

**Perceptions and Experiences of Parents of Children with Autism on  
Diagnosis and Treatment of Autism Spectrum Disorders: A  
Qualitative Research Study**

**Master of Public Health Integrating Experience Project**

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## **LIST OF ABBREVIATIONS**

**ASD**- Autism Spectrum Disorder

**US**-United States

**UK**-United Kingdom

**CDC**-Centers for Disease Control and Prevention

**WHO**-World Health Organization

**DSM**-Diagnostic and Statistical Manual of Mental Disorders

**LMIC**-Low -and middle-income country

**NGO**-Non-governmental organization

**ICDC**-International Child Development Center

**ABA**-Applied Behavior Analysis

**AMD**-Armenian Drams

## **ABSTRACT**

Autism spectrum disorders (ASDs) are complex life-long neurodevelopmental disorders, which affect a child's ability to relate to others. Epidemiological data suggests that globally one child in every 160 birth is diagnosed with ASD. In the United States, according to the Centers for Disease Control and Prevention (CDC) autism prevalence was estimated to be one in every 68 births in 2014. The lifelong nature of child's autism has deep implications for parents who face a wide range of challenges while caring for the child. Only a few studies have been conducted in low-and middle -income countries to understand how the health care systems of these countries meet the needs of children with ASDs and their families. This is the first study in Armenia to investigate perceptions and experiences of parents of children with autism and other stakeholders regarding diagnosis and treatment of ASDs. Qualitative semi structured in-depth interviews were conducted with 19 parents of children with ASDs (ages 3-19) who attended treatment centers in Yerevan, at the time of the interviews. Diagnostic and treatment system of autism was also explored by gathering data on the perspectives of 8 other stakeholders including policy makers and fieldwork specialists. Directed content analysis was used to analyze the data.

Many parents did not feel satisfied about the polyclinic pediatricians' competencies in caring for their children and the diagnostic procedures that were managed by psychiatrists. The most frequently mentioned challenges regarding treatment were the lack of family support programs, low access to free treatment services, high costs and insufficient number of services. Disconnected and uncontrolled actions of polyclinics, governmental bodies, and diagnostic and treatment services were commonly reported issue.

We recommend adapting a reliable tool by polyclinic pediatricians, which can promote early diagnosis of ASDs, and thus, early interventions for ASD treatment. We also recommend

to map all the centers that provide ASD services in Armenia, and license the frontline specialists of the organizations that are involved in ASD care to coordinate and control ASD service providers' activities and to provide the quality and continuity of the services.

## INTRODUCTION

Autism Spectrum Disorders are complex life-long neurodevelopmental conditions, which affect children's ability to communicate and interact with others.<sup>1</sup> Autism is a neurobehavioral disorder which is characterized by impairment of social relatedness, delayed and disordered communication, and preservative and stereotypic behavior patterns occurring in young children.<sup>2</sup>

ASD may range from mild to severe and can affect people differently.<sup>3</sup> Main characteristics of ASDs include communication problems (for example, with the use or comprehension of language), difficulty relating to people, things, events, or playing with toys and objects in unusual ways, difficulty adjusting to changes in routine and repetitive body movements or behaviors of their children.<sup>4</sup> Individuals' function can range from significant cognitive and language impairments to superior cognitive and language abilities. However, everyone on the autism spectrum does share challenges in social communication. Therefore, ASD is classified from mild to severe based on cumulative abilities of the individual (cognitive, behavioral, emotional, and other).<sup>4</sup>

ASD rates have grown globally in the past several years.<sup>5</sup> For example, in the US there has been an increase in autism rates during the past two decades. Such high rates in ASD could be explained by better detection of autism in countries like the US, the United Kingdom (UK), and Japan.<sup>5</sup> Another possible explanation can be the broader definition of ASD or the underreported ASD among children in lower income countries.<sup>6</sup>

Epidemiological data suggests that globally one child in every 160 birth is diagnosed with ASD.<sup>7</sup> In the US, CDC reports that in 2012 autism prevalence was estimated to be one in every 68 births.<sup>8</sup> Although there are not enough data on autism in low-and middle-income countries World Health Organization (WHO) reports that in 2013 about 1%-2% of the Asian,



European, and North American population were diagnosed with ASD.<sup>7</sup> ASDs in general are almost five times more prevalent in males than in females.<sup>9</sup>

In one study, conducted in 11 European countries (2007), the vast majority of the countries (91%) declared that public health departments gathered ASD data only when the person was diagnosed in a public health clinic.<sup>10</sup> It means that the prevalence of children with ASD who are diagnosed in private centers is still unknown in those countries.

Evidence about comparison of prevalence of autism in European countries and the US presents that systematic changes in survey methods, changing definitions, and case-finding methods, explain autism prevalence increases.<sup>11</sup> Therefore increased rates of autism are an urgent public health concern to further investigate and study.

ASD is in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)<sup>12</sup> including DSM-IV-Text Revision proposed diagnostic subcategories. Before the release of the DSM-5 there were five subtypes of this disorder: Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder while individuals with DSM-IV diagnosis of Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder not Otherwise Specified, should be given the diagnosis of autism spectrum disorder.<sup>12</sup>

The identification of ASD is possible by the age of two years but usually ASDs are diagnosed at the age of four.<sup>13</sup> Younger children (before the child's age of 3) benefit from the treatment more than older children.<sup>14</sup>

Nowadays, many methods are used for autism treatment.<sup>15</sup> Though each type of the treatment concentrates on specific aspect of child's development like cognitive skills, language skills, or sensor development, those may overlap with each other.<sup>16</sup> The most effective treatment

is a combination of specialized intervention with education programs, communication training (speech therapy), and social skills and behavioral training at early ages.<sup>16</sup> Children who have been diagnosed with ASD should be re-evaluated at times of transition (like from preschool age to primary school age), because the needs, strengths, difficulties of children with ASDs are changing periodically.<sup>17</sup>

Causes and contributing factors of autism are poorly understood though many studies have been conducted to explore them.<sup>18</sup> Research suggests the genetic etiology of ASD. More than 100 genes on different chromosomes may be involved in causing ASDs. People with autism have mutations in many of these genes. However, not everyone with autism has changes in every gene that scientists have linked to ASDs.<sup>18</sup> One study demonstrated that siblings of children with ASD have 2% to 8% risk for ASD.<sup>19</sup>

Other researchers emphasize the environmental risk factors in ASDs. Environmental factors might interact with genetic susceptibility to ASD.<sup>20,21</sup> Several studies support the hypothesis of the associations of ASDs among children and maternal gestational diabetes, pregnancy-related factors, like bleeding.<sup>22</sup> Thus, studies on autism etiology often yield inconsistent results and only a handful of autism risk factors like genetic, neurobiological and environmental risk factors are broadly accepted.

### **Parents' perceptions and experiences with ASD diagnosis**

Based on the American Academy of Pediatrics and the American Psychological Association recommendations, diagnosing an ASD takes two steps: 1) developmental screening and 2) comprehensive diagnostic evaluation.<sup>23</sup> According to the CDC, every child should be

screened for developmental challenges during regular well-child visits from birth to 24 months of age.<sup>24</sup>

Because of the variability in symptom type and severity, diagnosis requires "multidisciplinary" approach— multidisciplinary team of specialists' evaluation of the child.<sup>4</sup> It means no singular approach can be applicable for the diagnosis of ASD. Initial diagnostic tests and some validated autism screening tools are used to detect ASD or other developmental disabilities.<sup>25</sup> The guidelines of the American Academy of Pediatrics and the American Psychological Association improved the identification of ASD.<sup>26</sup> According to the European Autism Information System, some European countries do not follow specific protocols for diagnosis and treatment of children with ASDs.<sup>10</sup> Children are identified with ASD in private centers, in some countries they are identified as children with mental health problems, or there is no clear rule about the institution that is responsible for ASD diagnosis.<sup>10</sup>

Many studies show that families' experiences to obtain a diagnosis for their children are full of challenges.<sup>27</sup> <sup>28</sup> The process of diagnosis is made after a thorough evaluation, such as clinical observations, parent's interviews, physical and social developmental histories.<sup>29</sup> Diagnostic process of ASD can be complicated as behaviors often seen in a child depend on other factors as well, like child's age.<sup>30</sup> Accurate diagnostic assessment is a key for treatment planning.<sup>30</sup> Studies reported about dissatisfaction with diagnostic centers in many countries due to uncertainty of further actions of parents and time consuming stressful process.<sup>31</sup><sup>32</sup> The time when a child is diagnosed with ASD parents usually need to know about the causes, features of ASDs, and the importance of their role in helping their child.<sup>31</sup>

## **Parents' perceptions and experiences with ASD treatment**

The terms “treatment”, “therapy” or “intervention” are used interchangeably. ASD treatment types can be grouped into the following categories: Behavior and Communication Approaches, Dietary Approaches, Medication, and Complementary and Alternative Medicine.<sup>33</sup> The first method which requires intervention of a specialists team was very much accepted by parents and specialists and has already established its effectiveness.<sup>33</sup>

After the diagnosis of autism, parents' immediate reaction is a shock, increasing stress because of the day-to-day struggle for caring for a child with ASD.<sup>34</sup> In many countries, particularly in low- and middle-income countries (LMICs), autism remains a mystery for many parents.<sup>35</sup> Parents have poor access to necessary services including special education, speech therapy, and behavioral therapies among others. Even accurate information on ASD is not provided to them. An Iranian study demonstrated that LMICs' experiences show that some gaps in autism treatment services are due to a lack of trained personnel and low levels of literacy. In those countries ASD treatment services are only available in larger cities and probably only families with higher income have access to them.<sup>35</sup>

A study which was conducted in the US reported about 24% parental dissatisfaction with services referring to waiting time before receiving services, an inconvenient schedule of treatment and location of facilities.<sup>36</sup> Many studies indicated that parents' involvement in treatment for their children is perceived by them as a strong therapeutic alliance with the therapists. These findings underscore the importance of parent awareness of autism, autism treatment process and parents' impact on treatment effectiveness.<sup>37</sup>

Researchers have reported about higher stress level among parents of children with ASDs compared to the parents of children with other disabilities such as Down syndrome or other

mental development problems of children.<sup>38</sup> Some studies have shown that mothers of children with ASDs have poorer health (problems with cardiovascular, endocrine, and immune systems) than mothers of normally developing children,<sup>39</sup> and mothers tend to experience poorer health compared with fathers.<sup>40</sup> The degree of severity of ASD is highly correlated with parental stress.<sup>41</sup> The results of many findings indicate that parent's involvement in treatment activities lead to increases in parents' wellbeing and generalized increases in child's social functioning, including child eye contact and verbal initiations.<sup>41</sup> The structure of family relationships might be changed after ASD diagnosis because mothers might feel that they are required to pay more attention to the children with ASDs rather than the other children in the family.<sup>42</sup> Mothers of children with ASDs feel isolated from the family and society as they feel that there is lack of understanding of autism by the others.<sup>42</sup> Their social relationships decrease in quantity and quality also because of busy schedule of ASD treatment and stigma related to autism.<sup>43</sup>

Autism can negatively influence financial well-being of individuals, their families, and society as a whole.<sup>44</sup> In 2014, autism related costs have reached \$236 billion in the United States. Lifetime costs for one individual with autism and intellectual disability are more than \$2.3 million in the US and \$2.2 million in the UK.<sup>44</sup>

Children with ASDs need more medical expenses than those without ASDs. It is estimated that medical expenditures for individuals with autism are four to six times greater compared to those children without ASDs. The authors reported about too much expenditure on medications, special food, and safer equipment for their children.<sup>45</sup>

## **Autism in Armenia**

Armenia has experienced socioeconomic decline since the collapse of the Soviet Union. Economic conditions have had negative influence on the health care system in the country. Particularly, health issues of people with mental disabilities have not been properly addressed.<sup>46</sup> In a study conducted in 2005, it was reported that Armenian people with mental health problems faced unavailability of treatment services. Limited financial resources in most hospitals and other health care institutions prevented those organizations from providing even basic health care services.<sup>46</sup> Particularly those problems were more common in health care organizations located in small cities and rural areas, where the access to professional support services were extremely limited.<sup>47</sup> Findings of mental health sphere attested that in Armenia many people tried to hide or deny mental illness of their family member and even refused professional help because of stigmatization.<sup>46</sup>

Official statistics on autism prevalence in Armenia are not available. Based on non-official information from the representative of Minister of Health of Armenia ASD new cases for 2007 were 725, while for 2015 the number of ASD new cases was 1059.

The major centers in Armenia which provide some special services to the children with ASDs are ArBES<sup>48</sup> health care center and "My way" non-governmental organization (NGO)<sup>49</sup>. Mainly NGOs provide treatment/rehabilitation services to the children with disabilities including ASDs. Also there are some private centers that provide treatment services and are not officially registered. There is no centralized information on diagnosis of the beneficiaries and type of services the centers provide.

In 2014 the Minister of Health of Republic of Armenia ordered to follow a guide for early diagnosis and treatment provision named "Guide for providing early detection and early intervention activities for children with developmental disorders".<sup>50</sup> The "Guide" reports about child's development evaluation stages. The first stage is a child's health assessment by polyclinic pediatricians with the help of "Aerton's scale", which is a diagnostic tool for the early detection of developmental problems of children. In case if some problems are detected the child should be assessed by the developmental pediatrician, neurologist, rehabilitation physician, and psychiatrist (second stage). The third stage includes referral to any health care center or rehabilitation center for early intervention and for the child's health evaluation by multidisciplinary team of specialists. Parents involvement is considered to be crucial in all staged of early detection of developmental problems and early intervention.<sup>50</sup>

Since 2005 ArBES has been providing diagnostic and treatment services to children with ASDs.<sup>48</sup> It provides free services to about 70 children with ASDs and also pays for services including rehabilitation, psychosocial services as well as educational activities for children with ASDs.

The International Child Development Center (ICDC) (the largest organization for children with ASD in Armenia) declared that children with ASDs had received no care and autism had been regarded as a mental illness until the first treatment centers opened in 2006.<sup>51</sup> Since 2012, ICDC has been providing treatment services by "My way" training and rehabilitation center which adopted Applied Behavior Analysis method (ABA)<sup>52</sup> to work with children with ASDs.<sup>49</sup> It provides different services including psychological, speech therapy, integrative sensory and occupational therapies, and other services. Currently, more than 110 children are involved in the program, notwithstanding many children are still on the waiting list.<sup>49</sup>

Children with disabilities including children with ASDs are involved in inclusive school program in Armenia starting 2005.<sup>53</sup> The goal is to assure that, all mainstream educational schools in Armenia provide inclusive education to the children with disabilities in the country after assessing the severity of disability by August 1 of 2025. Within the scopes of the assessment project of Open Society Foundation in Armenia (2014)<sup>54</sup> the quality of the inclusive educational program is considered to be very low, because the school buildings do not have the necessary infrastructures and are not provided with special equipment for children with disabilities. Besides, children with disabilities are not provided with individual educational or other specific services at schools, and the teachers are not trained enough to work with children with disabilities.<sup>54</sup>

Though autism is a developing disorder that has been identified and diagnosed worldwide, many studies reported about the lack of data on diagnosis and treatment of ASD in LMICs, including Armenia. WHO recognizes the need to create new services or strengthen health care systems that support all people with autism spectrum disorders and their families and identifies key principle of quality, also the importance of affordable, equitable, accessible and available diagnostic and treatment system.<sup>7</sup>

Investigating the perceptions and experiences of parents of children with ASDs in Armenia can help to understand whether the health care system in the country adequately meets the needs of children with ASDs and their families. In addition, it is important to obtain data from the other stakeholders (including policy makers, administrative representatives of diagnostic/treatment centers, therapists, psychologists and health care providers) to have holistic picture of parents' perceptions and experiences of their children's ASD diagnosis and treatment.

Thus, the study will address the following research questions:



What are the perceptions and experiences of parents of children with autism on diagnosis and treatment of Autism Spectrum Disorders in Yerevan?

What are the other stakeholders' perceptions and experiences on diagnosis and treatment of young children with Autism Spectrum Disorders in Yerevan?

## **METHODOLOGY**

### **Study design**

This qualitative study produced rich descriptions of parents and other stakeholders' perceptions and experiences regarding diagnostic and treatment processes of young children with ASDs in Yerevan. Semi-structured in-depth interviews with parents and stakeholders were conducted. It allowed collecting in-depth data from the respondents about feelings and attitudes most important to them. The stakeholders were policy makers, administrative representatives, therapists, psychologists and health care providers of diagnostic/treatment centers of Yerevan.

### **Study population**

Two groups of participants were involved in this study.

1. Parents of children between ages 3-10 years diagnosed with Autism Spectrum Disorders who attended ASD treatment centers in Yerevan.
2. Stakeholders included policy makers, administrative representatives and frontline workers (therapists, psychologists and health care providers) of the diagnostic and treatment centers of Yerevan. Those centers were governmental, private and non-governmental facilities. The administrative representatives and frontline workers were recruited from three types of facilities of Yerevan in order to gather comprehensive data on diagnostic and treatment procedures of those centers. The policy makers were recruited from the child health and child protection departments of the Ministry of Labor and Social Affairs, the Ministry of Health of Republic of Armenia of Republic of Armenia.

In this study, children were preschool<sup>55</sup> and primary school age<sup>56</sup> children in Armenia. Preschool children are from the age of 3 to 5. This age range of children (3-5 years old) is chosen based on the fact that the early intervention (before the age of 3) is pivotal for treating a child with ASD. However, the mean age of diagnosis of “autism” is four. Therefore, the treatment experiences for children of 3-5 age group is very much different from the treatment experiences of the other age group children not only considering the differences of treatment services based on child’s age but the major gains from the treatment for this particular age group.

Primary school age children are from the age of 6 to 10. Children diagnosed with ASDs need to be re-evaluated in transition period, demanding needs-based treatment. The transition from preschool to grade school is one of such examples. In particular, ASD treatment process includes special education program.<sup>57</sup> Given that the child treatment requires modification and therefore additional intervention, there was a high need to study parents’ and other stakeholders’ perceptions and experiences in that regard, particularly for the age group of children from 6 to 10 (preliminary school age) as well.

### **Data sources**

Data was collected through semi-structured individual in-depth interviews. Additional data on child's age, duration and frequency of the attendance to the treatment center, the treatment methodology were collected from the documents of the treatment centers.

### **Participants' recruitment and data collection**

The directors of the treatment centers of children with ASDs gave their agreement to provide the student investigator with the contacts of parents, administrative representatives, and

frontline workers. The student investigator approached the directors of those centers with official letter from American University of Armenia. Official letters from AUA were sent to the chief of the staff of Ministry of Labor and Social Affairs, and Ministry of Health of Republic of Armenia to contact with the policy makers. The student-investigator contacted the other stakeholders by phone. The student-investigator was provided with the list of parents of children with ASDs and the schedule of their children's treatment sessions so that the she was able to meet parents in the treatment centers. The student-investigator explained the aim of the study and the study procedures and obtained their agreement to participate in the study. The study participants were scheduled for interviews after their agreement to participate in the study. The interviews were conducted anywhere appropriate to the study participants such as treatment centers and homes of parents, and workplaces of other stakeholders.

### **Interview Guide**

Two semi-structured interview guides (Appendix 7 and Appendix 10) were used to conduct the interviews: one guide was designed for parents and the second one for the stakeholders. The questions in the guide were asked irrespective predetermined sequences of the questions depending on the interview process. The interview guide of a study on the experiences of immigrant parents of children with autism in the Somali community ("Somali's study")<sup>58</sup> was used while developing the guide for the research; the questions were adapted for the local context to assure the questions were clear and understandable for the participants . Additionally, parents were asked questions on demographic information at the end of the interviews (Appendix 8), since some demographic characteristics could also impact on parents' perceptions and experiences of ASD diagnosis and treatment of their children. The questions of parents

interview guide focused on perceptions and identifications of autism, the process through which their children were identified as having autism and experiences and challenges getting needed services. The interview guide for other stakeholders focused on questions about their roles in ASD diagnosis and treatment processes and specifics of diagnostic and treatment services in Armenia. All the participants were asked to provide recommendations to improve services for families with a child with autism. The data collection was stopped after we achieved data saturation.

### **Data management**

All interviews were audio recorded with the study participants' permission. In case, if they refused their interview being recorded, the student investigator requested permission for taking notes during the interview.

All the recordings were translated from Armenian into English and were transcribed. As the participation in the study was anonymous, each participant was identified by his/her own identification (ID) number on the transcript. No personal identifiers like names, phone numbers, addresses, and work places were collected. All the recordings had passwords and were destroyed after completion of the study. Only student investigator and advising team had access to the data.

### **Data analysis**

Inductive approach to the data analysis was applied, and content analysis was utilized to analyze the data.<sup>59</sup> Demographic data were analyzed using “Microsoft Excel 2010 Spreadsheet Software”.

Data obtained from study participants was coded by words, meaningful phrases and sentences, which were helpful to identify categories and themes. The results were organized and manually analyzed according to the most common three themes that emerged. Descriptions elicited from the content analysis were based on study participants' specific perspectives. Information from study participants were collected without predetermined codes, categories and themes. The information obtained from parents of children with ASDs was triangulated with the other sources (other stakeholders) to understand the perceptions and experiences of parents of diagnosis and treatment of ASDs. This approach improved the credibility of the study.

### **Ethical considerations**

Parents of children with ASDs and other stakeholders gave their oral consent (Appendix 2 and Appendix 4) before starting the interviews. Parents were informed about the emotional concerns that the interviews might cause while talking about their experiences with their children's diagnosis and treatment. The participants were assured that the information that the student investigator gathered from them would be used for study purposes only. The quotes from study participants that were used in the study were de-identified. Data collection started after the Institutional Review Board of the American University of Armenia reviewed and approved the study protocol.

## **RESULTS**

### **Socio-demographic characteristics of participants**

Parents (16 mothers and 3 fathers) of children with ASDs were interviewed within one month to explore their perceptions and experiences regarding diagnosis and treatment of ASDs. In addition, 8 stakeholders (policy makers, administrative representatives and frontline specialists of autism treatment centers) were also interviewed. Overall, 26 in-depth interviews were conducted. On average the interviews lasted about 50 minutes. Four interviews with parents were conducted at homes, and fifteen in the centers where children with ASDs attended to receive treatment services. Psychosocial counselling followed the interviews with 3 mothers with mean session duration of 20 minutes.

The mean age of mothers was 36 years, ranging from 26 to 44. All of them were residents of Yerevan except one, who was a resident of Abovyan city. The vast majority of the interviewed parents had university education, was married and had two children, and almost half of them were unemployed at the time of the study (Table 1).

Out of eight stakeholders, two were psychologists, one was a speech therapist, one was a pediatrician (rehabilitation specialist), two were administrative staff representatives (program manager and director of the center- art therapist) and two participants were policy makers. All the stakeholders were interviewed in their workplaces, and the mean duration of interviews was 40 minutes.

From 18 children, whose mothers were interviewed, 15 were boys and 3 were girls. The mean age of children was 6 years, ranging from 3 to 10 years. From 18 children only 6 attended inclusive schools or inclusive kindergartens, others were not involved in the inclusive preschool and school education system.

## Perceptions of Autism

**Autism as a new concept in Armenia:** All parents mentioned that Armenian families know very little about autism. In addition, participants themselves had not been aware of the disease before having children with ASDs.

All mothers mentioned that autism was accepted differently by the society members due to lack of public awareness about the issue. People react in different ways to a child's disability. Sometimes they could be supportive, but many parents mentioned being dismissive and judgmental about children with disability. The most frequently reactions that parents mentioned was fear and avoidance of any contact with those children and their parents. Even parents, before having their child with ASD had similar reactions. One of the mothers reported:

*I was not aware of autism when I first met a child with ASD. We were guests in one of my friends' home. I was observing their child's behavior. I was so scared, that decided not to take my daughter to their house any more.*

*Mother of 4y/o twins*

Some parents and stakeholders mentioned that before having a child with ASD, they learned about autism from films. They pointed that in films autism was described as a disease that was common among extremely talented individuals, adding, that *that assumption was very far from the reality.*

Few stakeholder did not share the same opinion with the others reporting. They thought that nowadays autism is much spoken about on TV and in social networks. They added that there was a new tendency to organize charity programs for children with ASDs in order to increase awareness about ASD. Regarding the suggestion above one of the parents mentioned:



*"Even though autism is frequently discussed, society has steel distorted imagination about the disease".*

*Mother of 10 y/o girl*

As stakeholders noticed parents whose children had excessive or repetitive behavioral issues applicable to children with ASDs avoided taking their children to the public places, like cinemas, parks, yards. Sometimes people were not sure how to respond so they might say unhelpful or even hurtful things, even if they did not mean to. For example *"I am so sorry for your child", "Why does he/she do it?", "he/she looks normal but his/her behavior is strange".*

*Instead of encouraging and motivating you, people around can break you. So your hope is your husband and some relatives. Can you imagine the situation of women who are alone?*

*Mother of 4 y/o boy*

Majority of parents explained that when children were young, parents felt more comfortable with them in public places as their children's behavior were not obviously different from same-age peers' behavior. Child's behavior was not explained by any health problem but usually it was accepted as a part of "normal" development. Therefore, parents held onto the notion that the child would "grow out" of the behaviors.

*No one can guess if my child has autism, because he is still young. I do not want to imagine what will happen if he gets older. I do not want to imagine that.*

*Mother of 4 y/o boy*

Some participants reported about those who kept in secret their children's autism and hired specialists to attend their homes for their children's treatment. This was particularly related to the parents who had high social status and were famous in the society.

**Stigma related to autism:** Many parents noted about stigma surrounding autism which was a common theme in several of the interviews. Vast majority of parents mentioned that they became more vulnerable when people around could not differentiate autism from mental health problems. They sorrowfully pronounced the words “*idiots*” or “*retarded*” as frequently useful labels addressed to their children by the society members. One mother commented:

*My child is not mentally disabled. Children with mental problems look differently, like children with Down syndrome. My son is normal, he is autistic.*

*Mother of 6 y/o boy*

Regarding parents' sensitivity to the reactions of strangers one of the parents commented:

*As soon as the doors of the N6th bus (the bus to the treatment center) are opened I feel like the doors of heaven are opened. We can get out of the bus and I can breathe the air without the words “ill-mannered”, "schizophrenic" or "dumb child".*

*Mother of 5 y/o girl*

Autism is contradictorily perceived even by health care specialists as reported by some participants. For example, for the primary pediatrician of one of the participants children with autism were “*stupid and god save from that misfortune*”, while the gynecologist of one of the mothers defined autism as a disease of “*genius*” people.

**Identification of autism by family members:** Almost all study participants used the word “denial” when asked about how families reacted to receiving the diagnosis of autism.

Families initially reacted with denial possibility of the child to have any disease.

*I cannot agree with the specialist' assumptions. For example, they gave my child to align the cubes and he aligned the cubes from bottom to the top. The doctor said that it was one of the autism symptoms. I did the same experiment with the other children from his college and they did the same. So do all the children have autism?*

*Mother of 4 y/o boy*

Many parents mentioned that children's grandparents and fathers refused to believe in their children's diagnosis because they were not highly involved in the diagnostic and treatment processes. Family members' unawareness about autism was explained by being "*far from the problems of the child*".

Some parents reported that denial of the diagnosis was highly related to the fact that their children did not have developmental issues before the age of two. But in majority of cases some parents felt a loss of dreams that they initially had for their child with autism. They questioned themselves, wondering if they had done something wrong, and worried about the others' reactions. When trying to figure out what was going with their child sometimes they perceived autism symptoms as individual characteristics of their child. One of the parents explained:

*Within the symptoms you see some characteristics. I thought that my son is like my father. He is also accurate person and likes things to be in their places. I am still thinking about it.*

*Mother of 10 y/o boy*

However, as the vast majority of parents mentioned, they eventually accepted their child's diagnosis, even if they initially denied autism.

All parents declared that they were well informed about autism and mentioned internet as the main information source. All of them emphasized importance of early intervention for autism treatment. They used «*state*», «*developmental disorder*», «*functional disability*», «*developmental retardation*», «*emotional misbalance*», and in majority of cases, «*behavioral problems*» concepts while describing autism. All the participants mentioned about «*child's disability to have social communications*».

*They know quite a lot, but they do not know how to express their knowledge.*

*Father of 5y/o boy*

*The worst side of autism is that when the child does not have friends, nobody around will help him/her because he/she does not have communicative skills even to ask for help.*

*Psychologist*

One of the stakeholders noted that many parents avoid using the concept of "disease" while describing autism. During the interviews only three parents perceived autism as a "*serious disease which is not cured by medicine*".

**Perceptions of the risk factors of autism:** The idea that autism is a new concept, and most of the participants indicated about lack of knowledge about autism condition. Parents had different perspectives about causality of autism. Participants questioned risk factors of the disease developing their own theories about it. Only one mother was sure about genetic causality of autism despite she did not have anyone from her relatives with ASD. Some participants believed in different explanations of the risk factors *like child's stress, pain or fear from something*.

As mothers mentioned anger and blaming for their child's autism is common for family members which comes from not fully understanding the condition of autism. Some mothers mentioned that *mothers-in-law believe in genetic causation of autism*, and, particularly, *autism perceived to be inherited from mothers*.

*Though I have rhesus-negative blood type I did not have any difficulties during pregnancy and child delivery my mother-in-law connects my child's autism with my blood type.*

*Mother of 3y/o boy*

Almost all the parents and half of the other stakeholders spoke about the immunization concerns and vaccination as the main reason for ASD development. Some parents accused their pediatricians either for being less respectful toward their complaints or having financial incentives for vaccinations, or for the low quality of vaccines.

*When I took my son to the doctor for vaccination, he had some metabolic problems. Though I informed my pediatrician about my child's health condition she did not pay attention on it. He was vaccinated and it was the main reason for autism.*

*Mother of 3y/o boy*

*Before vaccination he was able to say certain phrases. Autism symptoms occurred 4 days after the vaccination: he stopped speaking and lost his eye contact. I used my personal connections and found out that for that period vaccines that were imported to Armenia were of low quality and were not kept in appropriate conditions.*

*Mother of 6 y/o boy*

Almost all parents did not welcome technology development because they considered it as a contributing factor for autism. One of the stakeholders believed in direct impact of high technologies on autism development:

*I worked in different marzes of Armenia and I did not meet autism cases in those marzes. In Yerevan high technologies are more developed that is why autism cases are much more here than in other cities of Armenia. Autism is a disease of developed countries*

*Art therapist*

## Diagnosis of ASDs

**Delaying diagnosis:** The diagnostic processes, starting from the time when parents connected with first-point-of services, till the diagnosis of autism, took parents about 8-12 months. Procrastination of diagnosis was mainly due to the lack of referrals to the appropriate diagnostic centers. Three stakeholders mentioned that though parents noticed the symptoms quite early (usually at the age of 2) they often waited to go to see a specialist. Generally, they chose to wait to enroll in diagnostic services because they wanted to see if the problem went away on its own. According to all participants, families' delayed in enrolling children in diagnostic services due to specifically understanding the childhood development process.

*"It is normal that child starts speaking at four years old, even at five...why not? Every child is individual"; my family members used to say. We did nothing until my child became 6. All our neighbors, relatives had different opinion about my child's development. I was alone with my worries.*

*Mother of 7y/o boy*

*My husband started to speak when he was four, and we all thought that our son is like his father. So we were waiting until he turned to four.*

*Mother of 9 y/o boy*

Some parents reported that having a child older than the child with ASD was helpful to identify autism symptoms earlier compared with those mothers who did not have other children. Majority of the participants reported about delayed speech as the main reason why parents asked for health care providers' help. Several parents mentioned that the explanation of child's delayed speech by family members and specialists was two languages spoken around the child since their birth. Consistent with this assumption one of the mothers reported:

*We speak Russian and Armenian at home. My son's speech was delayed and we thought that he was very nervous because he could not concentrate at any language. We hoped that when he started speaking he would stop his repetitive movements, which we called neurotic behavior due to speech delay.*

*Mother of 10 y/o boy*

Almost all stakeholders declared that the polyclinic pediatricians have a great role in early diagnosis of ASD. Regarding the reasons of delayed diagnosis almost half of the parents thought that polyclinic pediatricians were unaware of new diseases, including autism, particularly pointing out older pediatricians. Therefore, as parents mentioned, they could be frustrated for spending much time on inappropriate referrals of polyclinic pediatricians.

*I described all the symptoms to our pediatrician and she referred us to the doctor to check my child's hearing. I said that it is impossible. I switched on his lovely music in the dining room, and he entered dining room. Then I switched on the music in his room he entered his room.*

*Father of 4y/o boy*

*She (polyclinic pediatrician) is a soviet woman with soviet approaches and she knows nothing new. I do not like her. I will never ask her for advice. Once I did that mistake and lost our golden times for treatment.*

*Mother of 7 y/o boy*

One of the stakeholders declared about the polyclinic pediatricians' demotivation to learn and to do something without any incentives. She came up with that idea when their organization conducted a pilot program among polyclinic pediatricians. The goal of the program was to train polyclinic pediatricians to use a new validated tool to detect children's (who were registered in



their polyclinics) early developmental problems. After the evaluation of pilot program they found that majority of diagnostic tests were incomplete.

A pediatrician explained:

*Though we trained them and explained about the importance of early diagnosis pediatricians were indifferent toward the program because the procedure was not mandatory by the government and there were no financial incentives for them.*

*Pediatrician*

**Searching for treatment before diagnosis.** Parents reported about variable ways Armenian families first access the system of diagnostic services. Generally first point-of-services were pediatricians' services of polyclinics (where they were registered). Parents, whose children did not have obvious symptoms of autism, rather than speech delay, usually approached to the speech therapists.

As majority of parents mentioned after facing autism symptoms they did not follow the pediatricians' advice to wait and started searching for services to understand the health issues of their children. The consequences of those activities were waste of resources because of attending from one center to another, and from one specialist to another.

Related to the issues mentioned above one of the stakeholders noted:

*Our pediatrician advised us to wait and not to get in panic. I was not sure that everything was as perfect as she thought. Then I decided to take my child to the speech therapist. We had no results even after 6 months. I spent 5000 Armenian drams (AMD) for each half an hour session. My child's health became worse and worse till the time we got final diagnosis and started treatment with a new program.*

*Mother of 6 y/o boy*

Almost all parents mentioned that before final diagnosis they had received speech therapists', psychologists', neurologists', pediatricians' services. Those specialists were from development or rehabilitation centers, health care facilities or they provided private services.

*If the child has autism and he/she does not speak it is not just a speech delay. Specialists' approaches are different in case of autism and pure speech delay. I think speech therapist should require diagnosis of the child before intervention.*

*Speech therapist*

Only two parents reported about competent specialists from kindergartens and collages who noticed autism symptoms in their children and referred parents to the diagnostic centers.

*Very few kindergarten principals include speech therapists and psychologists. Usually those organizations are private ones and provide paid services. I hardly remember cases when those specialists notice childhood development problems and refer for ASD diagnosis, but I am glad to notice some changes in this field.*

*Pediatrician*

**Accessing diagnostic services:** Participants explained that children were more likely to be identified with autism first by neurologists and psychiatrists of polyclinics. After the child's examination, in case of detecting developmental issues, they referred parents to one of the rehabilitation centers of Yerevan where the final diagnosis were provided by the psychiatrist of the center. One of the stakeholders reported:

*It's like a monopoly of diagnostic service provision. Everyone takes their children to the psychiatrist of B... (Rehabilitation center) for examination. The guide requires team evaluation,*

*but he/she puts the diagnosis herself/himself. So sometimes during the intervention we find out that the child is not autistic.*

*Pediatrician*

Almost all parents reported about the same diagnostic procedures: interviews from parents about the child's health and children's observation by the psychiatrist. As majority of parents mentioned, the overall process took them one visit which typically lasted between 10 to 40 minutes. Majority of parents were frustrated with the duration of diagnostic procedures conducted by the psychiatrist. Dissatisfaction was related not only to the *quick observation* of the child but also *non-collaborative approach* of health care providers.

*Before entering the psychiatrist' room we were waiting in the corridor at least for two hours. My child was nervous because he was hungry and tired. The psychiatrist did not take into account the situation. It took him/her just one visit and 10 minutes for the diagnosis.*

*Mother of 5y/o boy*

*During the examination my child touched everything in the room. I noticed that the psychiatrist got nervous. He/she was strict with me and my child. After the short examination of my child he/she identified diagnosis of autism and mentioned about the importance of early intervention. I did not know what to do and where to go, who to ask for help.*

*Mother of 5y/o girl.*

One of the other stakeholders explained the situation by the following way:

*The long waiting time for the psychiatrist and short term examination is usually due to the shortage of qualified psychiatrists that could identify ASD symptoms. This is because the profession is not attractive due to the heavy responsibilities and low remuneration of those specialists.*

As parents mentioned in some cases when symptoms were complicated children were examined not only by the psychiatrist of the rehabilitation center but the developmental pediatrician as well. Many parents reported that their children were not diagnosed with autism, but autism symptoms. They should be observed and evaluated by multidisciplinary team of specialists in order to receive final diagnosis. As participants mentioned intervention was highly depended on parents' opportunity to pay for intervention. Final diagnosis was provided by the psychiatrist of rehabilitation center based on the specialists' conclusion of child's health status.

One of the parents reported:

*The psychiatrist reported that my child had autism symptoms. We have attended the treatment center about 1.5 years and I have no idea when the final diagnosis will be provided. I heard that parents should initiate final diagnostic procedures themselves and push the team of specialists to organize the process.*

*Father of 5 y/o boy*

Some participants mentioned that usually parents asked the health care providers for final diagnosis to receive disability certificate for disability pension.

**Autism Impact on family members:** At least one of two parents described feeling drained by the diagnostic process and by learning how to care for the child with autism. Isolation was one of the most reported autism impact for family members. Some parents reported about the relatives and friends who avoided having any relation with them. Almost all parents mentioned that they met other parents of children with ASDs from social networks and the treatment centers they attended, and shared similar interests.

The other problem that majority of parents mentioned was passive socialization of parents, particularly mothers. Half of the parents were unemployed others who worked had part time job or they scheduled their job appropriate to the child's treatment hours.

Very few parents reported that they coped well with the challenges that autism brought. Only three mothers mentioned that they became *stronger* after diagnosis.

*I became active and initiative. For example I got license and now I drive a car, because I think that it's a necessity for me and my child.*

*Mother of 10y/o boy*

One of the parents mentioned that autism made her husband been positively changed.

*After ASD diagnosis my husband felt that he had a lot of responsibilities and he had to work harder for our child's treatment. He had significant successes in his career.*

*Mother of 10y/o girl*

Parents thought that children with ASDs missed out on educational, leisure and life experiences that others at their age took for granted. Many parents reported that in order to provide equal opportunities to the children with ASDs parents spend lot of resources.

*I want my child to attend dancing classes. The teacher said she had to be trained individually before joining the dance group. She asked 7000 AMD for one hour, while other parents pay 10.000 AMD for monthly trainings.*

*Mother of 10 y/o girl*

Few mothers mentioned that their children followed specific diet and took vitamins as complementary treatment methods, which required them additional expenses.

*I know that my child should eat 1.5 kg meat, eight quail eggs and other specific food per month, so we should redistribute our family income to provide dietary treatment. We (she meant herself, her husband and the other son) can eat cheaper food, we will survive.*

*Mother of 7 y/o boy*

The choice of treatment centers usually was based on the costs of the services and distance from their home places. Parents mentioned that their monthly expenses for ASD treatment ranged between 50.000-300.000 AMD. Very few parents did not pay for treatment at all. However, parents reported that accept for free services still additional chargeable treatment services were needed.

For some participants autism impact was devastating for the relationships with their spouses. In particular, two mothers mentioned about their divorces, some of them mentioned that they lived apart from their spouses or had distorted relationships with them.

Autism impacted on family planning as well. After the diagnosis all parents postponed the birth of the other child. Parents mentioned that siblings of children with ASDs suffered from living in a stressful environment. Some became care takers for their autistic brother or sister in an effort to help their parents.

*My younger child who is not autistic does everything herself though she is still 6. She does not attend to the dancing, drawing or other classes, because of scarce time, resources that are mainly concentrated on my autistic son's health improvement.*

*Mother of 7 y/o boy*

*"Mom, I am tired of autism and my role in this family....everything. Live me alone, I have my life" my daughter use to say, when I ask her to help me cope with her brother. She has completely lost her patience. I understand that and do not complain.*

## Autism treatment

**Features of treatment services:** All the parents described ongoing intervention to be effective for their children's growth. Parents specifically indicated working toward goals related to child's communication, interactive play and behavior. A multidisciplinary team approach for ASD treatment was preferable by all study participants. Only two of the centers where the interviews were conducted followed specific guidelines and programs for ASD treatment. Regarding treatment specifics of the centers one of the stakeholders commented:

*Many NGOs do not have a specific program for autism treatment. Their work is like complementary treatment, thus, not a real treatment. They should use specific and experienced techniques to provide effective results.*

*Pediatrician*

Treatment services were provided based on the child's needs and the parents' opportunities to pay for them. Each treatment center had its package of services. Children received from 2 to 9 hours of treatment services each week, and in some cases up to 12 hours. Three parents mentioned that besides attending rehabilitation centers their children went in for some sport therapies like swimming and hypo therapy.

Because of scarce resources, sometimes parents had to choose only the most vital treatment services, with the majority of participants choosing psychological and speech therapy. Few parents mentioned that they took their children for swimming or hypo therapy. For all parents continuous treatment sessions were important, and those parents who experienced interrupted treatment reported that their children regressed.

For some stakeholders the effectiveness of treatment was highly related to the treatment method. Parents did appreciate those specialists who expressed love and kindness towards children irrespective of the method used. For example:

*Specialists from abroad provide interventions using protocols. They will never hug your child, while in Armenia greeting or encouraging a child consists of kisses, hugs. Thanks God, they are not as robotized as the professionals in abroad.*

*Father of 5 y/o boy*

Few parents reported that after some time children needed changes in intervention methods or additional intervention because they did not have as much improvements as they had had at the beginning of the intensive treatment.

*I like wood therapy sessions. It has been years he attended the rehabilitation centers, but after two years I noticed that those sessions gave him nothing. Now he enjoys the time spending with the male teacher. His approach is something new for my child. He is strong and treats him like an adult. My son was tired of female teachers' "bla-bla-bla".*

*Mother of 10y/o boy*

**Challenges receiving treatment services:** Almost all parents noted long waiting lists of free treatment services. Some parents found solutions to avoid any waiting list, like simultaneously registering the child in different rehabilitation centers or using personal relationships to breach the waiting list.

*I registered my son in A... (Rehabilitation center) and in B... (Rehabilitation center). Now my son attends those two centers for free. None of the staff of those centers is aware about our attendance to the other center.*



*Mother of 4 y/o boy*

Some parents gained free services from two organizations while other parents remained in the waiting list for a long time or had to pay for services.

Regarding "benefits" of personal relationships one of the parents declared:

*It's a year and six month we are still in their waiting list and none called me since our registration. My friend called me and said that she had a relative who had some connections with the administrative staff of that center and who helped them to breach the waiting list.*

*Mother of 10 y/o boy*

Some parents indicated that desired services were only available at inconvenient times. Treatment hours coincided with parents' working hours or school and kindergarten hours. This was one of the reasons that a few parents gave as to why they became unemployed.

Stakeholders reported that one of the major problems was a lack of access to the services in every marz. They mentioned that rehabilitation centers of ArBES were located in only seven cities of Armenia. The costs of services at those centers are cheaper than the same services provided at ArBES rehabilitation center in Yerevan. As some parents mentioned those who lived near Yerevan city were able to take their children to some rehabilitation centers despite the high cost.

*We lived in Edjmiatsin which is not so far from Yerevan. Every day I had to take my child to Yerevan for inclusive school. Twice a week we attend rehabilitation center. During wintertime we missed classes and treatment sessions because of the time consuming and costly traffic.*

*Mother of 5 y/o boy*

All parents whose children attended the free centers reported feeling distrustful of paid centers. Almost every respondent has used paid services and reported lack of value of money

spent versus beneficial treatment outcome. Many parents mentioned that the quality of intervention varied among free and paid centers, but gave preference to free services.

*Nowadays many NGOs have autism services and they are out of control. Governmental organizations are easy to control. That is why free services, which are financed by government, have higher quality than the paid ones.*

*Mother of 9y/o boy*

Some stakeholders and parents mentioned disconnect as well as uncontrolled actions of policlinics, governmental bodies, and diagnostic and treatment services were common issues while receiving treatment. There was no directory of governmental, non-governmental, and private services, and parents used their personal connections to find diagnostic and treatment services themselves. Overall, participants were frustrated with the lack of follow-through in the system between one service provider to the next. The comment by this policy maker is an example of fragmented ASD services:

*Once a man called to our department, declared that his son had an autism and asked about the organizations that could help him. I had a book where all Armenian NGOs, that provide services to children in difficult situation, were registered and I could not find anything about autism services.*

*Policy maker*

*I did everything myself. I found specialists for diagnosis and for treatment. Pediatrician was not aware of those that provide diagnosis, intervention centers were not aware of each other or treatment differences. No one was aware of anything what they had in the field.*

*Father of 5 y/o boy*

**Services required:** The study participants mentioned the importance of preschool and particularly school education for the development of children with ASDs. The majority of parents noted unqualified specialists in kindergartens, child developmental centers, and colleges and schools who were unaware of autism. Parents reported that most classes needed a teaching assistant to help the child cope with learning. The lack of appropriate support compelled some parents to attend school along with their children. Very few parents said they hired a specialist to help their child at school.

Regarding dissatisfaction from unqualified specialists one of the parents mentioned:

*Once when he was 3 his teacher of kindergarten slapped him and after he used to stand in the corner, slap himself saying "stand there, bad boy".*

*Mother of 6y/o boy*

One of the stakeholders explained the situation differently:

*I had many conversations with teachers and they are not enthused about the inclusive program. They told me that they had many difficulties with those children as they cannot coach 30 children including autistic child.*

*Policy maker*

Majority of parents thought that their children, particularly those with behavioral problems, needed to be involved in some classes of physical activities like swimming, dancing, gymnastic etc. Some of the parents referred to the lack of specific services (classes for playing musical instruments, sport clubs) for children with developmental problems.

One of the major concerns of parents was a lack of treatment services for teenage children or adults with ASDs. This led to parents to perceive their children's future as unpredictable and hopeless.

*Imagine who will take care of this man when he becomes elder and I die. The government will take him to the psychiatric clinic and his life will end up there. So I think about donating my house to someone who will be responsible for my childcare after my death.*

*Mother of 10y/o boy*

When asked by the interviewer about disability pension, some parents mentioned that they had never thought about obtaining a certificate that verified their child's disability. Those parents also noted a requirement for advocacy services in treatment centers.

A collaborative relationship between family members and service providers was a common theme for some study participants. In one mother's opinion the collaboration between parents and service providers could contribute their spouses' engagement in the treatment, as fathers were not highly involved in treatment processes. Very few parents mentioned successful collaboration between parents and the other stakeholders.

*There were times when I pretended to have bad headaches. So I asked my husband to take the child to the treatment center himself. I did it, as I wanted to involve him in the treatment process. Then I called to the psychiatrist of the center and asked to provide professional counselling with him about his importance in our child's life.*

*Mother of 5 y/o boy*

**Parental engagement in treatment:** All the study participants emphasized the importance of parental involvement in the treatment process even if a child with ASD attended a treatment center and many specialists were involved in their care. They thought that one of their missions was to illustrate autism to society and many of them believed in the effectiveness of their work.

*I had to speak with the manager of the 6th bus, which is the only public transport that comes to the treatment center. I want to put a signboard in the bus with those words: "You can meet children with autism in this bus". People will be interested what is autism, they will go and search for it.*

*Mother of 6 y/o boy*

Parents mentioned needing skills and learning methods to cope with their children. Inclusion in the treatment process and the need to observe the work of specialists was highly regarded. Some parents mentioned that they had studied treatment techniques from parental support groups found on public web sites. They appreciated having an opportunity to learn from experienced parents, having them as friends, receive advocacy and referral to the competent specialists.

Many parents used to learn intervention techniques from the Internet and provide professional treatment sessions to their children. Some mothers reported that without any theoretical knowledge of techniques they *intuitively* used them to treat their children with autism. Later on they found out that those techniques were evidence based and were highly useful among specialists.

*I noticed that he learnt from computer easily. I videoed me explaining him about many things, like animals, numbers, colors, etc. Then he watched my videos and I saw that my child*

*immediately caught the information. Our psychologist told me that I used professional technique without being aware of that.*

*Mother of 4 y/o boy*

Two of the mothers reported a desire to control the work of treatment providers and their involvement in each step of the treatment process, with the explanation that they did not trust the providers. Despite the fact that all parents wanted to be involved in the treatment process some of them perceived themselves to be less skillful to do that.

Parents believed in the effectiveness of multidisciplinary team interventions and supplementary treatment methods. They used dietary supplements containing omega-3 and reported following healthy lifestyles including the exclusion of chemicals from their children's lives. One of the mothers mentioned:

*I read Armand Colin and follow his diet. Instead of soap, but we use soda. Instead of salt we use sea cabbage. Each day we have to walk at least 300 meters. Now my child does not have any metabolic problems but 8 months ago it was a chronic problem for my child.*

*Mother of 6y/o boy*

Some parents mentioned about their importance in their child's life, for example perceiving themselves as “*USB connection of autistic child and the real world*”, but they needed encouragement from family members and the society to be able to overcome “challenges of autism”.

*My husband says that I do everything for my child. So may be God chose me to have this child to take care of him appropriately, because I am very strong. He encourages me. It gives me a new breath to continue my mission.*

*Mother of 9 y/o boy*

All the participants emphasized the importance of including fathers in the treatment process. As mothers mentioned their major role was to earn money and cover treatment expenses.

*Fathers do not usually attend treatment centers. But if fathers are included in the treatment process the improvement is twice higher. They are like right and left hemispheres of the brain. Together is more effective.*

*Director of a center*

All parents and majority of stakeholders mentioned that many programs and some autism treatment centers in Armenia existed because mothers use them to obtain care for their children.

*Without parents' motivation none of the policy makers would commit any funds or programs for children with autism.*

*Father of 3 y/o boy*

## **DISCUSSION**

This study is focused on parents' and other stakeholders' perception and experiences of diagnosis and treatment of ASDs in Yerevan. One of the main findings of this study indicates that autism is a new concept in Armenia. Lack of awareness and understanding about autism is common among parents, which could contribute to stigma associated with ASD and prevent people from seeking proper care. Our findings are consistent with other work: stigma towards mental illness in Armenia are reported by several studies.<sup>60,61</sup>

Parents can experience stigma and misunderstanding about autism from people at school, among relatives and friends, in public transportation, etc. People react and respond in different ways to a child with a disability. Some are open and supportive, some avoid relationships with children and their families, and others are dismissive and judgmental about children with ASDs.

Specific perception of childhood development (for example four years old child's speech impediment will resolve on its own) could influence diagnostic delays of ASDs. In western countries, childhood development is assessed by a series of developmental milestones appropriate at certain ages.<sup>62</sup> Such practice has not been observed in Armenia. The study findings show that parents wait or are advised to wait until the problem resolves itself as a child's development is perceived to be very individual, irrespective of any guidelines on children's developmental expectations at certain ages. Armenian families' experiences of delayed diagnosis can be explained by the specific perceptions of childhood development milestones, which are consistent with outdated practices in western countries or in countries with less developed ASD services.<sup>63</sup>

Denial and anger among parents are common reactions after their children receive an ASD diagnosis. Similar to the results of other studies, the findings of this study show that



reactions are due to a lack of understanding of the disorder, doubting the diagnosis given, or disbelief that such a thing can happen to them and their children.<sup>62,64</sup> Denials of the diagnosis is common for all family members, particularly for fathers and grandparents who, in general, are not involved in the diagnostic and treatment processes and are not as informed about autism as mothers are. Lack of awareness on autism etiology makes family members blame health care providers for vaccinating their children or blame mothers for transmitting the condition genetically.

Many parents are suspicious that their children may have autism before receiving an official diagnosis. Symptoms of autism are first apparent at around 2 years of age, but speech delay is the primary symptom that compels most parents to seek intervention. In the majority of cases, pediatricians of polyclinics initially dismiss the concerns of parents of children with autism, which contributes to diagnostic delays. Parents think that this is because polyclinic pediatricians do not have skills and competencies to properly diagnose new diseases or are less respectful toward parents' concerns. Study findings are consistent with the suggestions of the "Autism speaks" website, by which early diagnosis are possible, when physicians do act on the concerns of parents.<sup>65</sup>

In addition, early intervention is highly dependent on diagnostic tools that are used by polyclinic pediatricians to detect early childhood developmental problems. "Autism speaks" offers "ADOS"<sup>66</sup> as a reliable screening tool to detect early childhood developmental problems, whereas Armenian pediatricians use the "Aerton scale" even though there is no evidence of its effectiveness.

Findings in this study indicate challenges for families when trying to access autism diagnostic services. Before final diagnosis parents try a number of interventions to "cure" the

child. Indeed, parents have expectations from treatment before diagnosis but are frustrated with how much money they have to spend compare with the treatment's outcome. Final diagnoses are provided by a psychiatrist at one of the rehabilitation centers in Armenia. In case if the child is diagnosed with "autism symptoms" multidisciplinary team evaluation of a child's health is provided.

Many parents are dissatisfied with diagnostic services available in Armenia, in particular brief examinations of children. Those findings are inconsistent with findings in other studies. In western countries, diagnosing ASD requires multiple screenings, interviews, multidisciplinary team evaluations of a child's health, and considerable parental involvement in each process.<sup>67</sup>

The lifelong nature of autism has significant implications on for parents. Their personal lives, careers, leisure time, health, and financial resources (traveling costs, special food, etc.) are affected due to the great effort needed to take care of a child with ASDs. Mothers who are the primary caregivers of children also describe having to give up desired career opportunities and restricting social relationships (for example having no friends and few relatives) to care for their children. One of the consequences of having a child with ASD is considered to result in either a strained or in rare cases strengthened marriage. In some cases marital relationships reach the point of divorce, or couples delay efforts to conceive another child. Some report prioritizing the needs of their child with ASD versus the needs of their healthy children.

Parents strive to improve their knowledge of autism by discussing it with other parents and searching the Internet to obtain information. They try anything that will help their child. Particularly, parents highly emphasize the importance of an emotional relationship between the parent and the child. It might be a benefit for professionals to help parents redefine their perceptions of the child in a positive way in order to cope with the child, which in literature is

known as positive coping.<sup>68</sup> Caring for a child with autism can result in emotional consequences such as stress, depression, feeling of loneliness, and uncertainty regarding not only the child's but also the family's future. Additionally, the child's challenging behavior, makes parents feel uneasy and different. Consistent with the literature, a child who exhibited "difficult" behavior is significantly associated with increased parental stress level.<sup>69</sup>

There are limited treatment options in Armenia. All the stakeholders of treatment centers and parents, consistent with the findings in the literature think that multidisciplinary team intervention is the best method for ASD treatment.<sup>70</sup> Only two of the centers in Armenia follow specific methods and techniques for ASD treatment. Majority of the centers intervene with the same unstructured program without any difference if the child has autism or other developmental disabilities. Nevertheless, parents appreciate these specialists more, who express love and kindness toward their children irrespective of the treatment methods used.

The most frequently mentioned challenge to get treatment services is unavailability and unaffordability of health care services and long waiting lists for free treatment services. These problems are the main reasons for parents to obtain fewer sessions for their children than they would eager to. Armenian parents refuse giving medications to their children even if those children have serious behavioral problems. They more tend to complementary dietary approaches, like healthy food usage and vitamins or supplements.

Disjunction and a lack of coordination between polyclinics, diagnostic and treatment services, and governmental bodies are identified as another common challenge while receiving treatment services. Despite the fact that none of the treatment centers follow the criteria of American Academy of Pediatrics and the National Research Council<sup>71</sup>, "Autism Speaks" and CDC (structure, direction, organization of treatment centers, family participation and at least 25

hours per week intervention)<sup>72</sup> parents are satisfied with improvements in their child's behavior after receiving treatment services from the centers they attend at the time of the interviews.

Difficulties in engaging parents in treatment for their children are also identified. Parents' involvement in the therapy is perceived to be beneficial by all study participants. Parents desire adequate communication with health care professionals with regard to the child's treatment in order to be informed and involved. However, none of the centers have specific family support programs. Majority of parents appreciate learning from the experienced parents, who can help them with advocacy, counseling about daily care and referrals to the "competent " specialists. They provide their assistance particularly through support groups of social media.

All participants emphasize the importance of education in children's life. Most express dissatisfaction from inclusive schools and kindergartens, blaming the poor capabilities of the preschool and school education system. Little knowledge of autism by school personnel, a lack of assistance to teacher and a child during the classes make problems in child's learning and involvement in school life. Findings of this study show that most parents lower their future expectations of the child. Main concerns of parents are about saving finances and to care for the child in the future.

### **Study strengths and limitations**

To our knowledge this is the first study in Armenia that obtained information from parents about their perception and experiences of diagnosis and treatment of their children's ASDs. In addition, besides parents' interviews, other stakeholders' interviews were also helpful to gain additional information about the parents' perceptions and experiences of diagnosis and treatment of their children's ASDs.

Almost all the interviews were conducted in the centers where children attended to get treatment services. Though parents were provided with consent form about the confidentiality of the interviews, parents could feel uncomfortable to speak about the weaknesses of the treatment centers where their children attended at the time of the interviews. Therefore, interviewing parents in those centers could influence our findings.

## **Conclusion**

The number of children diagnosed with ASDs is likely to rise throughout the world but Armenian society remains unaware about the disease and the implications of this condition. In general, autism and mental health problems are not differentiated by society, which could contribute to the stigmas faced by people with both ASD and mental health issues.

Autism has negative impact on a parent's psychological wellbeing and that of family members. Various external factors contribute to a parent's wellbeing such as family members' perception of autism, financial constraints, lack of social support, and flaws of health care practices and policies.

Health care providers, particularly pediatricians of polyclinics who deliver screening and diagnostic services, have a great role in referring parents to other health care providers for diagnosis to gain crucial time for early intervention. Some study participants mentioned that final diagnosis proved to be insufficient because of the quick observation of the child regardless the guidelines for diagnostic procedures of a child's developmental problems. Professional manner, which is perceived as a professional's expression of love toward the child, seems to be an important determination of parental satisfaction from treatment services, irrespective of the treatment methods used.

Paid services are unavailable for many parents. Waiting lists and a lack of centralized information about the treatment services make parents search and wait for services for their children for long periods of time. Despite the lack of family based services, parental involvement is considered beneficial for the effective treatment. None of the existing centers had family support programs that are sorely needed by parents and families of children with ASDs.<sup>73</sup>

## **Recommendations**

The findings illustrate that significant areas in ASD care and services that should be strengthened, particularly improving the availability of affordable, and accessible services, could meet not only the needs of children but that of the family. Our recommendation is to develop home visit services in Armenia through treatment centers or as a separate service that parents can obtain for their children. This kind of treatment has already proved its effectiveness in Western countries in terms of enhancing the development of young children with autism and providing higher engagement of family members in therapy sessions.

Early diagnoses are highly dependent on diagnostic tools that pediatricians use for early childhood development problems. Thus, there is a need to adopt a reliable tool (like "ADOS") instead of the "Aerton scale" that pediatricians would have to use.

Each kind of intervention can be essential for a child's wellbeing, or lack of intervention or poorly designed interventions could harm the child. Licensing frontline specialists of organizations involved in ASD care - including kindergartens, colleges, inclusive schools, and rehabilitation centers - are highly recommended. It is also important to allow specialists to intervene immediately after a diagnosis.

Mapping all centers that provide ASD services in Armenia is another recommendation. Centralized information could be helpful to coordinate the work of the organizations that provide ASD services in Armenia. Information about treatment centers' location, addresses, treatment methods, and prices should be provided also in handbooks for parents. These handbooks could serve as guides for family members to raise awareness about autism, and avoid inappropriate expenses while searching for ASD centers or qualified specialists for autism treatment.

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**Table 1. Socio-demographic and personal characteristics of parents of children with ASDs**

<b>Characteristics N</b>	<b>Characteristics N</b>
<b>Residence</b>	
1. Yerevan	18 (95)
2. Marzes	1 (5)
<b>Relationship with the child</b>	
1. Mother	16 (84)
2. Father	3 (16)
<b>Age, Mean (Range)</b>	36 (26-44)
<b>Marital status</b>	
1. Married	16 (84)
2. Divorced	2 (11)
3. Widowed	1 (5)
<b>Education</b>	
1. Professional vocational education	1 (5)
2. Institute/University or higher	18 (95)
<b>Employment</b>	
1. Employed	8 (42)
2. Self employed	1 (5)
3. Unemployed	10 (53)
<b>Number of children at home (including the child)</b>	
1. One child	5 (26)
2. Two children	12 (63)
3. Three children	2 (11)

## **Appendix 1.**

### **Consent form for parents of children with ASDs (English version)**

#### **American University of Armenia**

#### **Institutional Review Board #1**

Hello, my name is Manya. I am a social worker and a graduate student of the Master of Public Health program at the American University of Armenia. We are conducting a study to better understand the parents' perceptions and experiences of diagnosis and treatment of their children with Autism Spectrum Disorders.

You are invited to participate in this study because your child attends one of the centers of Yerevan which provides treatment services to the children with ASDs. Participating in the project only involves this interview that will last for up to 1 hour. The interview will be conducted at a time and place that are convenient for you. Your participation in this study is voluntary. There is no penalty if you refuse to participate in this study. You may refuse to answer any question or stop the interview at any time. There is no benefit for you from your participation in the study, but your participation is valuable for us in terms of better understanding parent's perceptions and experiences of diagnostic processes and treatment of children with ASD, so that we can make recommendations for improvement. The interview may cause some emotional pressure but after the interview I, as a social worker, will be able to provide you with psychosocial counseling. I work in a specialized children home and have seven years' experience working with parents of children with ASDs and other developmental issues.

The information provided by you is fully confidential and will be used for this study purposes only. Your name will not appear on the questionnaire and in any presentation of the

project. Quotes from your speech may be used in the project but will be identified as one of the parents' opinion without names and any other personal identifiable information. If you do not mind I would like to use audio-recording not to miss any information provided by you. It is perfectly within your rights to ask to turn off the recorder at any time during the interview, whenever you want to. My notes and the recording will be stored without any identifiable information about you, and will be destroyed after we finish the analysis of the data.

Before we start the interview, you can ask anything about your participation. If you have any questions regarding this study you can contact the Dean of the School of Public Health of American University of Armenia, Varduhi Petrosyan, at (060) 612592. If you feel you have not been treated fairly or think you have been hurt by joining the study you should contact Dr. Kristina Akopyan, the Human Subject Protection Administrator of the American University of Armenia (060) 612561.

Do you agree to participate? Please say YES or NO.

Thank you. If yes, shall we continue?



**Appendix 2.**

**Consent form for parents of Children with ASDs (Armenian version)**

**Հայաստանի ամերիկյան համալսարան**

**Հանրային առողջապահության ֆակուլտետ**

**Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով**

**Իրագրվող համաձայնության ձև**

Բարև Ձեզ, իմանալով Մանյա Եսսոնցի ակնաշխատող Եմ  
և միածամանակ սովորում էմ Հայաստանի ամերիկյան  
համալսարանի հանրային առողջապահության ֆակուլտետի  
մագիստրոսական ծրագրի ավարտական կուրսում: Մենք  
իրականացնում ենք հետազոտություն՝ առևտիզումնեցող  
երեխաների հիվանդությունն ախտորոշման և բուժման մասին  
ծնողներին ընկալումն և փորձնումն ստիբել համար:

Դուք հրավիրված եք մասնակցելու այս հետազոտությանը,  
քանի որ Ձեր երեխան հաճախում է առևտիզումնեցող  
երեխաների ծառայությունն ախտորոշող Երևանի կենտրոններին  
մեկը: Ձեր մասնակցությունը սահմանափակվում է միայն մեկ  
անհատական հարցազրույցով, որը կտևի մոտ 1 ժամ:

Հարցազրույցը կիրականացվի Ձեզ հարմար ժամին և Ձեզ հարմար  
վայրում:

Ձեռք մասնակցությունն այս հետազոտությունը կամավոր է :  
Ձեզ ոչ ինչ չի սպասում, եթե Դուք հրաժարվեք մասնակցել այս  
հետազոտությունը : Դուք կարող եք հրաժարվել պատասխանել  
ցանկացած հարցի կամ ցանկացած պահի ընդհատել  
հարցազրույցը : Հետազոտությունը մասնակցելով Դուք որևէ  
անմիջական օգուտ չեք ստանա, սակայն Ձեռք մասնակցությունը  
չափազանց կարևոր է մեզ համար, քանի որ դակոգնիավելի խորը  
ուսումնասիրել առևտրի գումարնեցող երեխաների ծնողներին  
փորձը, և հնարավորություն կտան լորտի քարելավման  
ուղղված առաջարկություններ կատարել այս խնդրով զբաղվող  
կազմակերպություններին : Այս հետազոտությունը կարող է  
հուզել Ձեզ, ես պատրաստեմ հարցազրույցի ավարտից հետո Ձեզ  
հետսոցիալ-հոգեբանական խորհրդատվություն անցկացնել : Ես  
աշխատում եմ երեխաների մասնագիտացված խնամքի կենտրոնում  
և ունեմ 7 տարվա փորձ՝ առևտրի գումարագացման խնդիրներ  
ունեցող երեխաների ծնողներին հետաշխատելու :

Ձեռք կողմից տրված տեղեկատվությունը գաղտնի է և  
կկիրառվի միայն հետազոտական նպատակներով : Ձեռք անունը  
զրված չի լինի հարցաթերթի կնիքի վրա և ծրագրային  
զեկույցներում : Ձեռք խոսքերից որոշ մեջբերումներ կարող են  
ներկայացվել զեկույցում, բայց դրանք կներկայացվեն որպես  
ծնողի կարծիք՝ անանուն և առանց անձը նույնականացնող  
տեղեկատվություն : Եթե դեմ չեք, ես կձայնագրեմ մեր

հարցազրույցը, որ պե ս զ ի ռ չ մ ի կ արևո թ ի ն ֆ ո ռ մ ա գ ի ա ր ա գ  
 չ թ ո ղ ն է մ : Ձ ե թ ի թ ա վ ա ս ու թ յ ան ս ա հ մ ան ն ե թ ու մ է պ ա հ ան ջ ե լ  
 ան ջ ա տ ե լ ձ ա յ ն ա զ թ ի չ ը հ ա թ ց ա զ թ ու յ ց ի ց ան կ ա գ ա ծ պ ա հ ի , ե թ ե  
 Դ ու թ դ թ ա կ ար ի թ ը զ զ ու մ է թ : Ի մ գ թ ա ո ու մ ն ե ը և  
 ձ ա յ ն ա զ թ ու թ յ ու ն ն ե թ ը կ պ ա հ պ ան վ ե ն ա ո ան ց Ձ ե թ ան ձ ի մ ա ս ի ն  
 տ վ յ ա լ ն ե թ ի և կ ո չ ն չ ա գ վ ե ն տ վ յ ա լ ն ե թ ի ա մ փ ո փ մ ան ա վ ար տ ի ց  
 հ ե տ ո :

Մ ի ն չ հ ա թ ց ա զ թ ու յ ց ը ս կ ս ե լ ը Դ ու թ կ ար ո ղ ե թ ի ն ձ Ձ ե թ  
 մ ա ս ն ա կ ց ու թ յ ան վ ե թ ա ր ե թ յ ա լ ց ան կ ա գ ա ծ հ ա թ ց հ ղ ե լ : Մ ու յ ն  
 հ ե տ ա զ ո տ ու թ յ ան վ ե թ ա ր ե թ յ ա լ հ ա թ ց ե թ ու ն ե ն ա լ ու դ ե պ թ ու մ  
 կ ար ո ղ ե թ կ ա պ հ ա ս տ ա տ ե լ Հ ա յ ա ս տ ան ի ա մ ե թ ի կ յ ան հ ա մ ա լ ս ար ան ի  
 հ ան թ ա յ ի ն ա ո ո ղ ջ ա պ ա հ ու թ յ ան ֆ ա կ ու լ տ ե տ ի դ ե կ ան Վ ար դ ու հ ի  
 Պ ե տ թ ո ս յ ան ի հ ե տ հ ե տ ն յ ա լ հ ե ո ա խ ո ս ա հ ա մ ար ո վ ` (060) 612592: Ե թ ե  
 կ ար ծ ու մ է թ , ո թ Ձ ե զ հ ե տ ճ ի շ տ չ ե մ վ ար վ ե լ կ ա մ ո թ և ե կ ե թ պ  
 վ ի թ ա վ ո թ ե լ ե մ հ ա թ ց ա զ թ ու յ ց ի մ ա ս ն ա կ ց ու թ յ ան ը ն թ ա գ թ ու մ ,  
 Դ ու թ կ ար ո ղ ե թ դ ի մ ե լ Հ ա յ ա ս տ ան ի ա մ ե թ ի կ յ ան հ ա մ ա լ ս ար ան ի  
 գ ի տ ա կ ան է թ ի կ ա յ ի հ ան ձ ն ա ժ ո ղ ո վ ի հ ա մ ա կ ար գ ո ղ ` Ք թ ի ս տ ի ն ա  
 Հ ա կ ո թ յ ան ի ն հ ե տ ն յ ա լ հ ե ո ա խ ո ս ա հ ա մ ար ո վ ` (060) 612561:

Դ ու թ հ ա մ ա ձ ա ղ յ ն է թ մ ա ս ն ա կ ց ե լ : Խ ն դ թ ու մ ե մ ն շ ե լ Ա Յ Ո կ ա մ  
 Ո Չ :

ԴռԼ ք համաձայն է ք, որ ես միացնեմ ձայնագրիչը: Խնդրում եմ նշել ԱՅՈԿԿԱՄ ՈՉ:

Եթե ԴռԼ պատրաստ էք, մենք կարող ենք սկսել:

### **Appendix 3.**

#### **Consent form for policy makers, administrative representatives and frontline workers of diagnostic and treatment centers of autism (English version)**

##### **American University of Armenia**

##### **Institutional Review Board #1**

Hello, my name is Manya. I am a social worker and a graduate student of the Master of Public Health program at the American University of Armenia. We are conducting a study to better understand different stakeholders' perceptions and experiences of diagnosis and treatment of children with Autism Spectrum Disorders.

You are invited to participate in this study because you are directly or indirectly involved in the diagnostic and treatment processes of ASD. Therefore you can provide valuable information on better understanding stakeholders' perceptions and experiences of diagnostic and treatment processes of children with ASD. Participating in the project involves this interview that will take up to 1.0 hour. The interview will be conducted at a time and place that are convenient for you.

Your participation in this study is voluntary. There is no penalty if you refuse to participate in this study. You may refuse to answer any question or stop the interview at any time. There is no financial or personal benefit for you from your participation in the study and there are no known risks to you resulting from your participation in the study. Your participation is valuable for us in terms of better understanding stakeholders' perceptions and experiences of diagnostic processes and treatment of children with ASDs, so that we can make recommendations for improvement.

The information provided by you is fully confidential and will be used for this study purposes only. Your name will not appear on the questionnaire and in any presentation of the project. Quotes from your speech may be used in the projects but will be identified as one of the stakeholder's opinions without names and any other personal identifiable information. If you do not mind I would like to use audio-recording not to miss any information provided by you. It is perfectly within your rights to ask to turn off the recorder at any time during the interview, whenever you want to. My notes and the recording will be stored without any identifiable information about you, and will be destroyed after we finish the analysis of data.

Before we start the interview you can ask questions about your participation. If you have any questions regarding this study you can contact the Dean of the School of Public Health of American University of Armenia, Varduhi Petrosyan, at (060) 612592. If you feel you have not been treated fairly or think you have been hurt by joining the study you should contact Dr. Kristina Akopyan, the Human Subject Protection Administrator of the American University of Armenia (060) 612561.

Do you agree to participate? Please say YES or NO. Thank you. If yes, shall we continue?

**Appendix 4.**

**Consent form for policy makers, administrative representatives and frontline workers of diagnostic and treatment centers of ASDs. (Armenian version)**

**Հայաստանի ամերիկյան համալսարան**

**Հանրային առողջապահության ֆակուլտետ**

**Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով**

**Իրագրվող համաձայնության ձև**

Բարեգործական և Մանկաբույժական աշխատողներ  
և միաժամանակ սովորողներ Հայաստանի ամերիկյան  
համալսարանի հանրային առողջապահության ֆակուլտետի  
մագիստրոսական ծրագրի ավարտական կուրսում: Մենք  
իրականացնում ենք հետազոտություն՝ առևտիզմում ներդրում  
երեխաների հիվանդությունները և բուժման մասին  
նրանք տարբեր շահագրգիռ կողմերի ընկալումները փորձ  
նում մասնավորապես համար:

Դուք հրավիրված եք մասնակցել այս հետազոտությանը,  
քանի որ ուղակի կամ անուղակի Դուք ներգրավված եք  
առևտիզմի ախտորոշման և բուժման գործընթացում: Հետևաբար՝  
Դուք կարող եք տրամադրել առևտիզմում ներդրում երեխաների  
հիվանդությունները և բուժման մասին տարբեր  
շահագրգիռ կողմերի ընկալումները և փորձի վերաբերյալ  
չափազանց կարևոր տեղեկատվություն: Ձեր մասնակցությունը  
սահմանափակվում է միայն մեկ անհատական հարցազրույցով,

նրը կտնի մոտ 1 ժամ : Հարցազրույցը կիրականացվի Ձեզ հարմար ժամին և Ձեզ հարմար վայրում :

Ձեր մասնակցությունն այս հետազոտությունում կամավոր է : Ձեզ ոչինչ չի սպառնում, եթե Դուք հրաժարվեք մասնակցել այս հետազոտությանը : Դուք կարող եք հրաժարվել պատասխանել ցանկացած հարցի կամ ցանկացած պահի ընդհատել հարցազրույցը : Հետազոտությունում Ձեր մասնակցությունը ֆինանսական և անձնական օգուտ չի բերի, սակայն Ձեր մասնակցությունը չափազանց կարևոր է մեզ համար, քանի որ դա կօգնի ավելի խորը ուսումնասիրել առևտրի գումարնեցող երեխաների խնդիրները և հնարավորություն կտան ընտրել քարտեղավմանն ուղղված առաջարկություններ կատարել այս խնդրով զբաղվող կազմակերպություններին :

Ձեր կողմից տրված տեղեկատվությունը լիովին գաղտնի է և կկիրառվի միայն հետազոտական նպատակներով : Ձեր անունը գրված չի լինի հարցաթերթի կնեքի վրա և ծրագրային գեկույցներում : Ձեր խոսքերից որոշ մեջբերումներ կարող են ներկայացվել գեկույցում, բայց դրանք կնեքի կայացվեն որպես շահագրգիռ կողմի կարծիք՝ անանուն և առանց անձը նույնականացնող տեղեկատվության : Եթե դեմ չեք, ես կձայնագրեմ մեր հարցազրույցը, որպեսզի ոչ մի կարևոր ինֆորմացիա քան չթողնեմ : Ձեր իրավասությունն սահմաններում է պահանջել անջատել ձայնագրի չը հետազոտության ցանկացած



պահի, եթե Դուք դրակարիքը զգում եք: Իմ գրառումներն  
ձայնագրումը յունները կպահպանվեն՝ առանց Ձեր անձի  
նույնականացման և կոչնչացվեն տվյալներին ամփոփման  
ավարտից հետո:

Մինչ հարցազրույցը սկսելը Դուք կարող եք ինձ Ձեր  
մասնակցումը անվերաբերյալ ցանկացած հարց հղել: Սույն  
հետազոտումը անվերաբերյալ հարցերում ներկայումս  
կարող եք կապ հաստատել Հայաստանի ամերիկյան համալսարանի  
հանրային առողջապահումը ֆակուլտետի դեկան Վարդուհի  
Պետրոսյանին հեռհեռույալ հեռախոսահամարով՝ (060)612560: Եթե  
կարծում եք, որ Ձեզ հետճիշտ չեմ վարվել կամ որևէ կերպ  
վիրավորել եմ հարցազրույցի մասնակցումը ընթացքում,  
Դուք կարող եք դիմել Հայաստանի ամերիկյան համալսարանի  
գիտական էթիկայի հանձնաժողովի համակարգող՝ Քրիստինա  
Հակոբյանին հեռույալ հեռախոսահամարով՝ (060) 612561:

Համաձայնեք մասնակցել: Խնդրում եմ նշել ԱՅՈ կամ ՈՉ:

Շնորհակալ եմ: Սկսե՞նք:

## **Appendix 5.**

### **Parent's Interview Guide (English Version)**

ID:

Interview Date:

Provide consent form.

Introduction of the topic:

As a parent of a child with ASD you are highly involved in diagnostic and treatment processes of autism and you could provide important information on it. As I already mentioned in the consent form, the aim of this interview is to understand your perceptions and experiences of diagnostic and treatment process of autism. I would like to mention that your answers will be helpful for recommendations to improve intervention services of Autism in the country. If you do not mind we can start our interview.

#### **Discussion Questions:**

##### *[Perceptions of ASDs]*

1. People have different ideas about autism. What do you know about autism, what is autism?

##### *[Identification of ASDs]*

2. What were some of the first signs suggesting that something was different about your child's development? What did you do after noticing those differences?
3. People often wait to go to see a specialist after they notice differences in their child; what are some of the reasons parents wait?

*[Diagnosis of ASDs]*

4. Can you describe your experiences of going through the diagnostic processes of ASD (Probes: how long did it take, who was involved in the process, what specialists examined your child, etc.)?
5. What were the main challenges while going through the diagnostic processes?
6. How did the diagnosis impact you, the child's siblings/other family members, your expenses and your relationships within and outside of the family?

*[Treatment of ASDs]*

7. What interventions have you initiated in the years since the diagnosis was made?
8. What kind of services does the intervention include (please describe frequency and length of the services as well)?
9. Tell us more about times when it was difficult or you had problems getting services that your child or family needed?
10. What do you like about receiving services under the intervention program(s)?
11. What would you like to change about receiving services under the intervention program(s)?

*[Recommendations]*

12. What resources, policies, or programs do you feel are MOST needed in order to serve children with autism and their families more effectively?
13. Given your experience, what could improve the diagnostic and treatment services for ADS in Armenia?
14. Is there anything else that we did not discuss but you think is important for this research?

If you do not mind we can end up with few questions about yourself.

## Appendix 6.

### Demographic Questionnaire for Parents (English Version)

1. Identification of child's parent
  - a. Mother
  - b. Father
2. How old are you? \_\_\_\_\_
3. Where do you live? \_\_\_\_\_
4. Date of your child's (with ASD) birth \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_
5. What is your marital status?
  - a. Married
  - b. Separated/Divorced
  - c. Widowed
  - d. Single
6. Indicate the highest level of education that you have received.
  - a. No education
  - b. School (10 years or less)
  - c. Professional technical education
  - d. Institute/University or higher

7. Are you employed?

- a. Yes
- b. Yes, but on maternity/pregnancy leave
- c. No
- d. Self-employed
- e. Seasonal worker or farmer
- f. Student
- g. Retired
- h. Other (specify) \_\_\_\_\_

8. How many children do you have (including the child/children with autism)? \_\_\_\_\_

*Thank you for taking the time to talk with me.*

**Appendix 7.**

**Parent Interview Guide (Armenian Version)**

Հարցազրույցի անցկացման ամսաթիվը :

Ներկայացվում է ' ' իրազեկ համաձայնություն և ձևը ' ' .

Ներածություն :

Լինելով առևտրի գումարնեցող երեխայի ծնող՝ Դուք մեծապես ներգրավված եք առևտրի գումարի ախտորոշման և բուժման գործընթացում և կարող եք չափազանց կարևոր տեղեկատվություն տալ այդ մասին: Ինչպես արդեն նշեցի, այս հետազոտությունն պատակն է պարզել առևտրի գումարի ախտորոշման և փորձի մասին Ձեր ընկալումն ու փորձը: Կցանկանայի նշել նաև, որ Ձեր պատասխանները կօգնեն մեր երկրում ծանայությունները բարելավելու ուղղությամբ առաջարկներ մշակել: Եթե դեմ չեք, կարող եմք սկսել հարցազրույցը:

**Քննարկվող հարցեր**

*[Առևտրի գումարի ընկալումը]*

1. Մարդիկ տարբեր պատկերացումներ ունեն առևտրի գումարի վերաբերյալ: Ի՞նչ գիտեք առևտրի գումարի մասին և ի՞նչ է Ձեզ համար առևտրի գումարը?

*[Առևտրի գումարի հայտնաբերումը]*

2. Որ ո՞նք էին առաջին նշանները, որոնց վկայել են, որ Ձեր երեխայի գարգացումը ինչ-որ կերպ տարբերվել է, և ի՞նչ արեցիք Դուք այդ տարբերությունները նկատելուց հետո:
3. Մարդիկ հաճախ ձգձգում են մասնագետին դիմելու գործընթացը իրենց երեխայի գարգացման մեջ նման տարբերություններ նկատելուց հետո: Որ ո՞նք են ծնողներին՝ մասնագետին դիմելու հետաձգման պատճառները:

*[Առևտի գմի ախտորոշումը]*

4. Կպատմե՞ք առևտի գմի ախտորոշման Ձեր փորձի մասին (որքա՞ն ժամանակ այն տևեց, ովքե՞ր էին ներգրավված այդ գործընթացում, ի՞նչ մասնագետներ են հետազոտել Ձեր երեխային և այլն):
5. Ի՞նչ խոչընդոտներ էին հանդիպել ախտորոշման գործընթացի կազմակերպման ժամանակ:
6. Ինչ ազդեցություն ունեցավ <<առևտի գմ>> ախտորոշումը Ձեզ, ձեր մյուս երեխաների, ընտանիքի այլ անդամների, ընտանիքի անդամների և ընտանիքից դուրս այլ մարդկանց հետ փոխհարաբերությունների, ինչպես նաև Ձեր ծախսերի վրա:

*[Առևտի գմի բնույթը]*

7. Որ ո՞նք են եղել Ձեր կողմից իրականացված միջոցառումները երեխայի մոտ ու տիզմ ախտորոշելու և ցիվեք:
8. Ի՞նչ ծառայություններ են երառում մասնագիտական միջամտությունը (խնդրում եմ նկարագրել նաև ծառայությունների ստացման հաճախականությունն ու տևողությունը, կիրառվող մեթոդները):
9. Խնդրում եմ մանրամասն պատկերացնեմք այն մասին, թե որքանով է դժվար կամ խնդրահարույց եղել այնպիսի ծառայությունների ստանալը, որոնք համապատասխանել են Ձեր երեխայի կամ Ձեր ընտանիքի կարիքներին:
10. Միջամտական/բուժիչ ծրագրերի ո՞ր ծառայություններն են Ձեզ դուր գալիս?
11. Ի՞նչը կցանկանայիք փոխել երեխային տրամադրվող բուժիչ ծառայության (ծառայությունների) մեջ?

*[Առաջարկություններ]*

12. Որ ո՞նք են այն ԱՄԵՆԻՑ անհրաժեշտ նեոնրուները, քաղաքականությունը, ծրագրերը, որոնք առավել արդյունավետ կլինեն աուտիզմով երեխաների և նրանց ընտանիքների համար:



13. Ելնելով Ձեր փորձից՝ նշեք խնդրեմ, ի՞նչը կարո է  
բարելավել աուտիզմ ունեցող երեխաների ախտորոշման և  
բուժման ծառայությունները Հայաստանում:

14. Կա՞ ինչ-որ բան, որ մենք չքննարկեցինք, բայց Դուք  
գտնում եք, որ այն օգտակար կլիներ այս հետազոտության  
համար:

*Շնորհակալ եմ ժամանակ հատկացնել ու համար:*

*Եթե դեմ չեք, կցանկանայի մի քանի հարց էլ Ձեր մասին տալ:*

**Appendix 8.**

**Demographic Questionnaire for Parents (Armenian Version)**

1. Հարցմանը մասնակցող երեխայի ծնողը
  - a) Մայր
  - b) Հայր
  
2. Քանի՞ տարեկան եք: \_\_\_\_\_
  
3. Որտե՞ղ եք ապրում: \_\_\_\_\_
  
4. Առևտրի գ մ ն ն ե գ ո ղ երեխայի ծննդյան  
ամսաթիվը \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_
  
5. Ամուսնակցության կարգավիճակը:
  - a. Ամուսնացած
  - b. Բաժանված /ամուսնալուծված
  - c. Այրի
  - d. Միայնակ
  
6. Նշեք Ձեր ամենաբարձր կրթական աստիճանը:
  - a. Կրթությունն չունեմ
  - b. Դպրոցական (10 ամյա կամ ավելի քիչ)

- c. Տեխնիկական կրթություն
- d. Բարձրագույն

7. Աշխատանքներ:

- a. Այն
- b. Այն, բայց երեխայի խնամքի արձակուրդում է մ
- c. Ոչ
- d. Ինքնագրաված
- e. Սեզոնային աշխատող
- f. Ուսանող
- g. Թոշակառու
- h. Այլ (նշել) \_\_\_\_\_

8. Քանի՞ մարդ է ապրում Ձեր ընտանիքում (Դուք էլ միասին): \_\_\_\_\_

9. Քանի՞ երեխաներ (ներառյալ աուտիզմ ունեցող երեխան):

\_\_\_\_\_

## **Appendix 9.**

### **Other Stakeholders' Interview Guide (English Version)**

*[The stakeholder's role]*

1. Let's start with talking about your role in ASD diagnostic and treatment processes. Can you describe your role (describe the supports you provide)?
2. How many years have you been working in this field?

*[Perceptions of autism]*

3. Generally, how do you think people in Armenia view Autism?

*[Diagnosis and treatment of ASDs]*

4. What kind of difficulties parents face while looking for diagnostic and treatment services their child needs? Among the difficulties you have mentioned which are the most important ones. Why?
5. How do families with a child with autism get connected with you/your agency/other appropriate agencies?
6. Describe the supports your agency/other agencies in the country provide to the children of ASD and their families?
7. What kind of difficulties the interventionists/agencies/policy makers face when they try to support families of young children with autism?
8. What resources, policies, or programs do you feel are MOST needed to better serve the needs of children with autism and their families?

*[Current and future trends]*

9. What are the current and future trends in the diagnostic and treatment services of children with ASD in Armenia?

*[Recommendations]*

10. Given your experience, what would be your recommendations to improve the diagnostic and treatment services for children with ASD in Armenia?

11. Is there any other information that you would like to share with the research team?

*Thank you for taking the time to talk with me.*

**Appendix 10.**

**Other Stakeholder's Interview Guide (Armenian Version)**

*[Շահագրգիռ կողմի դերը]*

1. Եկեք խոսենք առևտրի գնի ակտիվացման և բնութագրի գործընթացում Ձեր դերի մասին; Կնկարագրե՞ք այն (Ձեր կողմից տրամադրվող ծառայություններ)?
2. Քանի՞ տարի է աշխատում եք սույն ոլորտում?

*[Առևտրի գնի ընկալումը]*

3. Ի՞նչ է կարծում, հիմնականում մարդիկ ինչպե՞ս են ընկալում առևտրի գնը:

*[Առևտրի գնի ակտիվացումը և բնութագրումը]*

4. Ի՞նչ դժվարություններ են հանդիպում ծնողները իրենց երեխային անհրաժեշտ ակտիվացման և բնութագրի ծառայություններ փնտրելիս: Ե՞վ ած դժվարություններն են նրանք են ամենակարևորները: Ինչն է:
5. Ինչպե՞ս են առևտրի գնի երեխաները և տանիքները կապ հաստատում Ձեզ/Ձեր կազմակերպության, այլ կազմակերպությունների հետ:

6. Նկարագրեք խնդրեմ առևտիզմ ունեցող երեխային Ձեր կազմակերպություն/այլ կազմակերպությունների կողմից տրվող ծառայությունները:
7. Ի՞նչ խոչընդոտներն են հանդիպում երեխայի հետ անմիջականորեն աշխատող մասնագետները/կազմակերպությունները, քաղաքական գործիչները առևտիզմ ունեցող երեխաների ընտանիքներին աջակցություն ցուցաբերելու հարցում:
8. Որո՞նք են այն ԱՄԵՆԻՑ անհրաժեշտ նեոնրուները, քաղաքականությունը, ծրագրերը, որոնք արդյունավետ կլինեն առևտիզմ ունեցող երեխաների և նրանց ընտանիքների կարիքները բավարարելու համար:

*[Ներկայանալու ամիտումները]*

9. Որո՞նք են Հայաստանում առևտիզմ ունեցող երեխաների ախտորոշիչ և բուժիչ ծառայությունների ներկայանալու ամիտումները:

*[Առաջարկություններ]*

10. Ելնելով Ձեր փորձից՝ նշեք խնդրեմ, ի՞նչը կարող է բարելավել առևտիզմ ունեցող երեխաների ախտորոշիչ և բուժիչ ծառայությունները Հայաստանում:

12. Կա՞յ լի ն ֆորմացիա, որը կցանկանայ իք կիսել մեր

հետազոտող թիմի հետ:

*Շնորհակալ եմ ժամանակ հատկացնելու համար:*