

CHALLENGES FACED BY FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Silvana FILIPOVA¹, Vasilka GALEVSKA-JOVCEVSKA², Dita TORTE-CHICHE²,
Renata JANKOVA³

¹Center for Rehabilitation of Pathology in Verbal Communication - Skopje, Faculty of Education - Tetovo

²Center for Rehabilitation of Pathology in Verbal Communication – Skopje

³ Institute of Forensic medicine, Criminalistics and Medical Deontology, Medical Faculty, Ss. "Cyril and Methodius" University - Skopje

Abstract

Introduction. Parents begin to make plans for the future of their family and for their children during the period when they are thinking about expanding the family or when a pregnancy is confirmed. Learning that their child has developmental disorder, drastically changes the parents' perspective and view of both parenting and the child itself, at the same time also requiring changes in parental expectations. When the parents realize that their child has long-term developmental issues, the outcome of which is uncertain, various types of psychological reactions may occur.

Subject. The subject of this research is the challenges faced by parents and the key processes they go through when confronting, reacting and accepting the diagnosis of their child.

Method. The "Reaction to Diagnosis Interview" (RDI) by Pianta and Marvin (Pianta & Marvin, 1992) was used as an instrument.

Results. The results have shown that among the "resolved" mothers, the most frequent subcategory are the "hinking-oriented" mothers, followed by "action-oriented" mothers. Among "unresolved" mothers, the majority are the "feelings orients", followed by "emotionally overwhelmed" mothers.

Conclusion. The results of this research have significant clinical implications about how unresolved parental relationships affect further family adaptation.

Keywords: autism spectrum disorder, acceptance of diagnosis, emotional overload, resilience.

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impairments in reciprocal social interactions, communication difficulties, and a restricted, stereotypical, and repetitive pattern of behaviors and activities (American Psychiatric Association). ASD is a complex neurodevelopmental disorder that affects all aspects of a child's personality: communication, motor skills, behavior, and learning. Autism is not an illness but a condition that one lives with throughout their life (Filipova et al., 2021; Greenspan, 1992).

Learning that a child has been diagnosed with Autism Spectrum Disorder (ASD) represents a tremendous shock and upheaval in the life of any family. This is because parents begin to make plans for the future of their family and their child, even during the period when they are contemplating expanding their family or when pregnancy is confirmed (Archer, 1999; Filipova et al., 2021). This period is filled with optimistic dreams of a future perfect, psychophysically healthy child who will confirm and fulfill parental hopes and aspirations for the future. The birth of a child is a unique and joyful event for most parents (Leerkes & Burney, 2007). However, the learning that the child has a disorder on the autism spectrum drastically changes parental perspective and views on both parenting and their child, shaping the need for a change in parental expectations (Graungaard & Skov, 2007).

When parents learn that their child has long-term health problems with an uncertain outcome, numerous psychological reactions can occur. In the initial moment, parents experience shock and disbelief. They may feel sad and frightened, but also angry and responsible because their

child is not healthy. Knowledge of the health condition and the diagnosis of the child introduce a specific situation into the family and impact the lives of all its members (Krstić, 2013).

Although medicine is constantly advancing, the number of children with ASD is not decreasing; rather, it is slightly increasing. This is because today we are able to save the lives of children who previously could not survive due to the lack of technological possibilities that would enable it (Ljubešić, 2013). As a result, there is a growing need for systematic support for families facing various health challenges with their child, aimed at helping them adapt and lead a quality life. Additionally, the social context is such that disabilities or impairments are often devalued, causing parents to feel emotionally burdened (Green, 2007). Raising a child with ASD is a significant challenge for most families and can have consequences not only for the functioning of the child but also for the long-term functioning of the entire family (Lin, 2000; Raina et al., 2005). The birth of a child with ASD can disrupt the balanced state of the family unit. Although only one member of the family may have some form of "disability," all its members are affected (Vash & Crewe, 2010).

Previous research indicates that children with Autism Spectrum Disorder (ASD) are at risk for lower quality of care in their families (Van Ijzendoorn et al., 2007; Rajić, Mihić, Kopunović-Torma, 2015). This is associated with the fact that the challenges imposed by parenting in families of children with ASD are numerous and more complex than in families of typically developing children. Challenges related to parenting generally begin with the birth of the child when parents need to redefine their expectations formed in accordance with idealistic notions about the child during pregnancy, according to the needs and characteristics of the real child (Hanak 2012; Leerkes & Burney, 2007; Zeanah et al., 1985; Zeanah, Zeanah & Stewart, 1990). This implies parents' readiness to define their new role and integrate it with other roles (Bradley, Whiteside-Mansell, Brisby & Caldwell, 1997). This process is further linked to accepting the diagnosis (ASD), as well as developing the representation of the child, which, among other things, involves cognitive and emotional acceptance of the implications of the child's developmental diagnosis and care for them (Barnett, Clements, Kaplan-Estrin & Fialka, 2003; Krstić, Bugarski, Brkić i Obradović, 2013; Marvin & Pianta, 1996).

Parents invest significant energy in raising a child and enjoy that role. When it comes to caring for a child with ASD, specific challenges arise, including financial, physical, and emotional challenges (DeMarle & le Roux, 2001). Numerous studies show that the mental and physical health of parents is greatly influenced by the child's condition, behavior, and the demands placed on them (Raina, et al., 2005; Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008). Although efforts are made to provide as much medical assistance as possible to children with ASD, this assistance is rarely or not at all directly provided to the parents. Therefore, this effort is directed towards parents caring for a child with ASD.

Studies exploring families of children with developmental disorders highlight that grief is a dominant emotion (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). The process of overcoming grief requires greater emotional and cognitive engagement from parents to cope with the child's diagnosis and align their expectations with the child's capabilities. It is essential to emphasize and recognize the positive aspects of caring for a child with developmental disorders, such as increased emotional closeness among family members, personal development, sensitivity to others, enjoyment of typical activities, and a positive relationship with professionals providing various services to the child (Grant, Ramcharan, McGrath, Nolan, & Keady, 1998; Green, 2007; Kearney & Griffin, 2001; Trute & Hiebert-Murphy, 2002).

One of the greatest challenges for parents with a child diagnosed with ASD is accepting the diagnosis. Acceptance of the diagnosis serves to address problems and for emotional regulation (Zotović, 2004). Parents' acceptance of the diagnosis is seen as an indicator of family resilience, meaning that even after experiencing strong emotional stress, the family functions with positive

consequences in terms of cognitive and emotional acceptance of the child's diagnosis and all related consequences by the parents (Krstić, 2013).

Findings from Pianta et al., for a sample of children aged 15-50 months, indicate that there is no correlation between the length of time parents have been confronted with the child's diagnosis and the resolution status in the mother (Pianta et al., 1996). In the study conducted with parents of children with mild to moderate impairments, approximately half of them were classified as unresolved regarding the child's diagnosis two or more years after its awareness (Barnett et al., 1999, cited in Barnett et al., 2003). Researchers concluded that time is not a predictor of the resolution status in parents regarding the child's diagnosis (Barnett et al., 1999, cited in Barnett et al., 2003; Pianta et al., 1996). Even when parents were interviewed again a year and a half after the initial interview, about half of them remained unresolved or became unresolved (Clements et al., 2001, cited in Barnett et al., 2003).

With the help of a longitudinal study, the relationship of parents towards the diagnosis of the child was examined, and the results showed that in 75% of cases, the "state of fatigue" in parents towards the diagnosis of the child remains stable over time. The sample of children included in the study was diverse, covering conditions such as cerebral palsy, epilepsy, myelomeningocele, and hydrocephalus (Barnett et al., 2006).

According to Pianta et al. (1996), concerning the subcategories of resolution, 50% of parents were oriented towards thinking. These parents emphasize cognitive processes and beliefs that help them accept the child's condition. Information related to the child's condition and illness is crucial to them. They tend to connect their feelings with their thinking and conviction (Schuengel et al., 2009). For parents of older children, the dominant pattern has been shown to be action-oriented. The authors believe that as parents become more accustomed to their role, their orientation towards action may come to the forefront, so the action-oriented subcategory can be expected in parents of older children. Research did not show a significant difference between age groups in the resolved relationship based on the feeling-oriented subcategory (Schuengel et al., 2009).

The longitudinal study conducted on children aged 18 to 30 months showed that in 63% of parents, regardless of the level of the main category, the subcategory changed. The most common change occurred from the strategy-oriented towards thinking in the category of action-oriented (Rentinck et al., 2010). The differences between age groups in the categories and subcategories of resolution may suggest that resolution is not acquired at a specific time but is an active process that changes during child development.

Research and Methodology Data

The subject of the research is the challenges faced by parents of children and the key developmental processes they go through during the confrontation, reaction, and acceptance of their child's diagnosis. The objective is to examine the mother's relationship with the child's condition, specifically her emotional and cognitive (non)acceptance of that condition.

Sample

The sample consists of 34 mothers who voluntarily agreed to participate in the research. According to Button, Pianta, & Marvin (2001a), the mother is the one who spends the majority of time with the child and bears the greatest burden in families of children with ASD. The mother provides the special care required by the child's condition, actively participates in the treatment program, and often plays a key role in the child's care. The inclusion criteria for mothers are that their child has received a diagnosis of ASD from a child psychiatrist. The mothers included in the sample are aged between 24 and 55 years ($M = 31.34$). At the time of

the interview, the children of the mothers were aged between 2 and 13 years ($M = 5.73$). Table 1 presents the remaining descriptive characteristics of the sample.

Table 1. View of the sample

Characteristics	Frequency
%	
Place of residence	
City	88.24
Village	11.76
Marital status	
Not married	0
Married	100
Divorced	0
Education	
Elementary	0
High School	44.12
University	55.88
Employment	
Permanent	2.94
Indefinite	82.35
Unemployed	14.71
Family Structure	
Nuclear	38.24
With spouse's parents	52.94
With her parents	8.82
With other members	0

N = 34

Regarding the sample, it should be emphasized that the majority of mothers live in the city, all are married, the majority have a high level of education, and are employed on an indefinite basis. What is noteworthy is that the majority of them live in a nuclear family with the spouse's parents.

Instrument

One of the tools used in the research is the Diagnostic Reaction Interview (Pianta & Marvin, 1992a), which is based on the Affect Matching Interview for adults but developed to examine resolution related to the awareness that the child has some form of developmental disorder or chronic illness. The interview is designed to assess parents' reactions and coping mechanisms. It is a standardized interview that takes about 15 minutes to conduct. The questions are open-ended and focused on:

- Initial observations of the child's issues.
- Thoughts and feelings related to the child's issues and the process of receiving the diagnosis.
- Changes in thoughts and feelings since learning about the diagnosis.
- Seeking/exploring the reasons and personal explanations for the child's condition.

Responses to the Diagnostic Reaction Interview are coded using the Classification System for the Diagnostic Reaction Interview (Pianta & Marvin, 1992b; Pianta & Marvin, 1993). The classification system describes elements of resolution and non-resolution, as well as rules for

recognizing these elements. It consists of a list of elements indicating resolution or non-resolution, categorizing them into two categories: resolved and unresolved, with two sets of subcategories associated with each of the main categories (Krstić, 2013).

Table 2 Indicators of resolution and non-resolution (Krstić, 2013)

<p>Elements of resolution</p> <ul style="list-style-type: none"> • Confirmation of emotional challenges upon receiving the diagnosis; • Recognition of changes in emotions since learning about the diagnosis; • Breaking away from the search for reasons for the child's condition (Why me? Why my child?); • Confirmation of changes in life; • Accurate (non-distorted) representations of the child's abilities; • Balanced and integrated statements regarding the gains and shortcomings related to the child's diagnosis
<p>Elements of unresolvedness</p> <ul style="list-style-type: none"> • Denial of the emotional impact of the diagnosis; • Cognitive distortions related to the child's diagnosis or abilities in the form of unrealistic beliefs and negation of the severity of the child's health condition; • Confusion and mental disorganization (contradiction within oneself, loss of memory); • Active search for an existential reason for the child's condition; • Grief, anger, or other emotions, sufficiently strong and pervasive to suggest that the individual is "stuck in the past" as if the diagnosis has just been given; • Boundary violations (attempt by the interviewer to engage against medical personnel). Denial of the emotional impact of the diagnosis; • Cognitive distortions related to the child's diagnosis or abilities in the form of unrealistic beliefs and negation of the severity of the child's health condition; • Confusion and mental disorganization (contradiction within oneself, loss of memory); • Active search for an existential reason for the child's condition; • Grief, anger, or other emotions, sufficiently strong and pervasive to suggest that the individual is "stuck in the past" as if the diagnosis has just been given; • Boundary violations (attempt by the interviewer to engage against medical personnel).

The reliability and validity of the Diagnosis Reaction Interview have been confirmed, with inter-rater agreement ranging from 88% to 96% (Barnett et al., 2006; Pianta et al., 1996). As an indicator of validity, it is noteworthy that children of parents classified as resolved were significantly more frequently securely attached (Barnett et al., 2006; Pianta et al., 1996).

In the study, three coders (evaluators) were involved. The evaluators had undergone training in assessing parental reactions to the diagnosis and the method of assessment using the Diagnosis Reaction Interview. Each individually listened to the recorded material, examined notes on maternal behavioral characteristics during the interview, and made their classification decision. In 91% of cases, coders (evaluators) agreed on the main categories. At the subcategory level, there was minimal disagreement among evaluators. All disagreements among coders (evaluators) were subsequently reconciled regarding both main categories and subcategories, and these reconciled data were accepted as the final classification decision.

The following are two brief excerpts from the Diagnosis Reaction Interview. Based on the first interview (excerpt 1), the mother is classified as resolved, while the second interview (excerpt 2) indicates an unresolved pattern. Both mothers have a child with ASD.

Excerpt 1

Evaluator: How did you feel when you were told about your child's diagnosis?

Mother: Terrible... Like I lost the ground beneath my feet. I could barely hold myself from falling. I literally felt like all my ships were sinking. Many thoughts crossed my mind, including self-blame, where did I go wrong, what did I do. I had to grieve. I wondered what I did wrong, why did this happen to me?

Evaluator: Have your feelings changed since then?

Mother: I am stronger, much more stable, and more resilient. It took time for me to accept the uncertainty about what will happen to my child and what will be required of me. The lack of knowledge and information was very difficult for me. However, I learned to be strong, to fight for my child. I acquired the knowledge needed to support my child and help him reach his full potential. I attended numerous educational sessions. I realized that much can be achieved through effort. I simply accepted it and work towards my child progressing, becoming as functional as possible.

Excerpt 2

Evaluator: How did you feel when you were told about your child's diagnosis?

Mother: I remember when the doctor told me about ASD, and I froze in that moment. I didn't know how to react. The whole world around me collapsed. I felt like I had received a life sentence. When I returned home, I started crying. My feelings were a mix of fear, anger, pain, and grief. The uncertainty, not knowing exactly what will happen to my child. I didn't know what to do. Where to start? What exactly is expected of me? Fear overwhelmed me. I wondered why this happened to me. Why my child? Broken, I admitted that I wouldn't be able to "defeat" autism.

Evaluator: Have your feelings changed since then?

Mother: Well, who knows. Maybe a little. Life with a child with ASD is full of challenges and sacrifices. I often face situations where I struggle. Sometimes I tell myself I have to accept it, but I can't. How can you be at peace when you have a problem at home? I didn't expect life to hit me this hard. I withdrew, I don't socialize much with my friends. I can't bear their sympathetic attitude towards me. Sometimes, I lose energy. I have support from my husband. Together, we organize and take him to various types of rehabilitation. Somehow, we cope with the challenges.

Results

Table 3: Mother's Attitude Towards the Child's Diagnosis

Attitude Towards the Diagnosis	Frequency
%	
Resolved	50
Unresolved	50

N = 34

From Table 3, it can be observed that interviewed mothers, in terms of accepting the diagnosis, are divided. 50% had a resolved attitude, and an equal 50% had an unresolved attitude. Mothers with a resolved attitude exhibit strategies that facilitate overcoming difficulties related to the diagnosis. Among these strategies, those oriented towards the present and the future, a realistic view of the child's condition, and not exploring the reasons leading to the child's current state are highlighted. Mothers who are resolved recognize the change in feelings since learning about their child's diagnosis. Their emotions are balanced and affectively appropriate.

Mothers with an unresolved attitude show strategies aimed at changing the reality regarding the child's condition, actively seeking answers to the causes leading to the disorder. They selectively remember past experiences and neglect the current reality. They are confused,

incoherent, and mentally disorganized in their discussion related to the experience of learning about the diagnosis. These mothers have not been able to overcome the initial crisis associated with the awareness of their child's diagnosis.

Table 4 Subcategories of the Attitude Towards the Child's Diagnosis in Resolved Mothers

Subcategory %	Frequency
Resolved - Emotionally Oriented	23,52
Resolved - Action-Oriented	35.29
Resolved - Thought-Oriented	41.17

Although resolved mothers, to a greater or lesser extent, show elements of resolution, they differ in the extent to which one of three recognized types of resolution is present.

The results of the research show that the majority of surveyed mothers, specifically 41.17%, are thought-oriented, using cognitive strategies that help them accept the diagnosis. For these mothers, information about the child and the disorder is of primary importance. They tend to respond to questions about feelings using statements related to their beliefs and thoughts.

Next, 35.29% of mothers showed an action-oriented orientation. They focus on the challenges associated with the diagnosis and concentrate on taking action and providing appropriate care tailored to the disorder.

The third group, comprising 23.52% of mothers, demonstrated the use of strategies oriented towards feelings. These mothers are focused on their emotions related to the traumatic event of learning about the diagnosis and facing it, which represented a crucial moment for overcoming the trauma associated with communicating the diagnosis.

Table 5 Subcategories of the Attitude Towards the Child's Diagnosis in Unresolved Mothers

Subcategory %	Frequency
Unresolved - Emotionally Overwhelmed	23.52
Unresolved - Preoccupied with Anger	29.41
Unresolved - Neutralized	0
Unresolved - Depressive/Passively Resigned	17.64
Unresolved - With Distortions	11.76
Unresolved - Confused	17.64

In the group of unresolved mothers, those preoccupied with the feeling of anger dominate. During the interview, anger directed towards various aspects prevails in 29.41% of surveyed mothers. They express anger towards doctors, the interview, the diagnosis, therapists, caregivers, teachers, family members, and other individuals involved in working with the child. They also seek to gain support and justification for their anger from the interviewer.

The second group of 23.52% of mothers expresses their unresolved attitude towards the child's condition by manifesting agitation, grief, and pain during the interview, indicating that the emotional crisis is still active. They feel the need for sympathy for their situation.

The third group of 17.64% of mothers showed depressive/passively resigned behavior and confusion. Depressive/passively resigned mothers are characterized by sadness, indifference, and passivity. During the interview, they provide minimal statements about their feelings and events related to the awareness of their child's diagnosis. They appear helpless in dealing with the grief they feel and incapable of coping with the challenges related to caring for their child. They seem hopeless about their child's future.

Confused mothers, constituting the fourth group at 11.76%, are incoherent during the interview. The content of their statements contains contradictions or confusion. They lose the primary idea, often oscillating between polarized observations related to the child's condition.

The fourth group at 11.76% of mothers manifested distortion, i.e., mothers who displayed clearly distorted expectations related to the child's condition and future. They show unbalanced observations such as unrealistic expectations and idealization of the child's condition.

In the group of unresolved mothers, there is also a fifth category described by Pianta & Marvin (1992a) as emotionally neutralized, who remember all events but cannot recall emotions. They seem to lack personal emotional reactions related to the diagnosis and avoid any explanations related to the presence of negative emotions. Such mothers were not observed in the study.

Discussion

The results of the study revealed that 50% of the total number of surveyed mothers, in relation to accepting the diagnosis, used strategies indicating a resolved attitude, while the other 50% had an unresolved attitude. Resolved mothers, for the most part, were oriented towards thinking, using cognitive strategies to accept the diagnosis. Some of them were action-oriented, concentrating on providing appropriate care adapted to the condition, and the third group was focused on the feelings associated with the traumatic event of learning about the diagnosis and coping with it.

Among unresolved mothers, the dominant emotion was anger. This anger was typically directed towards doctors, the interview, the diagnosis, therapists, caregivers, teachers, family members, and other individuals involved in working with the child. Throughout the interview, they sought to gain support and justification for their anger. Some were emotionally overwhelmed with painful feelings. Others exhibited depressive/passively resigned behavior and confusion, with a predominance of sadness, indifference, and passivity. A smaller number were confused and incoherent, with contradictions in the content of their statements. The fourth group was characterized by distortion and distorted expectations regarding the child's condition and future. In the group of unresolved mothers, emotionally neutralized mothers were not observed. The overall impression in the group of unresolved mothers is that they appear to lack a distinct emotional cycle compared to resolved mothers (from the initial shock to its gradual reduction) and do not communicate in a realistic manner that indicates acceptance of the child's condition. The interviews with them reveal the presence of conflicting representational models of behavior and a refusal to accept reality, an inability to refocus attention from the present to the future.

A review of studies that also used the Diagnosis Reaction Interview showed different results regarding the prevalence of resolved attitudes. The percentage of resolution varies from 33.3% to 81.6% (Barnett et al., 2006; Kearney et al., 2011; Lord et al., 2008; Milshtein et al., 2010; Oppenheim et al., 2009; Pianta et al., 1996; Rentinck et al., 2009; Schuengel et al., 2009), indicating significant differences in resolution rates.

These differences are due to variations in sample characteristics. Some studies in the research included parents of children with various medical diagnoses (cerebral palsy, epilepsy, phenylketonuria, ASD). On the other hand, others examined parents of children with uniform diagnoses (Barnett et al., 1999 cited in Milshtein et al., 2010).

Another complicating factor for comparing results across different studies is the varied age of the children at the time when the interviews with parents were conducted. The majority of studies examined parents whose children were up to 5 years old (Barnett et al., 2006; Pianta et al., 1996), while a smaller number investigated parents of older children (Schuengel et al., 2009).

The observed differences could also be explained by cultural norms where the consequences of the diagnosis are interpreted differently, as well as the unequal accessibility of medical and

professional services (Rentinck et al., 2009). A significant number of parents lack the opportunity to engage in some form of organized institutional support.

In previous studies, the lowest percentage of resolution was noted among mothers of children with ASD (Milhstein et al., 2010; Oppenheim et al., 2009). The cited reason for this is the weak self-regulation of emotional manifestations present in these children and the parents' inability to establish control over their behavior (Silva, Schalock, & Gabrielsen, 2011), which is a significant factor to consider when examining resolution (Krstić, 2013).

The results of our research indicate that the majority of mothers with secure attachment orientations align with the findings of Pianta et al. (1996). These findings also highlight a preference for using reflective thinking in the resolution process, as their beliefs enable a focus on the child and overcoming the burden of the past. This means that mental strategies guiding active engagement in cognitive processes are more prevalent in secure mothers.

Orme (2005) notes that cognitive strategies, while not dominant, are often present in other secure mothers oriented towards action and emotions. This is a significant finding as it emphasizes the need for developing cognitive interventions to assist mothers in the resolution process.

Studies involving parents of children with ASD have shown a higher prevalence of unresolved mothers in the emotionally overwhelmed subcategory (Milshtein et al., 2010). In contrast to our research where mothers with an unresolved attachment dominate among those preoccupied with loss.

Longitudinal studies examining short-term changes in the parental resolution status have shown that the resolution status regarding the acceptance of the child's diagnosis remains predominantly stable. However, 63% of parents classified in this category made changes at the subcategory level (Rentinck et al., 2010). This finding underscores the need to focus attention on subcategories, primarily for the practical preparation of therapeutic interventions over a specific time period.

Clinical Implications of the Obtained Results

The conducted research emerged as a response to the need for recognizing and understanding the parental relationship in relation to the child's health condition and gaining a better understanding of the family adaptation process. Parents of children with ASD play a crucial role in the implementation of rehabilitation treatment. For these reasons, it is crucial for parents to accept their child's health condition as quickly as possible and activate all family potentials to improve the child's functionality.

The results of the research provide significant implications for practical clinical activities but also pave the way for further research in this area. The diagnosis reaction interview can be of great benefit in clinical practice for gathering data that can provide rich and diverse information about the thoughts, beliefs, feelings, and interactions of parents (Ödman, Richt, & Öberg, 2009). In working with children with ASD, it is crucial to timely recognize the lack of resolution and provide appropriate support. The unresolved relationship can negatively impact the relationship with healthcare professionals because if parents perceive them as unrealistic, overly emotional, overly optimistic, or confusing, their collaboration may be hindered (Larson, 1998).

Conclusion

The awareness that a child has chronic health problems and raising such a child poses a special challenge for mothers and the family as a whole. It is known that families of children with ASD represent a vulnerable population (Britner et al., 2003; Raina et al., 2005), but very little is known about the parents' relationship towards the child's diagnosis itself. The parents'

relationship towards the child's health condition and family adaptation can greatly contribute to a better understanding of these families and identifying their complex needs. Parents of children with ASD face numerous challenges, both emotional and financial, which impact the psychological and physical health of the parents. One of the greatest challenges for these parents is accepting the child's condition, namely the diagnosis. The unresolved parental relationship towards the child's diagnosis is a risk factor for family adaptation. Resilience is a valuable concept for families of children with ASD as it shifts the focus from a pathocentric approach to activating the healthy strengths within the family.

When a child has ASD, the family grows and develops in that context. For professionals working with children with ASD and their families, it is crucial to recognize the parental relationship towards the child's health condition and the factors that can help achieve resolution to strengthen resilience in those families. It is essential to assess which families can adequately cope with the challenges and demonstrate resilience, and which ones may need additional support. The first and most important aspect is for parents to understand and begin accepting the child's condition. The ultimate goal is for children with ASD to grow and develop in a normal context, accepted by their families.

References

- [1] American Psychiatric Association (2013): Diagnostic and Statistical manual of Mental Disorders. DSM-5, 5th ed. Washington, DC: American Psychiatric Press, 2013, www.dsm5.org. Пристапено на 10.12.2022.
- [2] American Psychiatric Association: <http://www.psychiatry.org/autism>. Пристапено на 10.12.2022
- [3] Archer, C. (1999). Next steps in parenting the child who hurts. London: Jessica Kingsley.
- [4] Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: supporting parents' adaptation to their child with special needs. *Infants and Young Children*, 16, 184-200.
- [5] Barnett, D., Clements, M., Kaplan-Estrin, M., McCaskill, J. W., Hunt, K. H., Butler, C. M., Schram, J. L., & Janisse, H. C. (2006). Maternal resolution of child diagnosis: stability and relations with child attachment across the toddler to preschooler transition. *Journal of Family Psychology*, 20 (1), 100-107.
- [6] Bradley, R.H., Whiteside-Mansell, L., Brisby, J.A. & Caldwell, B.M. (1997). Parent's socioemotional investment in child. *Journal of Marriage and Family*. 59(1), 77-90.
- [7] Button, S., Pianta, R. C., & Marvin, R. S. (2001a). Partner support and maternal stress in families raising young children with cerebral palsy. *Journal of Developmental and Physical Disabilities*, 13, 61- 81.
- [8] DeMarle, D. J., & le Roux, P. (2001). The life cycle and disability: experiences of discontinuity in child and family development. *Journal of Loss & Trauma*, 6, 29-43.
- [9] Filipova, S., Vajraktarov, S., Krstevska Kokormanova, B., Durmishi, N. (2021): Живот со аутизам - предизвици и стратегии за поддршка. „Софија“. Богданци.
- [10] Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, 42, 58-71.
- [11] Graungaard, A. H., & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development*, 33, 296-307.
- [12] Green, S. E. (2007). We're tired not sad: Benefits and burdens of mothering a child with a disability. *Social Science and Medicine*, 64, 150-163.
- [13] Hanak, N. (2012). Prenatalna afektivna vezanost i psihološki procesi tokom trudnoće: priprema za roditeljstvo. U: Stefanović-Stanojević, T., Mihić, I., Hanak, N. (Ur.), *Afektivna vezanost i porodični odnosi: razvoj i značaj*. (str. 57- 81)Beograd: Centar za primenjenu psihologiju.
- [14] Kearney, J. A., Britner, P. A., Farell, A. F., & Robinson, J. L. (2011). Mothers' resolution of their young children's psychiatric diagnoses: associations with child, parent, and relationship characteristics. *Child Psychiatry and Human Development*, 42 (3), 334-348.
- [15] Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34 (5), 582-592.

- [16] Krstić, T. (2013). Majke hronično ometene dece: Prihvatanje dijagnoze i prevladavanje stresa. Doktorska disertacija, Univerzitet u Novom Sadu Filozofski fakultet odsek za Psihologiju, Novi Sad.
- [17] Krstić, T., Bugarski, V., Brkić, N. i Obradović. B. (2013). Odnos majke prema detetovoj dijagnozi cerebralne paralize. *Medicinski pregled*, 66(3-4), 181-184.
- [18] Larson, E. (1998). Reframing the meaning of disability to families: the embrace of paradox. *Social Science & Medicine*, 47 (7), 865-875.
- [19] Leerkes, E.M., & Burney, R.V. (2007). The development of parenting efficacy among new mothers and fathers. *Infancy*, 12, 45-67.
- [20] Lin, S-L. (2000). Coping and adaptation in families of children with cerebral palsy. *Exceptional Children*, 66(2), 201-218.
- [21] Ljubešić, M. (2013). Kako govoriti o prognozi razvojnog ishoda. In Grubić M., Ljubešić M., & Filipović-Grčić (Eds.), *Kako reći neželjenu vijest* (pp. 57-73). Zagreb: Medicinska naklada.
- [22] Lord, B., Ungerer, J., & Wastell, C. (2008). Implications of resolving the diagnosis of PKU for parents and children. *Journal of Pediatric Psychology*, 33 (8), 855-866.
- [23] Marvin, R.S. & Pianta, R.C. (1996). Mothers' reaction to their child's diagnosis: Relations with security of Attachment. *Journal of Clinical Child Psychology*, 25(4), 436-443.
- [24] Milshtein, S., Yirmiya, N., Oppenheim, D., Koren-Karie, N., & Levi, S. (2010). Resolution of the diagnosis among parents of children with autism spectrum disorder: association with child and parent characteristics. *Journal of Autism and Developmental Disorder*, 40, 89-99.
- [25] Ödman, P., Richt, B., & Öberg, B. (2009). Parents' conceptions of intensive group training. The case of cerebral palsy. *Disability and Rehabilitation*, 31 (4), 293-301.
- [26] Oppenheim, D., Koren-Karie, N., & Yirmiya, N. (2009). Maternal insightfulness and resolution of the diagnosis are associated with secure attachment in preschoolers with autism spectrum disorders. *Child Development*, 80 (2), 519-527.
- [27] Orme, D. M. (2005). A qualitative examination of mothers' resolution or non-resolution of their children's disability of Down syndrome or autism using a cognitive intervention. *The Qualitative Report Volume*, 10 (3), 561-592. Retrieved [on February 25, 2023], from <http://www.nova.edu/ssss/QR/QR10-3/orme.pdf>
- [28] Pianta, R. C., & Marvin, R. S. (1992a). The reaction to diagnosis interview. Unpublished materials. University of Virginia, Charlottesville.
- [29] Pianta, R. C., & Marvin, R. S. (1992b). The reaction to diagnosis classification system. Unpublished materials. University of Virginia, Charlottesville.
- [30] Pianta, R. C., & Marvin, R. S. (1993). Manual for classification of the reaction to diagnosis interview. University of Virginia.
- [31] Pianta, R. C., Marvin, R. S., Britner, P. A., & Borowitz, K. C. (1996). Mothers' resolution of their children's diagnosis: organized patterns of caregiving representations. *Infant Mental Health Journal*, 17, 239-256.
- [32] Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Rusell, D., Swinton M., Zhu, B., Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115, 626-636.
- [33] Rajić, M., Mihić, I., Krstić, T., Drezga, M. i Branković, J. (2015). Potreba za podrškom porodica dece sa smetnjama u razvoju: procena roditelja. Usmeno saopštenje na 11. Internacionalnoj konferenciji "Dani primenjene psihologije", Niš, 25-26. septembar 2015. Univerzitet u Nišu, Filozofski fakultet, Odsek za psihologiju, Knjiga rezimea 71. ISBN 978-86-7379-384-9.