here. They rarely care. He would say: “Why did I have to be on the television, people will now know that our children have autism?”*”.

According to parents' statements they have pretty good communication with their spouses. They mostly share the responsibilities. Although, it appears that mothers are more involved when it comes to taking care of the children. This is probably due to a patriarchal system that is strongly rooted in the country.

4.6. Theme 5 - Support Among Parents

This theme talks about how parents experience the support among other parents and how important is that to them. Support among parents can be a very useful coping strategy. Sharing the similar stories within the group of parents can bring the relief and ease the everyday struggle.

Aleksandra and Alma said that the communication as well as the connection with other parents in general was much better in the beginning of the diagnosis.

Alma says: *“Cooperation was better when they were in kindergarten. Now, I don’t really have much time for some communication, but I also think that the cooperation among parents is not organized very well.”* She continues explaining how there are not united and that there is no association. She adds: *“I know parents from the “other side” (referring to the West side of the city). However, we are not united under one roof. There is no association.”*

Aleksandra describes her experience with other parents. She said that she doesn’t really need other parents now as everybody has their own routines. It was more needed in the beginning. Now they just meet sometimes through organizational activities.

She says: *“Maybe when we were in the first phase, when we were trying to get and confirm diagnosis that we were suspecting on. It meant more back then. Now at this moment I think we already have a routine system, discipline and work.”* As she continues explaining the possible reason for not cooperating with other parents that often: *“Probably because everyone is in their own problematics and don’t have much time for other things.”*

Ibrahim said that he socializes with other parents more often. They usually hang out for a coffee and talk about common problems they encounter.

As he adds: *“Five or six of us goes to have a coffee sometimes. Most of the parents have the same goal. Everyone is fighting for their child so...And then conversation is...as soon as we see each other conversation is about that. What to include, how is progressing and so on.”*

Irma on the other hand didn't say much about communication with other parents. She says: *"From my point of view I am not really with a lot of parents."*

Parents state that the support among parents was better in the beginning when they were in search for answers and diagnosis. The reasons why they don't gather from time to time with other parents now is the lack of time. Having a child with ASD is time consuming and there is too many things that parents need to do throughout the day in order to ensure best possible development for their children. This can be very exhausting and not finding time for themselves can lead to potential burn-out. If parents had time at least once a week to meet other parents and share their stories and be heard it would be easier for them, because then they would know that they are not alone. Apart from that, they would probably feel a relief and refreshment to move forward.

4.7. Theme 6 – Getting Help from Provided Services

Another important theme when it comes to supporting parents on their not that easy journey is help from provided services. It is very important that a government provides certain services for both children and parents. This would include early intervention programs which are basis for directing a child's development in a right way; further treatment; securing the conditions for inclusive practices in school; offering different educational and supportive programs for parents etc. The following statements will reveal how these parents experience help from provided services and do they actually even exist.

Ibrahim's son is included in the NGO where he brings him every day. He explains how the government is not doing much when it comes to children with ASD.

He says: *"I don't think that government ever gave anything to help...You don't have enough space, enough professionals and new children keep coming...So, nobody will help you."*

Aleksandra explained similar thing in RS and adds how the system puts obstacles in front of them instead of helping them.

She says: “There were more things happening through NGO’s, these associations of citizens then through the system .Not just that we don’t have an adequate system, but someone also puts additional impediments like what we have is not enough already. That moment when he turned 7 on 2nd of April we were told not to bring him to the kindergarten again...So, I didn’t get any protection from the system, from the Mayer, from the city under which jurisdiction the kindergarten is, from the inspection nor from the ombudsmen for children.”

Irma adds about her situation when it comes to the services she uses: *“And then we included them in “Buducnost” (NGO), a program for children with autistic spectrum, where they use ABA principals. I paid for private kindergarten, I will pay for this as well.”*

Alma also says how she depends on NGO’s, especially in the beginning. She states: *“[...]so there were certain organizations, non-profitable organizations which [...] in cooperation with organization “Hope” they formed one room at the department for physical therapy where these children used to come for a physical therapy, because there were a lot of children. So, that gave me some stimulus...”*

All of the parents say that they mainly depend on NGO’s and that the government does little or nothing to ensure them with what they were supposed to be provided with by the law. In that case, parents have to find alternative ways for including their children in existing programs that are mostly initiated by NGO’s and they usually have to pay a certain amount of money for those since NGO’s depend on a very small budget in most of the cases. Lack of governmental support can be additional stressful factor for parents which just makes it harder to cope.

4.8. Theme 7 – Coping with Fear and Worries

This theme describes the fear and worries that parent's experience. It can be very hard to cope if the feeling of fear is constant and affecting us on daily basis. This can bring the misbalance in a family which can lead to family crisis.

Alma told how she was afraid that her son might sexually harass her daughter, because he doesn't really understands the relationship between a man and a woman.

She says: "For example, my daughter... Since he is big, maybe I should or should not mention it. Relatively early, 4 or 5 years backwards he started to, simply to sexually please himself, in his own way, so he goes to his room. However, sometimes I have a feeling that he understands a relationship between man and woman differently from the one between a child and a mother. I don't know how to define it. And she is much smaller than him, weaker and I am afraid...Simply I am afraid to leave him alone with her sometimes."

Aleksandra describes her fear of future. She says: *"[...] if I think too much about the future of my child and us with him then it becomes a little too hard, because then I start to worry how it will be for him in the future, especially when there will be no support system, when we are gone or relatives or anyone who would and should help him. And also non-acceptance from the people in his environment."*

Irma is also afraid of regressing and what future might bring. She says: *"The hardest for me is when I regress again. I say when it strikes me...You know, I always try to work with them so that everything is fine. I behave like everything is OK with them, talk to them no matter if they hear or not, but sometime there comes the situation when I read some literature and realize what is waiting for me. When you are aware of the future, especially in this country."*

Ibrahim shares the same fear of regressing. He says: *"The hardest is when, for example, 15 days ago he was in a phase where he is drowning again...And when he regresses again you cannot make a contact, he cries..."*

Parents mostly have a fear of the future and what awaits for their children when they are gone and when there is no support system whatsoever. This is not easy to bear, it is a daily reminder for uncertainty of the future. Even though it is very hard when they think of it, parents state how they don't focus too much on that, but on hard work with their children. Although, this can be a good coping mechanism it can be overwhelming to constantly be focused on a hard work and not being able to think of their own well-being which can potentially lead to burn-out. It would be better though if they had support groups where they would have a chance to share these worries with others and use groups as a vent for accumulated stress regarding their fear of the future.

4.9. Theme 8 – Coping with Social Attitudes

Social stigma and lack of awareness about autism can affect family in so many ways. It can give them feeling of shame, affect them in a way that they are in a constant denial, make their everyday harder by judging them and so forth. It can be extremely hard for parents to cope with social stigmatization that is impossible to avoid on almost every corner or situation. The following are parents' experiences regarding the aforementioned.

Aleksandra told that she haven't really had a lot of negative experience directly and when she does she reacts in a very protective way.

She says: *“Well, for instance there was one situation in the kindergarten when Dejan transferred to a group of older children and when that one teacher...First day she called me to have a conversation with me because Dejan didn't want to eat his lunch like other children and I said: “Well, OK, he doesn't need to eat his lunch”. Then she called me again saying: “He is impossible, listens to me nothing”. This and that. For one hour she was complaining on him. I was just quiet and went to complain about her and to get her off my back.”*

Irma explained how she doesn't care about what will people say about her children. Her husband doesn't think that way, he is often worried what will others say about his children as she said. She says: *"My husband said that everybody saw us on television as well as the kids. He said that our kids were mostly videotaped. I said: "Well, camera loves beautiful people, it's not going to video tape the ugly ones, is it?" (laugh) If I don't stand behind my child, who will?."*

Ibrahim told how in a place where he lives people will always help and will not judge. He also describes how society sees his child.

He explains: *"When they see a child that nothing is physically wrong with him they immediately think that he is a thief or without any manners."*

Alma says how she explains to people sometimes if they are staring too much.

She says: *"When the situation allowing me I always explain."* She showed a lot of understanding towards other people. As she adds: *"I cannot blame a child who is passing by him and staring, because that child haven't learnt not to stare at that child."*

Parents express quite resilience and positive attitudes when it comes to social stigma. They are aware of it, but don't allow themselves to be over affected. This is a good sign of coping on a daily basis, especially in the country where being different in any possible way is a potential taboo.

5. Discussion, conclusion and recommendations

This study focused on the experiences of parents who have children with ASD. The goal was to examine their perspectives on coping strategies they use on daily basis to overcome the various stressful situations. In order to conduct their stories qualitative semi-structured interviews were used.

The discussion is based on the findings in chapter 4 in the connection with the background of the study in chapter 1, theoretical framework and literature review in chapter 2.

5.1. Discussion

This study shows that getting the diagnosis for ASD usually takes a longer time and that the system is dysfunctional regarding the health services in B&H. Professionals show lack of education within this field which affects a child in a long run as well as the family in whole. Delfos (2010), in her report regarding children with ASD and their family in B&H stated that there is only two diagnostic centers in the country and *“there is no general system of diagnose in B&H [...] health care is not well organized and is very costly [...] not everyone has access to Health care”* (p.18). Among many stressful factors, parents of children with ASD must deal with complex care services which are often slow with diagnostic procedures and have access impediments for treatment. The core problem is insufficient communication among doctors and educators who work in a educational system with limited resources (Exkorn, 2005; Shapiro, 1993; Kahana, 2015, p. 154). Parents from this study confirm the aforementioned in their statements. They wondered for a quite some time before they got the diagnosis. Even then the diagnosis was not specific enough which also affects the decision on adequate therapy for a child. All this was very stressful for parents and constant feeling of

uncertainty about getting the diagnosis was leaving them in a status quo position. According to Lazarus and Folkman (1984), during the primary appraisal when we experience a certain kind of a threat this automatically puts us in the stressful position where we are uncertain what will happen in the future (p. 34). This uncertainty triggers secondary appraisal which evaluates the situation and question what can be done about the stressful encounter. This is where the coping process begins (Lazarus, 1999, p. 77).

During this period of uncertainty parents were hoping that everything will be fine in the end. When getting the diagnosis all of them skipped the despair or denial phase which is not always the case, especially not in Eastern developing countries. For example, Dababnah & Parish (2013), found out that some parents of children with ASD in Palestina denied that they had ASD even if they knew the diagnosis from the start they decided not to do anything about it (p. 1675). On the other hand, parents of this study acted as soon as they got the diagnosis. They employed the problem-focused strategies. Problem-focused strategies focus on changing the person-environment relation which is causing the distress (Folkman et al., 1986, p. 993). It identifies the problem, uses available resources and starts acting upon the problem. Parents were aware of the situation and that they needed to do anything to help their child. This was the most important thing for them. There was no time for despair, but just fight as they state. Having positive attitudes along the way indicated the resilience in parents' stressful encounters. Using double ABCX model we can visualize better how parents cope with such a stressful life situations. Having a child with ASD brings along pile up of stressors (Aa factor) which are necessary to act upon fast. This could be one of the reasons that phase of despair was skipped, because parents had to focus on solving these problems rapidly in order to provide their children with the best possible development.

Cc factor indicates the definition of the problem which in this case was getting the diagnosis in order to move on further in problem-solving direction.

Bb factor refers to use of new resources that added up upon initial resources that family used in the beginning. There are individual, family or community resources that family can use. One of the most relevant resources is social support which can either help to prepare to cope successfully or prevent the potential crisis (McCubin & Patterson, 1983, p.11). Within this study, parents state that uses of social or health services were quite limited which enhanced

the stress within the family. According to Gray's research (2003), one of the most important coping strategies are the treatment services and family support. Especially the use of treatment services was of a big relevance to parents since it is crucial for young children to learn the life skills (2006, p. 973). According to the OHR of B&H (2010), usually parents go through process of acceptance on their own without support services provided by the government (p.62). Despite that, parents use any possible resources in order to help their child. This is mostly provided by the NGO's for autism. It appears that NGO's are very precious resource for parents in B&H since government provides little or no services at all.

Another precious resource is support from a spouse and other members of the family which in this study mostly shows accessible. Findings indicate that mothers are more dedicated than fathers. This is probably connected to a patriarchal society and socially divided gender roles. On the other hand, use of grandparents as one of the valuable resources that parents in this study use a lot appears to enhances better coping. As parents of children with ASD require to spend a lot more time to take care of their children than parents of typical developing children this resource gives them opportunity to take a "break" and do other things which would be difficult to perform if they didn't have this kind of a support in the first place. Prior research showed grandparents as a valuable resource to help in reducing family stress with their social, emotional, and financial support as well as advocating for their grandchildren (Hillman, 2007; Lee & Gardner, 2010; Kahana et al., 2015, p. 157).

Parents support groups can be also a very useful resource that enhances the coping. In Clifford & Minnes's (2012) research, group of parents who were using these support groups stated that they were beneficial for them and it helped them use more adaptive coping strategies unlike the other group which used them before and stated that they weren't beneficial enough, because of being more informative and not emotionally supportive enough at that time. Also, the group of parents who didn't participate in the groups, because of the lack of time and child care were neutral in their opinions (p. 183). In the findings of this study, parents state that meeting with other parents was quite beneficial in the beginning, but later on they just didn't have time for it. Although, one parent state that he meets with other parents sometimes for a coffee and that it helps to be able to share mutual experiences. Lack of time as they state is probably related to dysfunctional system in general regarding services from the government that were supposed to be provided in the first place and give parents

more time for themselves and their well being. Parents need to have mutual help so they prevent a potential burn-out for themselves (Delfos, 2010, p. 25). Reaching for a support groups would be emotion-focused coping strategies that usually helps parents cope better with their worries and fears. Being able to share all these feelings with the rest of the group that share similar stories help relieve the stress and function better in daily activities. Unfortunately, in B&H are little or no such groups and even if they were parents of this study state they don't have time for that.

Another important resource is finances. All parents that were interviewed in this study are luckily employed. This is not always the case, especially in B&H society where unemployment rates are quite high. On the other hand, one parent is often obliged to deprive themselves from work, because they have to stay home and take care of the child which affects monthly income negatively ("DUGA", 2006, p.13). For example, one parent states that his wife has to stay home and take care of the child. Even though parents do work, still the income is not sufficient sometimes to cover all the expenses. They even use monthly income for a child's care sometimes for the aforementioned reasons. As results show, the financial help for a child differs between two entities RS and FB&H. According to OSCE (2012), social welfare for persons with disabilities is around 219KM to 396KM in FB&H which also depends on a degree of a disability. In RS this right practically does not exist, the only social help that is provided is the one that includes assistance of another person which is 41KM monthly (p. 39). These are all the factors that influence the coping in a positive or negative way.

XX factor indicates the outcome of the stressful encounters and it can be shown as a continuum with maladaptive negative end on one side and bonadaptive positive end on the other side. On which end will family end up it depends on how they define the problem and the resources they employ and the interaction between them (Wilmoth & Smyser, 2009, p.158). The findings show that parents are using problem-focused coping strategies which help them plan the steps in order to help a child as well as use of different kind of resources as it was mentioned above. These facts puts them on the positive side of the continuum which is the bonadaptive positive end even though the use of resources were limited when it comes to health and social support.

There is almost no public awareness about autism in B&H (Delfos, 2010, p.15). Yet, parents of this study seem to handle social stigmatization and lack of awareness about autism quite well. They show determined fight for their children every day even though there are numerous social impediments. In dealing with social stigma it seems that they are using problem-focused strategies such as taking the action of dealing with the problem and not disengaging. It is not easy when your child is perceived as spoiled or has no manners in society where you live. Children with autism don't stand out with their physical outlook from typical developing children so when they, for example, are having tantrums in public people often judge their parents as not teaching them to behave "properly". This is often very stressful for parents and they have to live with it every day. Numerous research studies have been conducted regarding increased parental-related stress in connection with a child behavior. For example, one of them focused on comparison between mothers of toddlers with ASD and mothers of toddlers with developmental delays (DD) when it comes to impact of a child's behavior to parental-related stress and psychological distress. Study revealed that mothers of toddlers with ASD expressed much higher parental-related stress and psychological distress than mothers of toddlers with DD (Estes et al., 2012, pp.136-137). Another study examined maternal fatigue in parents of children with ASD regarding their behavior problems which showed increased maladaptive coping strategies such as self-blame and denial. These are negative emotion-focused strategies that rather increases stress than the other way around (Benson, 2010; Hastings et al., 2005; Seymour et al., 2013, pp.1552-1553).

5.2. Conclusion

Even though there are many stressful factors that findings showed which makes it harder for parents to cope with the situation, parents showed great resilience when it comes to handling such difficulties. Mostly they expressed positive attitudes in moving forward and not regressing. As they state that there is no time for despair, just fight and do everything they can to help their children.

What seems to worry them the most is fear of regressing and what will happen in the future with their children. As it is shown that system in B&H is dysfunctional regarding services for children with ASD and their families, parents of this study show justified pessimism for their future. This uncertainty that is posed as a constant threat for parents is stressful on daily basis. Unlike in other cases where they mostly use problem-focused coping strategies in this case parents use positive emotion-focused coping strategies. This means that they don't allow to spend too much time to worry about the future, but focusing on positive things and what can be changed now. They are using these strategies actively to make a positive change even though the situation cannot be changed at the moment (Lazarus & Folkman, 1984, p.151), but in combination with problem-focused coping strategies this changes are possible.

Although, they mostly use problem-focused strategies, positive emotion-focused strategies are not being used that often. For example, they don't have support groups with other parents which can be very useful for better coping. Support groups often offer a safe space where parents with mutual problems can share with each other and relate. This can help parents to canalize the accumulated daily stress and fill them up with the new energy to keep them going forward. Otherwise, they potentially can end up with having a burn-out. Unfortunately, the government doesn't offer this kind of a help which is not surprising since they do almost nothing regarding these issues. If there is some support groups they are probably within NGO's where parents usually find first help in informing themselves about the new situation they encounter.

Having NGO's offers a good platform for further changes in the country. They can be a great resource for parents and their children from getting the first information to lobbying for their rights and changing the system. On the other hand, parents lack time to be more involved in acting upon the dysfunctional system that is affecting them negatively on so many levels. This is understandable since the lack of the time is a result of a dysfunctional system that doesn't provide them with necessary resources which they were supposed to get by the law in the first place. This is a vicious circle that is hard to break, but not impossible. This is why we need more NGO's that will represent children's and parents' voices to make changes in the system and improve their lives in general.

5.3. Recommendations for further research

This research has given an insight in how parents of children with ASD in B&H cope with the whole situation and what kind of strategies they usually use. The research is very important for these and other families with the similar situations since there is little or no studies on this topic in B&H. Future research on similar topic should maybe have a bigger sample so the study goes more in depth and gets a bigger picture. Also, criteria should maybe include unemployed parents since unemployment rate is quite high in B&H. It would be interesting to see how these parents cope since we already know that there is little or no help from the government. It would also be interesting to interview both parents and compare the stories since B&H society is rather patriarchal and mothers are usually more involved in the taking care of the children.

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7. Appendices

Appendix 1

University of Oslo

Department of Special Needs Education

Researcher: Anela Gosto

Supervisor: Ivan Morken

INFORMED CONSENT FORM FOR RESEARCH PARTICIPANTS

Information Sheet

As part of my master programme at the University of Oslo I am obliged to carry out a research study. The study is concerned with parents who have children with autistic spectrum disorder, their experiences and coping strategies they use. It will take place in couple of cities in Bosnia and Herzegovina.

The study will involve conducting interviews in four bigger cities in B&H which are Tuzla, Banja Luka, Mostar and Sarajevo. Participants will be parents of children with autistic spectrum disorder. Interview will not last more than 2 hours. The interview will take place in the safe space such as NGO's, Associations etc.

You have been asked to take part in this study because You are a suitable candidate for this specific research. Expectations from You are to have at least 2 hours of Your time and answer questions in details as much as possible in order to make this research more valid. Interview has ten questions and are related to all relevant segments about Your experience with having a child with ASD.

You don't have to take part in this study, because participation is voluntary. Once you have signed this consent form you get to keep the copy for yourself. You can withdraw any time before the study commences, even if You agreed to participate. You can also withdraw after data collection has started if You think that transcribed information from the interview is identifiable and You don't feel comfortable or secure to participate any longer.

All the information that You share will be anonymous in the writing process of the thesis. Any extracts from what you say and are being quoted will be entirely anonymous.

The data will be kept safe from the third parties during the period of study. Once the thesis is completed the data will be kept for another six months and then destroyed.

The results of the study will be presented in the thesis. The thesis will be accessible to future students and might be published in a research journal.

This study has been approved by the University of Oslo – Department of Special Needs Education.

If You agree to participate in this study, please sign the consent form that is presented on the next page.

CONSENT FORM

I have received information about the study and I am willing to participate.

Researcher _____

Date _____

Appendix 2

Interview guide

1. Introduction of myself and the research itself
2. How and when did you find out that your child has ASD? How was it for you then?
3. What is your most important experience as a parent to a child with ASD?
4. What was/is the most difficult for you as a parent?
5. What about cooperation among you and your spouse, or other parents?
6. What kind of support do you get from the local services? How are they helping?
7. What kind of support do you get from other members of the family?
8. How do you feel about society towards you child?
9. What do you want to tell other parents about being a parent to a child with ASD?
10. Do you want to tell me anything more about having a child with ASD?

Appendix 3

UiO : Faculty of Educational Sciences
University of Oslo

GOSTO, Anela

Date: 25 June 2014
Your ref.:
Our ref.: int./2014 JBH/db

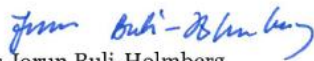
TO WHOM IT MAY CONCERN:

This is to certify that **GOSTO, Anela**, date of birth 25.09.1984, is a full-time student pursuing a course of study at the Department of Special Needs Education at the University of Oslo, Norway, leading to the degree of Master of Philosophy in Special Needs Education (M. Phil. SNE).

This is a continuous two-year programme run on the "sandwich" principle, which involves periods of study and field work/research in both Norway and the home country. The student has successfully completed both the first and second semester of the initial study period in Norway and is now working on the collection of data and the writing of a thesis during the autumn semester 2014. This involves a period of field work in Bosnia-Herzegovina. The student will return to Norway at the beginning of January 2015 and the period of study will be completed at the end of May 2015 in Norway.

The main responsibility for supervising the research, developmental work and thesis remains with the Department of Special Needs Education, University of Oslo, Norway. However, we would kindly request that the relevant authorities give the student the access required to the schools and educational establishments necessary in order to undertake field work and research. We would also be most grateful for any assistance that is afforded to the student which enables him to carry out this work, particularly the use of facilities such as access to telephone, fax, e-mail, computer services and libraries at the various educational establishments.

Yours sincerely



Associate Professor Jorun Buli-Holmberg

Joint Academic Head of International Master's Programme

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Appendix 4

Norsk samfunnsvitenskapelig datatjeneste AS

NORWEGIAN SOCIAL SCIENCE DATA SERVICES



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Vår dato: 21.10.2014

Vår ref: 39544 / 3 / IB

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 22.08.2014. Meldingen gjelder prosjektet:

39544

*Having a Child with Autistic Spectrum Disorders in Bosnia and Herzegovina:
Parents' Experiences with Coping Strategies*

Behandlingsansvarlig

Universitetet i Oslo, ved institusjonens øverste leder

Daglig ansvarlig

Ivar Morken

Student

Anela Gosto

Etter gjennomgang av opplysninger gitt i meldeskjemaet og øvrig dokumentasjon, finner vi at prosjektet ikke medfører meldeplikt eller konsesjonsplikt etter personopplysningslovens §§ 31 og 33.

Dersom prosjektopplegget endres i forhold til de opplysninger som ligger til grunn for vår vurdering, skal prosjektet meldes på nytt. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>.

Vedlagt følger vår begrunnelse for hvorfor prosjektet ikke er meldepliktig.

Vennlig hilsen

Katrine Utaaker Segadal

Inga Brautaset

Kontaktperson: Inga Brautaset tlf: 55 58 26 35

Vedlegg: Prosjektvurdering

Kopi: Anela Gosto aleks.gosto@gmail.com

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Avdelingskontorer / District Offices

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Referring to email 15.10.14 and phone call 20.10.14.

Based on the information we have received about the project, the Data Protection Official cannot see that the project will entail a processing of personal data by electronic means, or an establishment of a manual personal data filing system containing sensitive data. The project will therefore not be subject to notification according to the Personal Data Act.

The Data Protection Official presupposes that all information processed using electronic equipment (audio recordings and notes/transcript) in the project is anonymous.

Anonymous information is defined as information that cannot identify individuals in the data set in any of the following ways:

- directly, through uniquely identifiable characteristic (such as name, social security number, email address, etc.)
- indirectly, through a combination of background variables (such as residence/institution, gender, age, etc.)
- through a list of names referring to an encryption formula or code, or
- through recognizable faces on photographs or video recordings.

Furthermore, the Data Protection Official presupposes that names/consent forms are not linked to sensitive personal data.

We recommend that consents are given orally (to avoid the registering of names), and that informants are encouraged not to give any names (on persons or places/institutions) in the audio recordings.