

**Needs and Gaps in Education and Healthcare for Children with
Neurodevelopment Delays in Yerevan, Armenia:**

A Qualitative Study

Master of Public Health Integrating Experience Project

Professional Publication Framework

by

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Table of Contents

Acknowledgements.....	iii
List of Abbreviations.....	iv
Abstract.....	v
1. Introduction.....	1
1.1 Definition and Magnitude.....	1
1.2 Situation in Armenia.....	5
1.3 Territorial Pedagogical Psychological Support Centers and Multidisciplinary Team Members in Yerevan.....	7
2. METHODOLOGY.....	11
2.1 Study Design.....	11
2.2 Study Population.....	11
2.3 Data Sources.....	11
2.4 Data Collection.....	12
2.5 Interview Guide.....	12
2.6 Data Management.....	13
2.7 Data Analysis.....	14
2.8 Ethical Considerations.....	14
3. RESULTS.....	15
Socio-Demographic Characteristics of the Participants.....	15
Theme 1: Needs and Gaps in Healthcare for Children with NDDs.....	16
Subtheme 1.1 Delayed Diagnosis: Parents Identifying the Delay.....	16
Subtheme 1.2 Parents' Reluctance to Accept the Diagnosis.....	18
Subtheme 1.3 Availability and Affordability of the Treatment Services.....	19
Subtheme 1.4 Need in Psychological Support.....	20
Subtheme 1.5 Low Capacity to Meet the Needs of the Children.....	21
Theme 2: Needs and Gaps in Education for Children with NDDs.....	22
Subtheme 2.1 Child's Assessment for Educational Needs: Lack of Parental Consent.....	22
Subtheme 2.2 Schools' Experience in Inclusive Education Provision.....	24
Subtheme 2.3 Environmental Accessibility.....	25
Subtheme 2.4 Lack of Awareness.....	26
Subtheme 2.5 Lack of effectiveness of Services Provided by TPPSC.....	26
Subtheme 2.6 Lack of Cooperation between Healthcare and Education.....	28

Theme 3: Challenges of Socialization	29
Subtheme 3.1 Public Perception	29
Subtheme 3.2 Stigma	29
DISCUSSION	31
Study Strengths and Limitations	33
Recommendations	34
REFERENCES	36
Table 1. Characteristics of Participants of the Study Stakeholders in Yerevan, 2022	39
Figure 1: Main themes and subthemes of the study findings	40
Appendix 1	41
Appendix 2	42
Appendix 3	45
Appendix 4	47
Appendix 5	50
Appendix 6	53
Appendix 7	56
Appendix 8	58
Appendix 9	61
Appendix 10	63
Appendix 11	66
Appendix 12	68
List of Appropriate Journals	71

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List of Abbreviations

AUA – American University of Armenia

CDC – Centers for Disease Control and Prevention

CNS– Central nervous system

ENT – Ear Nose Throat

HIV – Human immunodeficiency virus

ICF – International Classification for Functioning

IDI – In-depth interview

IRB – Institutional Review Board

LMIC – Low and middle income countries

MPH – Master of Public Health

NDD– Neurodevelopment Delay

PHC – Primary Health Care

RA – Republic of Armenia

TPPSC – Territorial Pedagogical Psychological Support Center

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

UNICEF– United Nations International Children’s Emergency Fund

US – United States

Abstract

Background: Neurodevelopment delays describe the delay in the skill development of children compared to typical development. There is a tendency of increase in any development delay among children worldwide. According to the 2021 UNICEF Report, 93 million children aged 14 years and younger have severe or moderate development delays worldwide. There are 8000 registered children with disabilities in Armenia and this comprises one per cent of the child population according to the 2014 UNICEF Report. As children with disabilities are a vulnerable group, this study aims to understand whether healthcare and education systems adequately meet the needs of children with NDDs in Armenia and what are the existing gaps in both spheres. Specifically, the current study focuses on the following research questions: (1) what are the existing needs and gaps in education, (2) what are the existing needs and gaps in healthcare, (3) what are the perceived barriers to receive appropriate care and (4) what are the perceived barriers to receive appropriate education.

Methodology: A qualitative study was conducted through 13 semi-structured in-depth interviews with parents of children up to 18 years old with NDDs and different stakeholder groups: school principals, multidisciplinary team members, PHC pediatricians and Territorial Psychological Pedagogical Support Center (TPPSC) specialists. The participants were selected through purposive convenience sampling method. The data were collected in March 2022 face-to-face. Inductive approach was applied and content analysis was used for the data analysis.

Results: Twelve participants were females and one was male, their age ranged from 26-58 years. The specialists' work experience ranged from 7-32 years. The age of children (3 boys and 2 girls) ranged from 5-18 years. Three main themes were identified: (1) needs and gaps in healthcare; (2) needs and gaps in education; (3) challenges of socialization. It was revealed that parents themselves identified the delay and the diagnosis was delayed, they were reluctant to accept the diagnosis. The treatment services provided to children with NDDs from the state were very limited and the parents faced a serious financial burden to utilize private therapies. All the parents were in need of psychological support while going through the child's diagnostic process. The healthcare system faces difficulties in terms of early identification of children with NDDs due to lack of specific guidelines and trainings. As to the needs and gaps in education, lack of timely parental consent to child's assessment process might be a frequent reason for delaying the provision of tailored education to the child. It was revealed that the more experience the school had in inclusive education, the better it performed. The schools faced environmental accessibility issues as they had lack of ramps and other commodities needed for children with NDDs. Lack of comprehensive awareness of the issue was also identified among all the stakeholder groups and general population. The services provided by TPPSC were not effective enough because of lack of continuity. There was also no cooperation between healthcare and education systems. Public perception and stigma were identified to be the main challenges for parents and children to socialize.

Conclusion: The study identified the need of initiating NDD-related awareness rising activities among the general population and trainings among all stakeholder groups. In order to achieve early diagnosis and intervention for children with NDDs, healthcare services should be

enhanced. Environmental adjustments, as well as promotion of accessible education and review of individual education plans should be carried out in order to improve inclusive education. Psychological support should be provided to parents and family members during the diagnostic process and, if necessary, in the follow-up as well. Some measures should be undertaken to improve the team work between healthcare services and education providers, as well as parents. Also, further research to investigate the trends in NDD rates in Armenia is recommended.

1. Introduction

1.1 Definition and Magnitude

The term neurodevelopmental delay (NDD) describes delays in the skill development of infants and young children. There are a number of different definitions of NDD in the literature, however, they are all used to identify delays in one or more development domains compared to typical development.¹ Child development is a process of continuous acquisition of new motor skills, intellectual functioning, and adaptive behavior throughout childhood. Developmental delays may cause temporary or permanent disability.² The possible causes of mal-development of the brain may be different, including a number of perinatal and postnatal conditions and exposures. Some common causes of NDDs might be maternal gestational diabetes, increased unbound bilirubin levels in newborn, neonatal hypoglycemia, HIV infection, CNS infections (meningitis, encephalitis, brain abscess), nutritional abnormalities, and disorders of neuronal migration.³ Factors such as physical or social environment can affect the course and outcomes of NDDs.⁴ Almost all children have similar patterns and timing of neurodevelopmental skills. For instance, early development, which is considered from one to three years, is characterized by the development of gross motor abilities such as crawling, rolling, standing, walking and fine-motor skills, such as pincer grasp, self-feeding, drawing lines and circles.¹ The development of each skill is closely related to the development of other skills. Primary care physicians should identify developmental delays at routine check-ups and according to identified issues should direct the child to specialized developmental monitoring and screening.⁵ In high-income countries the early identification of a child having a developmental delay is one of the main characteristics of good healthcare provision. The American Academy of Pediatrics showed the importance of early identification for children with development delays which in most of the cases were missed. The

data showed that early identification and intervention, as well as specialized therapy care and necessary equipment utilization are important factors in supporting to the growing child to get the utmost benefit.⁶ Developmental monitoring means observing your child's growth to see whether your child is compatible with the typical developmental milestones, such as sitting, standing, speaking, moving, etc.⁷ Parents and other caregivers can be involved in developmental monitoring. Developmental monitoring can help to ascertain if your child's development is corresponding to the typical development and identify whether early intervention services might be necessary.⁷

Developmental Screening means observing your child's development more closely.⁸ It might be a quick test or a checklist about your child's development. Developmental and behavioral screenings are used to measure your child's development through different tools, such as questionnaires, checklists, tests, etc.⁹

The Canadian Task Force on Preventive Health Care studied the effectiveness of development screening and behavioral interventions on the population level, as well as the accuracy of screening tools in primary care settings.¹⁰ The American Academy of Pediatrics suggests that at all well-child visits children go through thorough examination, as well as at nine, 18 and 30 months they need to have standardized screenings.

Regarding the rates of NDD, it is difficult to ascertain true incidence rates of this condition on a larger scale, as there are multiple factors and barriers that make this process challenging both in high-income countries as well as in low and middle-income countries. These barriers include differences in healthcare access levels or application of different data collection methods and measurement tools for identifying NDD cases, as well as lack of direct measurements in some

countries and, hence, reliance on caregivers' reports, or official sources, such as service utilization.

According to the US National Health Interview Survey data, during the period of 2009 - 2017, there was a tendency of increase in any developmental disorder among children in USA, including autism, intellectual disability, attention deficit, etc.

US CDC studies have shown that for the period 1997 to 2008 the prevalence of developmental disabilities in the US was 13.7% which indicated that the number of children with development delays was 1.8mln more in the US in the period 2006-2008 than a decade earlier.⁶

In France, more than one million children are affected by NDD annually, which costs 20 billion Euros and by 2050 these figures will be tripled if no preventive measures are initiated.

Few studies about children with NDDs were conducted in low and middle-income countries and this might affect the planning of specific interventions in order to prevent NDD in these countries. The brain development is affected by childhood risks which are closely related to environmental factors, such as poverty, malnutrition, stress and this in its turn can result in deregulation of the hypothalamic-pituitary-adrenocortical system and the electrical activity of the brain regarding cognitive processing can be changed.³

Literature evidence shows that parents of children with disabilities face a lot of challenges, both emotional and financial, when they learn about the disability of the child. Some other factors that affect the parents' perceptions and experiences with NDD diagnosis are insufficient healthcare services, stigmas, family beliefs, etc.

A study conducted in 2016 estimated that 43 % of children under five living in low and middle income countries (LMICs) have developmental delays because of poverty, malnutrition and lack of access to basic services.¹¹

According to a study conducted in 2007, over 200 million children under 5 years, mostly from south Asia and sub Saharan Africa, obtain delays in cognitive development due to poverty, poor health, malnutrition and insufficient care.

A study assessing the experiences of parents and practices of healthcare professionals conducted in United Kingdom revealed that programs for information provision addressed to parents, support and collaboration of key specialists should be implemented. The parents in this study mentioned that during the diagnosis they were badly in need of information, particularly related to educational and social services, as well as there was lack of support from specialists.

Children with NDDs are frequently excluded and experience loneliness more in comparison with their peers.¹² Loneliness and social isolation might negatively impact both physical and mental health. Social interaction is a crucial component in human experience. The greatest benefit of inclusiveness is a society that values diverse identities of its members and develops into a strong community that makes our world a better place to live.¹³ A study in Uzbekistan found that inclusive education plays a vital role in children's social development.¹⁴ The literature review showed that another study conducted in Zambia revealed inclusive education only concerned children with special needs or disabilities.¹⁵ However, according to the UNICEF definition of inclusive education, all children are in the same classrooms; in the same schools. It means that inclusive education provides real learning opportunities for children with disabilities. Inclusive education allows learning and developing the necessary skills, growing side by side that everyone gains. Inclusive education implies that all students attend their neighborhood schools,

age-appropriate, regular classes and are supported to benefit in all the aspects of school life. Nowadays, treatments for NDD are symptomatic, but it would be better to stop the pathological process before symptoms appear. Ultimately, the effective way to this would be to identify high risk population who would develop NDD and the relevant predictive signs. The literature suggests administering potentially neuroprotective drugs to children at risk before the onset of symptoms or at the initial stage of the pathological process.

1.2 Situation in Armenia

There is no statistical information separately about NDDs officially published in Armenia. However, according to the annual statistical report by National Institute of Health in 2020, 1307 children from age 0 to 14 were first diagnosed to have mental disorders and 2517 children of the same age group were diagnosed to have neural system disorders.¹⁶

There are 8,000 registered children with disabilities in Armenia and this comprises one per cent of the child population according to the 2014 UNICEF Report. The 2012 UNICEF report estimated that 13 % of children with disabilities live in institutions; 18 % do not attend schools; 77 % aren't provided any rehabilitation services; and one-third of these children do not participate in any community events. Hence, children with disabilities are a vulnerable and marginalized group in Armenian society. According to the same report¹⁷, the available information on how many children with disabilities received services was very limited and did not reflect the actual situation in Armenia. One in five children with disabilities did not go to school. In rural areas, one in four children with disabilities did not go to school.

UNICEF also published a report on rapid assessment of publicly available data on children with disabilities in Armenia in January, 2019. The study showed that the unique source of information on children with disabilities are periodical publications of RA National Statistical Service and it

revealed that there is no statistical information on children with disabilities at pre-school settings.¹⁸

There is a considerable gap between the needs of children with NDDs and disabilities and the availability, accessibility and the affordability of services obtainable for them in Armenia.¹⁸

According to RA law “On Amendments and Additions to the Law on General Education” adopted on December 2014, a universal inclusive education system will be introduced in Armenia by August 1, 2025.¹⁸

Inclusive education is envisaged to ensure maximum participation in the educational process.

The inclusive schools provide necessary conditions and adapted environment in accordance with the specific needs of every child with disabilities. A three-level system for responding to the child’s needs is implemented in Armenia. Children with disabilities receive pedagogical and psychological support at three levels: public schools, territorial and republican pedagogical and psychological support centers.¹⁹

Though the first inclusive school in Armenia dates back to 2001, the perceptions of inclusive education and attitude towards it among general population are diverse. UNICEF 2012 report¹⁷ reflects the results of the survey conducted within the framework of “Approximation of Inclusive Education in Armenia to International Standards and Practices” project by Open Society Foundations –Armenia. According to it, 50% of survey respondents considered that a child with physical disability should go to a special school, whereas 86% of the respondents mentioned that if a child had an intellectual disability, he/she should go to a special school. At the same time, 83% of the respondents considered it acceptable for their child to have a classmate with physical disability, but only 48% of the survey participants found it acceptable for their child to have a classmate with intellectual disability.¹³

1.3 Territorial Pedagogical Psychological Support Centers and Multidisciplinary Team Members in Yerevan

Multidisciplinary team is functioning in inclusive schools and the school principal forms the team according to the needs of the children with special needs in the school. There is no fixed and strict composition of the multidisciplinary team. In general, multidisciplinary team members are recruited based on the needs of the school children. Multidisciplinary teams may include special teachers, speech therapists, oligophrenia teachers, sign language teachers, tiflo teachers, psychologists, social educators and teacher assistants. The primary role of this needs-based staff is to make sure that all children are effectively included in the classroom teaching and learning process. If a child has a difficulty in acquiring some knowledge or skill, they work with him/her individually after or in between of their classes to catch up with learning requirements.

There are 4 Territorial Pedagogical Psychological Support Centers (TPPSCs) in Yerevan. Every TPPSC itself provides services to 51-54 schools in Yerevan and only TPPSC 4 provides services to 78 schools.²⁰

If the school lacks some specialists, the TPPSC staff members visit the school and provide the services.^{21,22}

1.4 Study Aim

The review of the existing information sources indicates that healthcare and educational services in Armenia, as well as public perception of those with NDDs could be inadequate in terms of providing optimal conditions for development and social adaptation of children with NDDs. There is no research in Armenia that studied the existing barriers to adequate education and healthcare for children with NDDs, thus exploring the gaps and needs in education and

healthcare services from the perspectives of parents of children with NDDs, as well as from the perspectives of healthcare and education professionals in Armenia. Knowledge on these matters can assist to understand what can be done in education and healthcare system to improve the situation in the country. So the aim of this study is to understand to what extent the healthcare and education systems in Armenia and, particularly, in Yerevan, meet the needs of children with NDDs and what are the existing gaps in both spheres.

Thus, the study will address the following research questions:

1. What are the existing needs and gaps in education for children with NDDs in Yerevan?
2. What are the existing needs and gaps in healthcare for children with NDDs in Yerevan?
3. What are the perceived barriers to provide appropriate care for children with NDDs in Yerevan?
4. What are the perceived barriers to provide appropriate education for children with NDDs in Yerevan?

2. METHODOLOGY

2.1 Study Design

A qualitative study was conducted through in-depth interviews (IDI) with parents of children who have NDDs and different stakeholders from healthcare and education spheres, such as principals, school teachers, multidisciplinary team members (speech therapists, psychologists, special educators), primary healthcare providers from polyclinics, specialists from Children's Republican Rehabilitation Center, as well as specialists from Territorial Pedagogical Psychological Support Centers (TPPSC)¹.

Due to the paucity of information on the study topic in Armenia, qualitative research design provides more opportunities to understand the needs and gaps in education and healthcare for children with NDDs.

2.2 Study Population

The study participants included parents of children up to 18 years old with NDDs or any emotional disorder, primary healthcare providers, education and TPPSC specialists.

All the stakeholders were involved from different schools and healthcare institutions in Yerevan.

2.3 Data Sources

The data were collected through semi-structured in-depth interviews from key-informant groups in polyclinics, schools, Rehabilitation Centers and in TPPSC.

¹ TPPSC turned out to be key informant group during the data collection process

2.4 Data Collection

The recruitment process of the participants was carried out through purposive convenience sampling method through snowball technique as well as using personal network of the student-investigator. The healthcare and education professionals were selected from primary healthcare facilities; Children's Republican Rehabilitation Center, inclusive schools and the parents were involved from all these institutions. At the first encounter, the student-investigator approached the school principal and only after that met the school staff members as well as parents of children who were available at the time of the visit. The same concept was used in case of healthcare professionals. Regarding the parents of children with NDDs, the school staff members contacted the parents of children with NDDs and arranged a further meeting with the student-investigator. The school staff members also asked permission from parents of children with NDDs to give their contact information to the student-investigator and only after that the student-investigator contacted the parents and explained the aim of the study and arranged a further meeting for the in-depth interview. The in-depth interviews were conducted at a place and time convenient for the study participants such as Children's Republican Rehabilitation Center and workplaces of the stakeholders. During the data collection, the student-investigator ascertained another key-informant group: specialists from Territorial Pedagogical Psychological Support Center and conducted in-depth interviews with them as well.

2.5 Interview Guide

Four different semi-structured interview guides (see Appendices 5-12) were used for the in-depth interviews: for healthcare professionals, for education specialists, for parents of children with NDDs and for specialists in TPPSC (the latter was an adapted version of the guide designed for education specialists). The guides were developed by the student-investigator after reviewing

previous MPH thesis projects in similar fields.^{23, 24} The guides for education specialists included questions concerning the role of the specialists, their perceptions, the school admission process, perceived needs in education of children with NDDs, in their support, necessary resources, collaboration with other stakeholders, as well as suggestions for improvement. As to the interview guide with the healthcare professionals, the following domains were included: identification and diagnosis of NDDs, the treatment process, the needs in healthcare, service provision, collaboration with other stakeholders, as well as suggestions for improvement. The interview guide designed for parents included identification of the delay, follow-up steps, going through the diagnostic process, how the parents responded to the diagnosis and what effect it had on their families. The interview guide designed for parents also included sections regarding service provision, support, school integration process, public perception, the attitude of the peers and their parents towards the children, as well as collaboration of the stakeholders and suggestions for improvement. The data collection started at the end of March and was stopped after the student-investigator achieved data saturation.

2.6 Data Management

All interviews were recorded after obtaining the consent of the study participants not to miss any important information. All the recordings were transcribed. The student-investigator initiated ID numbers on each guide containing the demographic data. All the acquired data was stored without any identifiable information in the student-investigator's password protected laptop and will be destroyed immediately after data analysis. Only the student-investigator and the advising team have access to the data.

2.7 Data Analysis

All the interviews were transcribed verbatim. The student-investigator conducted the transcription and analysis manually. Inductive approach was applied and content analysis was used for the analysis. The acquired data from the participants were coded by words, phrases and sentences to identify categories and themes. The information from the study participants was collected without any predetermined codes, categories and themes. To enhance the trustworthiness and credibility of the data analysis triangulation and member checking techniques were applied.

2.8 Ethical Considerations

All the participants gave their oral consent (See Appendices 1-4) before starting the interviews. Parents of children with NDDs were informed in the beginning of the interview that they might go through emotional feelings when telling about the process of going through the diagnostic and treatment processes or when being admitted to school. All the participants were assured that the information provided would be used solely for the study purposes. The quotes from the study participants were used without any identifiable information. The data collection started after Institutional Review Board of the American University of Armenia had reviewed and approved the protocols of the study.

3. RESULTS

Socio-Demographic Characteristics of the Participants

Thirteen in-depth interviews were conducted with three pediatricians, three education professionals (school principals and a multidisciplinary team member), two TPPSC specialists and five parents (mothers) of children with NDDs. The data collection was conducted within one-month period. The mean duration of the interviews was 30 minutes. The interviews were conducted at the workplaces of the education and healthcare professionals and in TPPS centers. The parents were interviewed in Children's Republican Rehabilitation Center and one parent was interviewed at AUA.

The interviewed participants' age ranged from 26 to 58 years, while the specialists' work experience ranged from 7 to 32 years. The age range of children (3 boys and 2 girls) was from 5 to 18 years (Table 1). Children with diverse experience regarding their inclusion and socialization were involved in this study. All of the participants were residents of Yerevan at the time of interviews.²

Three main themes were identified by the student-investigator: (1) needs and gaps in healthcare for children with NDDs; (2) needs and gaps in education for children with NDDs; and (3) challenges of socialization. Under the first theme the following subthemes were covered: delayed diagnosis or parents identifying the delay, parents' reluctance to accept the diagnosis, availability and affordability of the treatment services, need in psychological support to parents, and low capacity of the healthcare system to meet the needs of the children. The second theme covered the following subthemes: assessment process: lack of parental consent, school staff experience in

² One parent lived in Stepanakert for two years and received free Rehabilitation services there.

inclusive education, lack of environmental accessibility, lack of awareness, lack of effectiveness in services by TPPSC, as well as lack of cooperation between healthcare and education. The third theme included the following subthemes: public perception and stigma.

Theme 1: Needs and Gaps in Healthcare for Children with NDDs

Subtheme 1.1 Delayed Diagnosis: Parents Identifying the Delay

One of the important findings of this study was that the parents themselves identified the issue and turned to the pediatricians at the child's age of two years and more. Only in one case the disability was detected at two months of age. All the PHC pediatricians mentioned that their role in diagnostic process was only identifying and referring the children to different specialists: neurologists, ENT (Ear nose throat) specialists, pediatric psychologists and development specialists. The healthcare professionals confessed they had problems with early identification of NDDs because of lack of tools, trainings, guidelines and protocols and because parents might be taking the children to the polyclinics very rarely. One of the pediatricians reported:

“It depends how frequently the parent brings the child to the polyclinic, if they come not so often, we might not identify the issue early, you can't force the parent to bring the child to the polyclinic, if the parent is educated, he/she might come with some complaints and then we refer [the child] to the relevant specialist”. (PHC Pediatrician, 53 y/o)

The pediatricians blamed the parent for not taking the children to the polyclinics in time and for bad cooperation, which results in delaying the early identification for the problem.

“In many cases pediatricians miss early identification of the development delay, as the parent is not from our team; they consider it normal that the child speaks late, reasoning that the parent or one of the relatives also spoke late”. (PHC Pediatrician, 47y/o)

Whereas the parents were of the opposite opinion, they described indifferent, unacceptable behavior of PHC pediatricians. Parents mentioned the specialists never followed up the child and in general they were all discontent with the diagnostic process and went through many challenges and difficulties. One of the parents stated:

“There is no need to go to PHC, the specialists are very rude, I had an awful experience there and the pediatrician used so offensive words in diagnosing the child. The situation in PHC facility is very bad: wrong diagnosis and treatment”. (Mother of 5 y/o girl)

Another parent expressed how ignorant approach she received while going through the diagnostic process:

“It took the pediatric psychiatrist 40 minutes to diagnose my child to have autism; she was just looking from side and announced the diagnosis. I didn’t know what that meant, I asked questions and received answers such as ‘go and read in the internet’, ‘time will show’, such situations...” (Mother of 18 y/o boy)

The parents also confessed that they didn’t treat the problem seriously at the beginning; they hoped that it would pass and referred to superstitious methods such as opening the church door in the morning, etc. and only after some time they turned to specialists.

“We found the issue with the child at the age of 2 years and 7 months, it coincided with the stress of going to the kindergarten and he fell very badly, we didn’t treat it seriously, thought it would pass, then we used traditional methods, the grandparents took him to the church in the morning to open the church door and it was a long journey until we realized what was going on”.

“Mother of 10 y/o boy”

All the parents had difficulties in the diagnostic process, one mother reported:

“At that time MRI was prohibited with anesthesia for kids, my daughter was 1 year and 2 months old and they referred us to another country, so we went through the diagnostic process in Italy”.

(Mother of 9 y/o girl)

Subtheme 1.2 Parents’ Reluctance to Accept the Diagnosis

The specialists noted that the parents were not ready to accept the diagnosis; most of them deny and refuse the professional conclusion. One of the pediatricians noted that parents’ initial reaction to the diagnosis was mostly reluctant:

“The patient doesn’t want to accept the news, the child doesn’t look in your eyes [the child avoids visual contact], the parent says, no, no, everything is all right, he doesn’t only say words and expressions, the majority of the parents resist”. (PHC pediatrician 53 y/o)

The parents themselves confessed that they were not ready for the diagnosis and it took them some time to accept the reality.

“I came home and denied for myself, why it happened to my child? I blamed the doctor, why she spoke so rudely to me? In the beginning there was immense resistance. For 4-5 months I did not imagine what was happening, I read and did not understand” (Mother of 18 y/o boy)

“It was so stressful, as if it was the end of the world. I denied and did not cope with the idea, and then you feel that you must accept, that it is for your child, it becomes normal and you are adjusted to the situation”. (Mother of 5 y/o girl)

The pediatricians mentioned that they encountered parents, who accepted the child’s diagnosis from the very beginning and it was helpful, but these were very rare cases.

“I can say we also meet very educated mothers who do not make a tragedy of the problem”.

The parents reported that when the problem was identified, they'd better start taking actions rather than waiting.

“If there is a problem and you understand what is it... I don't think when you sleep and wake up day by day, anything will change [waiting without action will not solve the problem]. You need to support the child from the very beginning”. (Mother of 10y/o boy)

Subtheme 1.3 Availability and Affordability of the Treatment Services

All the healthcare professionals indicated that the polyclinics provided no treatment. They referred children with NDDs to different facilities, including 3-4 rehabilitation centers in Yerevan. The pediatricians mentioned that the child is provided a limited number of referral certificates (four times per year) but if need be, they can somehow solve this issue. There was triangulation here, as the parents also mentioned that state services were limited and were not sufficient. Some of the parents mentioned that they were not provided any state rehabilitation services in Yerevan and utilized only private specialists' services.

“To tell the truth, we do not deal with the treatment, they go to the centers, we only see the results and we know from parents that they pay for most of the services”.

(PHC pediatrician 53 y/o)

“We were not provided any state services in Yerevan, we were only provided with free rehabilitation in Stepanakert [when living there], in Yerevan we found private speech therapists and psychologists that visited us at home and worked with the child”. (Mother of 10y/o boy)

“The state services are so limited that we do not make any use of it, we hire private specialists, who come home and provide the services”. (Mother of 9y/o girl)

“There is great financial burden on the parent: we provide some referrals, they go to the rehabilitation centers, but they [state-funded services] are not enough and the parent faces lots of financial issues, as these services are not cheap”. (PHC pediatrician 58 y/o)

There was triangulation regarding the financial burden on the parents and affordability of the services. The parents mentioned that all the good specialists were very expensive and they either could not afford these specialists or worked with all the family members to provide treatment for the child.

“The monthly pension that is given to us is not a dignified amount, it is hardly equivalent to the child’s one-day expenses for the therapies, we work with all the family members to provide my daughter with the necessary therapies”. (Mother of 9 y/o girl)

Subtheme 1.4 Need in Psychological Support

All the stakeholders mentioned that parents were in need of psychological support. The collected data triangulated on this. One of the pediatricians mentioned:

“The ‘treatment’ should start from the parent. If we do not provide psychological support to the mother, we will not have good results”. (PHC pediatrician 47 y/o)

“It happens that when speaking to the parent you realize that the parent is in need of psychological support more than the child”. (TPPSC Specialist 30 y/o)

“We were psychologically in very bad situation, until now when I remember I go deep into that psychologically very bad situation, I keep myself, I know that everything has already gone, we have overcome”. (Mother of 6 y/o boy)

“I think the majority of parents of children with special needs are mostly in need of psychological support”. (School Principal 47 y/o)

“Today the parent is alone with the problem. Most parents are in need of a psychologist, the parents also need support, it is very difficult for the parents that they are alone to overcome all these things. It is difficult both financially and psychologically, you need to experience yourself to understand. One thing is to work or educate a child with autism, quite another thing is to live with an autistic person”.

(Mother of 18 y/o boy)

Subtheme 1.5 Low Capacity to Meet the Needs of the Children

Healthcare professionals expressed their opinion that recently lots of screening projects had been launched, there were some new questionnaires and checklists such as M-CHAT (Modified Checklist for Autism in Toddlers),²⁵ but the most important gaps that almost all the pediatricians noted, were the lack of trainings and professional skills for right assessment of children with NDDs.

“I would like to note that pediatricians have not passed that qualification training to use the checklist, it is not just all about asking questions. Pediatricians do not have skills for right assessment, even based on the parents’ right answer: be it positive or negative”.

(PHC Pediatrician 47 y/o)

“We did not participate in any seminar or qualification training on autism for instance, all our knowledge comes from our experience and the literature. They [MOH specialists] need to work with us, so that we work better with the children. It would be better if we were provided some guideline or protocol at least”.

(PHC Pediatrician 53 y/o)

The pediatricians also mentioned that there was no clarity in the sphere as if the diagnosis is left to the parents’ discretion.

“There is no clarity, the borders are blurred, I can say that as if the diagnosis is left to the parents’ discretion, that is if you see negative approach and the parent is more reluctant to [accept the] development delay, you put the diagnosis of psycho-speech delays, and the gap is that the child can reach the age of 7 years and he/she has no [correct] diagnosis... We need to understand what the primary problem of the child is”.

(PHC Pediatrician 47y/o)

“There are gaps in the sphere: doctors do not know ICF [International Classification for Functioning] at all, but we have rehabilitation specialists who are very much familiar with the tool, but the thing is that these doctors are in the primary healthcare facility and they are the ones who see the children first. There are such gaps in the sphere”.

(PHC Pediatrician 53y/o)

Theme 2: Needs and Gaps in Education for Children with NDDs

Subtheme 2.1 Child’s Assessment for Educational Needs: Lack of Parental Consent

According to RA law on Education,²⁶ the parent selects a school for a child and the school principals cannot object to this decision for any reason. All of the education professionals mentioned this but some of the school principals as well as TPPSC specialists mentioned that there was lack of awareness on education laws and regulations both among parents and school principals and stated:

“Awareness is very important, first we need to raise awareness among school principals and then among teachers, we have pupils that come from far distances, from different administrative communities and mention that the school principal in their communities did not admit them

because of not having a specialist, but it is not right, we started universal inclusion since 2014 and the [lack of] specialist [in the school] is not a problem”.

(School Principal 43y/o)

“TPPSC has no mechanisms to influence on the school principals, [but this is critically needed] as we have a school principal who, in the presence of the child’s parent, states that he/she will strive to make [the school he/she directs] a foundation, which will allow him/her not to admit this kind of children in his/her school”. *(TPPSC specialist 31 y/o)*

Both the education professionals and the TPPSC specialists described the assessment process of children with special education needs in the same way and mentioned that in case of any disagreement the issues were settled.

“The professional conclusion regarding the child’s education need is carried out in stages. First stage is when the school staff members assess the child and if we notice that the child differs from other children, we assess [the child]with the tools available for us and then, of course with the consent of the parent, because if the parent does not give the consent we cannot do anything, we turn [the child] to TPPSC specialists and they come to certify the child. ”

(School Principal 47 y/o)

The education specialists also mentioned that the parents’ role in the assessment process was very important. If the parent doesn’t give a written consent for the child to be assessed and certified, the specialists do not have any right to invite TPPSC specialist, no matter how great the child’s need is.

“There have been cases that the school teachers, multidisciplinary team members noticed that the child had mental delay but we couldn’t persuade the mother to give written consent to assess the child... Working with mothers and persuading a mother is a very difficult issue”

(School Principal 43 y/o)

“Now we do the assessment only with the written consent of the parent, it would be better to quicken the process of the draft law that the parent’s consent won’t be necessary any more, pedagogical and psychological team members will go and assess the child, and if there is a need [for further assessment], we do not take into consideration whether the parent wants or doesn’t want”.

(TPPSC Specialist 31y/o)

Only one of the school principals mentioned about the following gap in the law:

“The process of the child to be certified takes a long period and I think we have a little gap here, we receive the professional conclusion about the child’s need at the end of January, but during these 4 months [September through January] our specialists provide support services. I would like that the policy makers in education sphere review this issue, which is a gap, that is the Government doesn’t pay the school for these 4 months, but because we are humane, the team works for free as the services are free”.

(School Principal 47 y/o)

Subtheme 2.2 Schools’ Experience in Inclusive Education Provision

From all the interviewees’ responses it was evident that the schools that had been implementing inclusive education for longer period, were more experienced and inclusive education was organized better there in comparison with those schools that had started recently.

“There are schools where education is organized comparatively well and there are schools where there are so many gaps. The gaps are there, because the teachers are not ready to accept

this kind of children and all the difficulties arise here, but we cannot blame as it is new in the school and the teachers do not have the experience”. (TPPSC Specialist 30 y/o)

“When I moved to this school, they had already been implementing inclusive education for more than 6 years, it [the school] had been included in the pilot project of inclusive education and I must say that I learned a lot from them, they were so experienced”.

(School Principal 47 y/o)

Subtheme 2.3 Environmental Accessibility

There was a triangulation between the education professionals and the TPPSC specialists regarding the lack of environmental and educational adjustments as an existing gap.

“Dependent on each child, so many difficulties arise, such as educational and environmental adjustments; the teachers should have a special planning for the child and in most of the cases it is missing”.

(TPPSC Specialist 31y/o)

“For instance, I have an issue with the ramp, the school is not adjusted, the restrooms are not adjusted, and we do not have any adjustment. The building is a typical type building; I don't know what I can do”.

(School Principal 43y/o)

“There are so many gaps, this sphere is still neglected and there is much room for improvement starting from stairways, ramps, environmental issues, a lot of things need to be done”.

(Multidisciplinary team member/ Speech therapist 33y/o)

Some schools are physically sufficiently adjusted for inclusive education according to one of the school principals who noted:

“I don't want to complain, the school is in a very good state in comparison with other schools, we have all adjustments, we have sense integration room, we have special restrooms, the support

services are carried out separately, every specialist has his/her own room, we have a ramp near the central entrance, we wanted to have a ramp from the first to second floor, but because of some financial issues it is delayed". (School Principal 47 y/o)

Subtheme 2.4 Lack of Awareness

All the specialists both in schools and in support centers mentioned that trainings both among the parents and among the teachers are very important and urgently needed.

"It would be better if we could provide trainings and follow-up counseling, very often there is a need to educate the parent, the staff, and continuous learning is important to have better results". (TPPSC Specialist 30 y/o)

"We have initiated a lot of awareness rising sessions in the beginning, more trainings and seminars should be organized both for parents and teachers". (School Principal 43 y/o)

Subtheme 2.5 Lack of effectiveness of Services Provided by TPPSC

Regarding the role and the work of the TPPSC in inclusive education, most of the specialists were discontent, as the specialists from support centers came and see the child twice per week for only 20-30 minutes and it was considered not enough for providing necessary support to the child with special needs.

"To tell the truth, I do not want to underestimate TPPSC work but it's already been two years that I do not understand their work as each specialist needs to be in school. For instance, you are an outsider, you see the child for 30 minutes, but you will know more about the child if you are an insider and see the child both during the break, during the lessons and if there is a need to cooperate with teacher. During the discussions in the Government they spoke about taking

multidisciplinary teams out from schools, I expressed my opinion that thus we would lose inclusive education at all and it wouldn't work".

(School Principal 43 y/o)

"We do not have a special educator, the specialist comes from TPPSC, once a month the specialist is changed, they do not cooperate with the psychologist, special educator, teacher, they just think they need to come, sit and work according to their own plan, they deal with a child, the child has a parent, a teacher, you need to cooperate, if you do not cooperate with the teacher you will never have a result".

(Multidisciplinary team member/ Speech therapist 33y/o)

Another school principal also agreed that TPPSC specialists do not cooperate well. However, she mentioned that they were still in the first stage of the development.

"I think it is not right to centralize [the work of] TPPSCs and overload them with so much work, as they are still in the process of development and cannot completely carry out all their functions".

(School Principal 47 y/o)

One of the pediatricians mentioned that a physical training group was defined by the pediatricians for children with NDDs, but in fact these children did not attend their physical training classes, whereas this could be their rehabilitation in the school.

"Once a year we give a reference to the child to join a physical training group there [in the school], but in general we do not even have specialists in schools to do the physical training classes with them [children in need]. However, the physical training for children with disabilities is a rehabilitation treatment, and if it is an inclusive school, the child needs to be provided the

rehabilitation services in the school. In reality, these children are freed from their physical training classes”. (PHC pediatrician 47 y/o)

Subtheme 2.6 Lack of Cooperation between Healthcare and Education

Another main finding of this study, the validity of which was assured by triangulation, was that there was no cooperation between the two spheres: healthcare and education for children with NDDs. All the stakeholders noted that healthcare and education spheres did not cooperate; no meetings or discussions between healthcare and education professionals were being organized.

“I don’t remember a case that they called a pediatrician or they invited [a pediatrician] to some case discussion. I only remember one case that they called me from a TV talk show. But we speak of a child who is a patient in one case and a student in another case, but this is the same child, it would be better that these two spheres had close cooperation, it would be good if there were any [combined] working groups”. (PHC pediatrician 47 y/o)

“Unfortunately we do not cooperate, I am the only speech therapist in the school and I am too overloaded. I would like that a PHC speech therapist also worked and we cooperated, but there is no cooperation”. (Multidisciplinary team member/ Speech therapist 33y/o)

“We only refer the parents to a narrow-specialized healthcare specialist; that is the only cooperation”. (School Principal 43 y/o)

“Unfortunately our cooperation is limited to just referring the parent to a specialist for bringing some document, we only cooperate with the doctor from republican pedagogical psychological assessment center to jointly identify the diagnosis-specific needs of a given child.”.

(TPPSC Specialist 31 y/o)

Theme 3: Challenges of Socialization

Subtheme 3.1 Public Perception

All the parents had difficulties regarding socialization and how they were treated either in the families or in the society. Parents had difficulties to go outside with the children, as people looked at them with pitiable glances.

“The grandparents changed their attitude towards the child, they treat two of my children differently, they go and kiss the other child, but the one who has a delay, they do not approach at all, they were not supportive at all and my attitude changed towards them”.

(Mother of a 6 y/o boy)

“First in the very beginning it was difficult to go outside, to see these glances, contemptible and pitiable glances, but we have overcome it, during these years the people surrounding you also change or my viewpoints have changed, but there is a change. There have been cases when neighbors told me: ‘this will not become a child for you’ pointing out at the child, but thanks God, I haven’t paid attention” *(Mother of a 9y/o girl)*

“The only problem was when we were in a new surrounding, other children did not know and when your child started to speak, they got nervous and told him to stop... As a parent, it is painful for you”. *(Mother of a 10y/o boy)*

Subtheme 3.2 Stigma

According to the interviewed specialists, the education professionals take measures to improve public perceptions. They organize parental meetings before each academic year to prepare the parents in case there is a child with special needs in their class. One of the school principals stated:

“At the beginning of each academic year I organize parental meeting and prepare the parents that there might be students with special needs in their classrooms, none of us is guaranteed. I bring several such examples. I might say that public awareness rising has good results and thus we break all the stereotypes, [convincing other parents] that these children are full members of the society and it means nothing that he or she uses a wheelchair or has a special behavior. Children are pure creatures, they admit their friends as they are and they are very supportive, if parents accept, children accept as well”. (School Principal 43 y/o)

“I had a child whose mother was a healthcare worker, the mother naturally realized the child’s problem but she concealed it. In our society we still have the concept of keeping it confidential, maybe it is mother’s instinct [telling her that when it is kept in secret] the child is more protected, and he/she is not differentiated in the society, but we as educators evidently see the problem”. (School Principal 47 y/o)

“We see them now in the streets, before we didn’t see and it seemed that there were no such children before, but the integration goes on, also because now they go to schools, but we have an issue that parents hide the problem. We need to explain that there is nothing shameful and we are ready to socialize these children”. (PHC Pediatrician 47 y/o)

“The schools with little experience face lots of problems: if the teacher is not ready to accept the child, the other peers in the classroom do not accept the child and thus the inclusion of the child is imperfect. The same with other children’s parents, if the parents do not accept a child with special needs, the children do not accept as well”. (TPPSC Specialist 30 y/o)

DISCUSSION

This study explored the needs and gaps in healthcare and education for children with neurodevelopment delays in Yerevan. Three main themes and thirteen subthemes were identified: (1) needs and gaps in healthcare; (2) needs and gaps in education; and (3) challenges of socialization. The subthemes of the first theme: “Needs and gaps in healthcare”, included the delay in the diagnostic process, parents identifying the delay, low availability and affordability of the treatment services, need in psychological support, as well as low capacity of the healthcare system to meet the needs of the children in terms of lack of skills, guidelines and protocols. As to the theme: “Needs and gaps in education”, the following subthemes were identified: assessment process: lack of parental consent, school staff experience in inclusive education, lack of environmental accessibility, lack of awareness, lack of effectiveness in services of TPPSC as well as lack of cooperation between healthcare and education systems. The main theme: “Challenges of socialization” touches upon public perception and stigma.

The study findings indicated that the diagnostic process of children with NDDs is hindered and, in most of the cases, early identification is lacking. Often, the parents themselves identify the delay, and our finding is consistent with other research findings.^{27,28}

Another important finding was that parents can resist to the diagnosis as often they are not psychologically ready to have a child with disability. Denial is a common reaction among parents of children diagnosed with NDDs and studies conducted in other countries have similar findings.²⁹

We found that parents of children with NDDs were in need of psychological support and other studies also indicate that appropriate professional, particularly, psychological support is necessary to family members who have children with development delays.^{29,30}

Another issue identified was low access to care and affordability of services. Parents go through some financial difficulties while trying to seek appropriate treatment for the child.³¹ This finding is similar to the findings of a cross-sectional study conducted in the US from 2009-2010.³²

Another main finding of this study was that healthcare facilities have low capacity to meet the needs of children with development delays, in terms of inadequate skills of providers, lack of guides and training resources for them. In low-resourced settings, there is similar picture according to one study.³³

An important issue is the need for awareness rising on needs of children with NDDs among different stakeholders: school principals, healthcare professionals, as well as parents of healthy children. This finding triangulated between all the stakeholders: all of them expressed the same opinion on this issue. A similar finding was marked in a study conducted in Ethiopia from 2017-2018.³⁴

The study revealed that parents play a significant role in the assessment process of the child with a development delay. The school professionals and TPPSC specialists mentioned that without parents' written consent the specialists are not allowed to assess the child and provide relevant professional support. This can have a negative effect on the child's development, as the educational process is delayed and the child misses the necessary services by the specialists.

The study results showed that schools with more experience in inclusive education have better performance than those that are just going to adopt general inclusion. Related to this, schools

also face environmental accessibility and educational adjustment issues. Many steps have been made in Armenia towards the improvement of inclusive education and this finding goes in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) estimations. The estimations proved that many improvements have been marked in Armenia during 2014-2017.³⁵ Educating the parents and school teachers are among the core needs that schools have nowadays.

The findings of this study indicate that the cooperation between TPPSC and schools is not yet on its highest level. It has been two years since TPPSCs were launched and they are still in the primary stage of development. Related to this there was absence of similar findings in the literature.

Parents who have children with development delays find it difficult to go out. They see pitiable glances and it is painful for them. The main concerns of the parents are related to public perception. Our findings are similar to the findings of other studies related to stigma towards children with development delays.³⁶ A similar study conducted in Ethiopia showed that some parents felt the negative consequences of stigma and isolated themselves from the society.³⁴

Another main finding of this study, which was validated by triangulation from all the stakeholders, was lack of cooperation between healthcare and education sectors. There was no similar finding in the literature in terms of lack of cooperation between healthcare and education sectors.

Study Strengths and Limitations

This study investigated the needs and gaps in education and healthcare for children with NDDs from the perspectives of four different stakeholders: healthcare and education professionals,

TPPSC specialists and parents. To our knowledge, this was the first study to explore the issue with these many key-informant stakeholders, which helped to achieve higher credibility of findings due to triangulation. Another strength of the study was that both code and meaning saturation was reached after the 11th interview, but the data were collected from 13 interviewees to be more convinced in the results. All the interviews were conducted face-to-face, which insured direct interaction between the interviewer and the interviewees and enriched the collected data by enhancing the rapport with the respondents. However, several limitations were noted in this study. One of the limitations could be that among the five interviewed parents there were only mothers, so the involvement of fathers might influence the findings. Another limitation of the study could be that other key-informant stakeholders, such as polyclinics' speech therapists were not interviewed, because the student-investigator could not access any of them. Another limitation might be that the study was conducted in Yerevan and the findings might be not quite applicable to other regions of Armenia.

Recommendations

Based on the study findings, the following recommendations were developed:

- Awareness rising activities among school staff members and parents should be initiated all over the country to improve the process of inclusion of children with development delays.
- Trainings and seminars among education and healthcare specialists are recommended to promote the provision of services to children with NDDs in both spheres.
- For provision of inclusive education, it is recommended to initiate environmental adjustments. These adjustments need to consider the specific needs of children with development delays.

- We recommend that parents and family members are provided psychological support both at healthcare and education institutions. The psychologists that provide counseling in schools can provide psychological support to parents as well. As to the healthcare sphere, the psychologists need to be together with the parents and family members while going through the diagnostic process and if need be in the follow-up as well.
- It is evident that the government spends many resources for children with disabilities, but this resources do not reach the children sometimes, so we recommend to direct the financial resources not to the institutions but to the specific needs of children.

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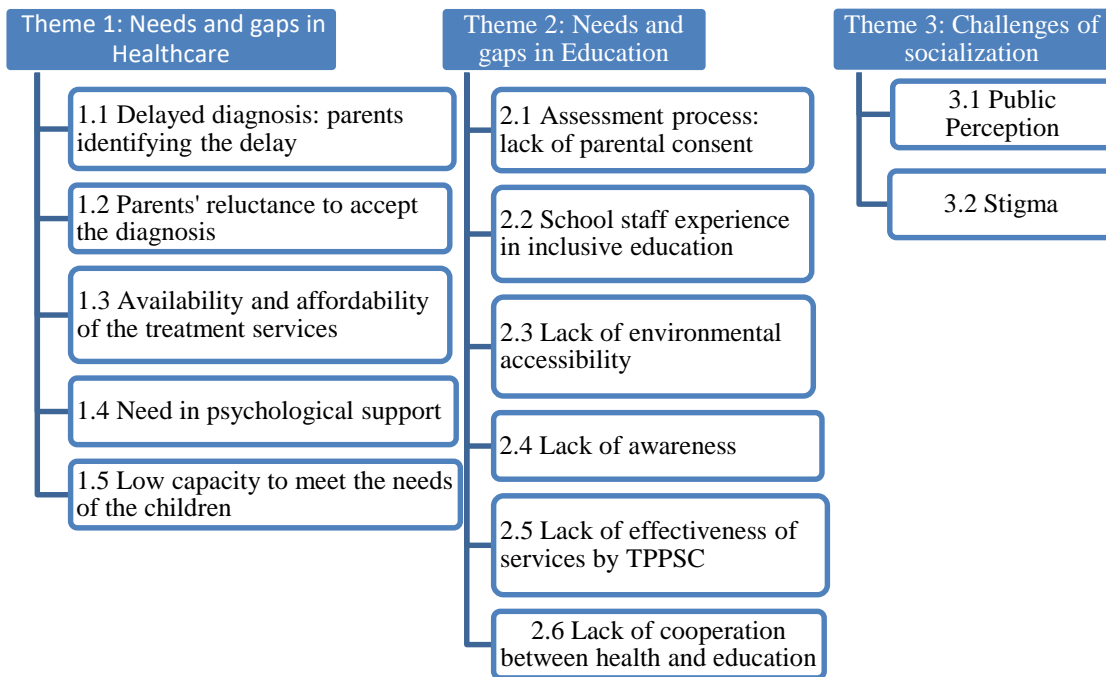
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Table 1. Characteristics of Participants of the Study Stakeholders in Yerevan, 2022

	Age range	Sex		Work experience range	Child's age range
		Male (n)	Female (n)		
Education specialists	26-58	0	3	7-32	-
TPPSC Specialists		1	1		
Healthcare specialists		0	3		-
Parents		0	5		5-18
Total		1	12		

Figure 1: Main themes and subthemes of the study findings



Appendix 1

Consent Form for Stakeholders: Healthcare, Education and TPPSC staff members (English Version)

American University of Armenia

Turpanjian College of Health Sciences

Institutional Review Board #1

Oral Consent Form

Hello, my name is Lilit, I am a graduate student of the AUA Turpanjian College of Health Sciences. In the scope of my MPH thesis, I am doing a research on the needs and gaps in healthcare and education of children with neurodevelopmental delays (NDDs).

You are invited to participate in this study as you are directly or indirectly involved in healthcare and education processes of children with NDDs. Thus, you can provide essential information for this study. You will participate in one in-depth interview which will last approximately 40-60 minutes. The interview will be conducted at a time and place 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. You do not have any direct benefit from this interview, there is no financial or personal benefit for you in this study, however, your participation is very valuable for us in terms of understanding needs and gaps in healthcare and education of children with NDDs. The information you provide is fully confidential and will be used solely for this study purposes. Your name will not appear on any questionnaire and in the study report. Some quotes from your speech might be used in the report, but they will be anonymous without any identifiable information and will be mentioned as healthcare or

education professional's opinion. I guarantee the confidentiality of the information you provide. All study data will be stored in a password protected laptop without any identifiable information.

If you do not mind I will audio record the interview not to miss any important information. If need be, you may ask to turn off the recorder at any time during the interview. My notes and recordings will be stored without any identifiable information about your personality and will be destroyed immediately after the data analysis.

You may ask any question you want related to your participation. If you have any questions related to this study you can contact Anahit Demirchyan, Professor at Turpanjian College of Health Sciences via (060) 61 25 62 phone number: If you think you haven't been treated fairly or I have hurt you during the interview you can contact Varduhi Hayrumyan, Human Protections Administrator of the American University of Armenia via (060) 61 25 61 phone number.

Do you agree to participate in the interview? If yes, may I turn on the audio-recorder? If you do not mind, let's start. Thank you.

Appendix 2

Consent Form for Stakeholders: Healthcare, Education and TPPSC staff members (Armenian Version)

Հայաստանի ամերիկյան համալսարան

Թրփանճեան առողջապահական գիտությունների ֆակուլտետ

Գիտահետազոտական Էթիկայի թիվ 1 հանձնաժողով

Իրազեկ համաձայնության ձև

Բարև Ձեզ, իմ անունը Լիլիթ է: Ես սովորում եմ Հայաստանի ամերիկյան համալսարանի Թրփանճեան առողջապահական գիտությունների ֆակուլտետի մագիստրատուրայի ավարտական կուրսում: Իմ ավարտական թեզի շրջանակում ես նյարդաբանական զարգացման հապաղում (ՆՁՀ) ունեցող երեխաների կարիքների և նրանց մատուցվող բուժական և կրթական ծառայություններում առկա բացերի վերաբերյալ հետազոտություն եմ անցկացնում:

Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, քանի որ ուղղակիորեն կամ անուղղակիորեն ներգրավված եք ՆՁՀ ունեցող երեխաների առողջապահության կամ կրթության կազմակերպման գործընթացում: Ուստի, Ձեր կողմից տրամադրած տեղեկատվությունը չափազանց կարևոր է այս հետազոտության համար: Դուք մասնակցում եք ընդամենը մեկ անհատական հարցազրույցի, որը կտևի մոտ 40-60 րոպե: Հարցազրույցը կիրականացվի Ձեզ հարմար ժամին և Ձեզ հարմար վայրում:

Ձեր մասնակցությունն այս հետազոտությանը կամավոր է: Ձեզ ոչինչ չի սպառնում, եթե հրաժարվեք մասնակցել հարցազրույցին: Դուք կարող եք հրաժարվել պատասխանել ցանկացած հարցի կամ ընդհատել հարցազրույցը ցանկացած պահի: Դուք չունեք որևէ անմիջական օգուտ այս հարցազրույցից. հետազոտությանը Ձեր մասնակցությունը ֆինանսական կամ անձնական որևէ օգուտ չի բերի Ձեզ, սակայն չափազանց կարևոր է մեզ համար, քանի որ կօգնի հասկանալ՝ որոնք են ՆՁՀ ունեցող երեխաների բուժական և կրթական կարիքները և ինչպիսի բացեր կան նրանց մատուցվող ծառայություններում: Ձեր կողմից տրված տեղեկատվությունը լիովին գաղտնի կպահվի և կկիրառվի միայն հետազոտական նպատակներով: Ձեր անունը գրված չի լինի հարցաթերթիկների վրա և հետազոտության զեկույցում: Ձեր խոսքերից որոշ մեջբերումներ կարող են ներկայացվել զեկույցում, բայց դրանք կներկայացվեն անանուն, առանց անձը նույնականացնող տեղեկատվության՝ որպես առողջապահական կամ կրթական ոլորտի մասնագետի կարծիք: Ես երաշխավորում

եմ Ձեր տվյալների գաղտնիությունը: Հետազոտության ընթացքում ձեր բերված բոլոր տեղեկությունները կպահվեն ծածկագրով պաշտպանված համակարգում և Ձեր անունը չի կցվի այդ տվյալներին:

Եթե դեմ չեք, ես կձայնագրեմ մեր հարցազրույցը, որպեսզի ոչ մի կարևոր տեղեկություն բաց չթողնեմ: Դուք իրավասու եք պահանջել անջատել ձայնագրիչը հարցազրույցի ընթացքում՝ ցանկացած պահի, եթե դրա կարիքը լինի: Իմ նշումները և ձայնագրությունները կպահպանվեն առանց Ձեր անձի հետ նույնականացման և կոչնչացվեն տվյալների վերլուծության ավարտից անմիջապես հետո:

Դուք կարող եք ինձ ցանկացած հարց տալ՝ Ձեր մասնակցության վերաբերյալ: Սույն հետազոտության վերաբերյալ հարցեր ունենալու դեպքում կարող եք կապ հաստատել Հայաստանի ամերիկյան համալսարանի Թրփանձեան առողջապահական գիտությունների ֆակուլտետի դասախոս Անահիտ Դեմիրճյանի հետ հետևյալ հեռախոսահամարով՝ (060) 61 25 62: Եթե կարծում եք, որ Ձեզ հետ ճիշտ չեմ վարվել կամ որևէ կերպ Ձեզ վիրավորել եմ հարցազրույցին մասնակցության ընթացքում, կարող եք դիմել Հայաստանի ամերիկյան համալսարանի գիտական էթիկայի հանձնաժողովի համակարգող Վարդուհի Հայրումյանին հետևյալ հեռախոսահամարով՝ (060) 61 25 61:

Դուք համաձայն եք մասնակցել հարցազրույցին: Եթե այո, կարո՞ղ եմ միացնել ձայնագրիչը: Եթե դեմ չեք, սկսենք: Շնորհակալություն:

Appendix 3

Consent Form for Parents of Children with NDDs (English Version)

American University of Armenia

Turpanjian College of Health Sciences

Institutional Review Board #1

Oral Consent Form

Hello, my name is Lilit, I am a graduate student of the AUA Turpanjian College of Health Sciences. In the scope of my MPH thesis, I am doing a research on the needs and gaps in healthcare and education of children with neurodevelopmental delays (NDDs).

You are invited to participate in this study as you are a parent of a child with NDDs therefore, you can provide essential information for this study. You will participate in one in-depth interview which will last approximately 40-60 minutes. The interview will be conducted at a time and place 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. You do not have any direct benefit from this interview, there is no financial or personal benefit for you in this study, however, your participation is very valuable for us in terms of understanding needs and gaps in healthcare and education of children with NDDs.

Your frank answers are highly valuable for this study. The information you provide is fully confidential, the collected data will be generalized and will be used solely for this study purposes. Your name will not appear on any questionnaire and in the study report. Some quotes from your speech might be used in the report, but they will be anonymous without any identifiable information and will be mentioned as the opinion of a parent who has a child with NDDs. Your participation or refusal will not have any effects on the healthcare or education that your child is provided and/or will be provided in the future. I guarantee the confidentiality of the information you provide. All study data will be stored in a password protected laptop without any identifiable information.

If you do not mind I will audio record the interview not to miss any important information. If need be, you may ask to turn off the recorder at any time during the interview. My notes and recordings will be stored without any identifiable information about your personality and will be destroyed immediately after the data analysis.

You may ask any question you want related to your participation. If you have any questions related to this study you can contact Anahit Demirchyan, Professor at Turpanjian College of Health Sciences via (060) 61 25 62 phone number: If you think you haven't been treated fairly or I have hurt you during the interview you can contact Varduhi Hayrumyan, Human Protections Administrator of the American University of Armenia via (060) 61 25 61 phone number.

Do you agree to participate in the interview? If yes, may I turn on the audio-recorder? If you do not mind, let's start. Thank you.

Appendix 4

Consent Form for Parents of Children with NDDs (English Version)

Հայաստանի ամերիկյան համալսարան

Թրփանճեան առողջապահական գիտությունների ֆակուլտետ

Գիտահետազոտական Էթիկայի թիվ 1 հանձնաժողով

Իրազեկ համաձայնության ձև

Բարև Ձեզ, իմ անունը Լիլիթ է: Ես սովորում եմ Հայաստանի ամերիկյան համալսարանի Թրփանճեան առողջապահական գիտությունների ֆակուլտետի մագիստրատուրայի ավարտական կուրսում: Իմ ավարտական թեզի շրջանակում ես նյարդաբանական զարգացման հապաղում (ՆՁՀ) ունեցող երեխաների կարիքների և նրանց մատուցվող բուժական և կրթական ծառայություններում առկա բացերի վերաբերյալ հետազոտություն եմ անցկացնում:

Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, քանի որ Ձեր երեխան ունի ՆՁՀ, և Ձեր կողմից տրամադրած տեղեկությունները չափազանց կարևոր են այս հետազոտության համար: Հետազոտությանը մասնակցելու են նաև 10-15 ՆՁՀ ունեցող այլ երեխաների ծնողներ: Դուք մասնակցում եք ընդամենը մեկ անհատական հարցազրույցի, որը կտևի մոտ 40-60 րոպե: Հարցազրույցը կիրականացվի Ձեզ հարմար ժամին և Ձեզ հարմար վայրում:

Ձեր մասնակցությունն այս հետազոտությանը կամավոր է: Ձեզ ոչինչ չի սպառնում, եթե հրաժարվեք մասնակցել հարցազրույցին: Դուք կարող եք հրաժարվել պատասխանել ցանկացած հարցի կամ ընդհատել հարցազրույցը ցանկացած պահի: Դուք չունեք որևէ անմիջական օգուտ այս հարցազրույցից. հետազոտությանը Ձեր մասնակցությունը ֆինանսական կամ անձնական որևէ օգուտ չի բերի Ձեզ, սակայն չափազանց կարևոր է մեզ համար, քանի որ կօգնի հասկանալ՝ որոնք են ՆՁՀ ունեցող երեխաների

բուժական և կրթական կարիքները և ինչպիսի բացեր կան նրանց մատուցվող ծառայություններում:

Ձեր անկեղծ պատասխանները շատ կարևոր են այս հետազոտության համար: Ձեր կողմից տրամադրված տեղեկությունները գաղտնի կպահվեն, հավաքագրված տվյալներն ընդհանրացված կերպով կօգտագործվեն միայն հետազոտական նպատակներով՝ առանց մասնակցի նույնականացնող տվյալները նշելու: Ձեր անունը գրված չի լինելու հարցաթերթիկների վրա և հետազոտության զեկույցում: Ձեր խոսքերից որոշ մեջբերումներ կարող են ներկայացվել զեկույցում, բայց դրանք կներկայացվեն անանուն, առանց անձը նույնականացնող տվյալների՝ որպես ՆՁՀ ունեցող երեխայի ծնողի կարծիք: Ձեր երեխայի ստացած բուժօգնությունը կամ կրթությունը ներկայումս և հետագայում չի տուժի հետազոտությանը մասնակցելու կամ չմասնակցելու հետևանքով: Ես երաշխավորում եմ Ձեր տվյալների գաղտնիությունը: Հետազոտության ընթացքում ձեռք բերված բոլոր տեղեկությունները կպահվեն ծածկագրով պաշտպանված համակարգչում և Ձեր անունը չի կցվի այդ տվյալներին:

Եթե դեմ չեք, ես կձայնագրեմ մեր հարցազրույցը, որպեսզի ոչ մի կարևոր տեղեկություն բաց չթողնեմ: Դուք իրավասու եք պահանջել անջատել ձայնագրիչը հարցազրույցի ընթացքում՝ ցանկացած պահի, եթե դրա կարիքը լինի: Իմ նշումները և ձայնագրությունները կպահպանվեն առանց Ձեր անձի հետ նույնականացման և կոչնչացվեն տվյալների վերլուծության ավարտից անմիջապես հետո:

Դուք կարող եք ցանկացած հարց տալ ինձ՝ Ձեր մասնակցության վերաբերյալ: Սույն հետազոտության վերաբերյալ հարցեր ունենալու դեպքում կարող եք կապ հաստատել Հայաստանի ամերիկյան համալսարանի Թրփանձեան առողջապահական գիտությունների ֆակուլտետի դասախոս Անահիտ Դեմիրճյանի հետ հետևյալ հեռախոսահամարով՝ (060) 61 25 62: Եթե կարծում եք, որ Ձեզ հետ ճիշտ չեմ վարվել կամ որևէ կերպ վիրավորել եմ Ձեզ հարցազրույցին մասնակցության ընթացքում,

կարող եք դիմել Հայաստանի ամերիկյան համալսարանի գիտական էթիկայի հանձնաժողովի համակարգող Վարդուհի Հայրումյանին հետևյալ հեռախոսահամարով՝ (060) 61 25 61:

Դուք համաձայն եք մասնակցել հարցազրույցին: Եթե այո, կարո՞ղ եմ միացնել ձայնագրիչը: Եթե դեմ չեք, սկսենք: Շնորհակալություն:

Appendix 5

Interview Guide for Parents of Children with NDDs (English Version)

Interview date: ____ / ____ / ____ (DD/MM/YY)

Interviewee ID: _____

Start time: ____ : ____ (HH:MM)

Hello, my name is Lilit, I am a graduate student of the AUA Turpanjian College of Health Sciences. I highly appreciate that you agreed to participate in this interview. In the scope of my MPH thesis, I am doing a research on the needs and gaps in healthcare and education of children with neurodevelopmental delays (NDDs). Would you, please, share with me your opinion about the education of children with NDDs and your experience as a parent of a child with NDD? The interview will last approximately 40-60 minutes. I am interested in your frank answers as they are highly valuable for this study. Whatever you share here with me, will be kept confidential, no identifying information will be provided with that information and it will be used solely for this study purposes.

Introductory question: Would you please tell me little bit about your child?

1. When did you first notice that something is different about your child's development?

Probe: Which were the first signs?

How did you understand that the child has a difficulty?

2. What were the next steps when you learnt that the child has a developmental delay?

Probe: Who were the specialists you consulted with and when/after how much time did you consult with them when you noticed that something is different?

3. Can you describe your experience in the diagnostic process as a parent of a child with NDD?

Probe: Where were you referred to?

What kind of examinations did the child undergo and how many times?

4. How did you first respond to the diagnosis of NDD?

Probe: Did your attitude change/didn't change towards the doctors/your child and how?

5. In your opinion, what affect did the diagnosis have on your family members/your friends?

Probe: How did it affect the relations with other people?

How did it affect your family expenses?

What other needs emerged?

6. What healthcare and social services was the child provided after the diagnosis?
Probe: How often was he provided these services?
 What obstacles did you have during this period?
 What would you change in these services?
 What were you content/discontent with?
7. What support were you provided in the healthcare facilities?
Probe: What about pharmacological, psychological, professional support?
8. What resources are necessary to support children with NDDs and their parents?
Probe: Think of financial, material, psychological and professional support.

The following questions are addressed to parents whose children attend schools.

9. Would you describe please the process of being admitted and integrated to school?
Probe: What were the stages before you were admitted to school?
 What was your experience at this period?
 Who was the specialist you mostly cooperated with?
 Would you describe the process?
10. How is the child viewed and accepted by his peers?
Probe: What is the attitude of other children's parents towards you and the child?
 What is the attitude of the teachers and the school staff members towards you and the child?
11. How would you describe the collaboration of healthcare and education systems?
Probe: How are you involved in this collaboration, if you are?
12. How would you suggest improving the education and social integration of children with NDDs?
13. Is there any other information that you think is important and you would like to add?

Demographic Data:

Your age	_____
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Your sex (Don't read this question aloud)	1. Male 2. Female
Your child's age	_____
End time	____:____

Thank you for participating and sharing your thoughts with me.

Appendix 6

Interview Guide for Parents of Children with NDDs (Armenian Version)

Հարցազրույցի ուղեցույց ծնողների համար

Ամսաթիվ՝ ____ / ____ / ____

ID՝ _____

Սկիզբ՝ ____ : ____

Բարև Ձեզ, իմ անունը Լիլիթ է: Ես սովորում եմ Հայաստանի ամերիկյան համալսարանի Թրփանճեան առողջապահական գիտությունների ֆակուլտետի մագիստրատուրայի ավարտական կուրսում: Ես բարձր եմ գնահատում, որ համաձայնեցիք մասնակցել այս հարցազրույցին: Իմ ավարտական թեզի շրջանակում ես նյարդաբանական զարգացման հապաղում (ՆՉՀ) ունեցող երեխաների կարիքների և նրանց մատուցվող բուժական և կրթական ծառայություններում առկա բացերի վերաբերյալ հետազոտություն եմ անցկացնում: Ինձ հետաքրքիր է Ձեր կարծիքը և Ձեր փորձառությունը այդ մասին՝ որպես ՆՉՀ ունեցող երեխայի ծնողի: Հարցազրույցը կտևի մոտ 40-60 րոպե: Ձեր անկեղծ պատասխանները շատ կարևոր են այս հետազոտության համար: Ձեր կողմից տրամադրված տեղեկությունները գաղտնի են պահվելու, հավաքագրված տվյալներն ընդհանրացված կերպով օգտագործվելու են միայն հետազոտական նպատակներով՝ առանց մասնակցին նույնականացնող տվյալներ նշելու:

Ներածական հարց: Կպատմե՞ք մի փոքր Ձեր երեխայի մասին:

14. Ե՞րբ առաջին անգամ նկատեցիք, որ Ձեր երեխայի զարգացումը տարբերվում է:

Probe: Որո՞նք էին առաջին նշանները:

Ինչպե՞ս հասկացաք, որ երեխան ինչ-որ խնդիր ունի:

15. Ի՞նչ հետագա քայլեր ձեռնարկեցիք, երբ իմացաք, որ երեխան ունի զարգացման հապաղում:

Probe: Ի՞նչ մասնագետի հետ եք խորհրդակցել և ե՞րբ՝ խնդիրները նկատելուց ինչքա՞ն ժամանակ հետո:

16. Կարո՞ղ եք նկարագրել ախտորոշման գործընթացի միջով անցնելու Ձեր փորձառությունը՝ որպես ՆՉՀ ունեցող երեխայի ծնող:

Probe: Որտե՞ղ են ուղղորդել:

Ի՞նչ հետազոտություններ է անցել երեխան և քանի՞ անգամ:
Ի՞նչ դժվարություններ էք ունեցել ախտորոշման գործընթացում:

17. Ինչպե՞ս առաջին անգամ արձագանքեցիք այդ ախտորոշմանը:
Probe: Փոխվե՞ց արդյոք և ինչպե՞ս փոխվեց Ձեր վերաբերմունքը բժիշկների կամ երեխայի նկատմամբ:
18. Ձեր կարծիքով, ի՞նչ ազդեցություն ունեցավ այդ ախտորոշումը Ձեր, Ձեր ընտանիքի անդամների և Ձեր ընկերական շրջապատի վրա:
Probe: Ինչպե՞ս դա ազդեց մարդկանց հետ փոխհարաբերությունների վրա:
Ինչպե՞ս դա ազդեց Ձեր ընտանեկան ծախսերի վրա:
Ինչպիսի՞ կարիքներ ի հայտ եկան:
19. Ի՞նչ առողջապահական և սոցիալական ծառայություններից է երեխան օգտվել ՆԶՀ ախտորոշվելուց հետո:
Probe: Ի՞նչ հաճախականությամբ է օգտվել այդ ծառայություններից:
Ի՞նչ խոչընդոտներ էք ունեցել այդ ընթացքում:
Ի՞նչ կփոխեիք այդ ծառայությունների մեջ:
Ինչի՞ց էք գոհ կամ դժգոհ:
20. Ինչպիսի՞ աջակցություն են Ձեզ տրամադրել առողջապահական հաստատություններում:
Probe: Ի՞նչ կասեք դեղորայքային, հոգեբանական, մասնագիտական աջակցության վերաբերյալ:
21. Ինչպիսի՞ ռեսուրսներ են անհրաժեշտ ՆԶՀ ունեցող երեխաներին և նրանց ծնողներին աջակցելու համար:
Probe: Մտածեք ֆինանսական, նյութական, հոգեբանական կամ մասնագիտական աջակցության մասին:

Հաջորդ հարցերն ուղղված են դպրոցահասակ երեխաների ծնողներին:

22. Կնկարագրե՞ք երեխայի դպրոց ընդունվելու և ներառվելու գործընթացը:
Probe: Ինչպիսի՞ փուլեր էք անցել նախքան դպրոց ընդունվելը:
Ինչպիսի՞ն էր այդ ընթացքում ձեր փորձառությունը:
Ո՞ր մասնագետի հետ է եղել ամենաշատ համագործակցությունը:

Կնկարագրե՞ք այդ գործընթացը:

23. Ինչպիսի՞ն է երեխայի նկատմամբ հասակակիցների վերաբերմունքը:
Probe: Ինչպիսի՞ն է այլ երեխաների ծնողների վերաբերմունքը երեխայի և Ձեր հանդեպ:
 Ինչպիսի՞ն է ուսուցիչների և դպրոցի անձնակազմի վերաբերմունքը երեխայի և Ձեր նկատմամբ:
24. Ինչպե՞ս են համագործակցում առողջապահական և կրթական ոլորտները:
Probe: Դուք որևէ կերպ ներգրավվա՞՞ծ եք այդ համագործակցության մեջ:
25. Ինչպիսի՞ փոփոխություններ կառաջարկեք ՆՁՀ ունեցող երեխաների կրթությունը և սոցիալական ինտեգրումը բարելավելու համար:
26. Կա՞ ինչ-որ բան, որ մենք չքննարկեցինք, սակայն կարծում եք, որ կարևոր է և կցանկանայիք ավելացնել:

Ժողովրդագրական տվյալներ

Ձեր տարիքը	_____
Ձեր սեռը՝ (այս հարցը չկարդալ և լրացնել ինքնուրույն)	1. Արական 2. Իգական
Ձեր երեխայի տարիքը	_____
Ավարտ	_____ : _____

Շնորհակալություն մասնակցության և Ձեր մտքերն ինձ հետ կիսելու համար:

Appendix 7

In-depth Interview Guide with School Staff Members: Principals, Teachers, Multidisciplinary Team Members (English Version)

Interview date: ____ / ____ / ____ (DD/MM/YY)

ID: _____

Start time: ____:____ (HH:MM)

Hello, my name is Lilit, I am a graduate student of the AUA Turpanjian College of Health Sciences. I highly appreciate that you agreed to participate in this interview. In the scope of my MPH thesis, I am doing a research on the needs and gaps in healthcare and education of children with neurodevelopmental delays (NDDs). Would you, please, share with me your opinion about the education of children with NDDs and your experience in this sphere? The interview will last approximately 40-60 minutes. I am interested in your frank answers as they are highly valuable for this study. Whatever you share here with me, will be kept confidential, no identifying information will be provided with that information and it will be used solely for this study purposes.

Introductory question: Would you please tell me little bit about yourself, for instance, how many years you are working in this school and what is your background?

1. What is your role as a school principal/ teacher/psychologist/speech therapist in supporting children with NDDs?
Probe: What kind of work experience do you have with children with NDDs?
2. Based on your experience, what is the general approach towards children with NDDs?
Probe: How are they viewed and accepted at school?
What about the attitude of the peers?
What about the attitude of the parents of other children?
3. Can you describe the process of admission of a child with NDD to school and how the child is integrated to school?
Probe: What kind of difficulties do you face when trying to involve the child in the classroom activities?
4. In your opinion, what are the main needs of children with NDDs in Armenia?
Probe: What are their specific needs in education?
What are their specific needs in socialization?
What are their specific needs in healthcare?

5. How do you try to address the specific educational needs of children with NDDs?
Probe: What measures do you take?
 What obstacles do you face in meeting those needs?
 Can you share with us a few examples?
6. What support do you/your school or community provide to children with NDDs and their family?
Probe: What about financial support, material support, professional support?
7. What resources do you need to support the children with NDDs and their parents?
Probe: Think of financial/material/psychological/professional support.
8. How would you describe your collaboration with healthcare system when admitting and integrating children with NDDs to school?
Probe: How do you work with healthcare providers?
 With what kind of providers do you collaborate (if any)?
 Would you please describe what the process looks like?
9. How would you describe your work with parents of children with NDD when integrating children to school?
Probe: How could the work with parents be improved?
10. How would you suggest improving the education and social integration of children with NDDs in Armenia?
11. Is there any other information that you think is important and you would like to add?

Demographic Data:

Your age	_____
Your sex (Don't read this question aloud)	3. Male 4. Female
How many years have you worked by your profession?	_____
End time	____:____

Thank you for participating and sharing your thoughts with me.

Appendix 8

In-depth Interview Guide with School Staff Members: Principals, Teachers, Multidisciplinary Team Members (Armenian Version)

Ամսաթիվ՝ _____ / _____ / _____

ID՝ _____

Սկիզբ՝ _____:_____

Բարև Ձեզ, իմ անունը Լիլիթ է: Ես սովորում եմ Հայաստանի ամերիկյան համալսարանի Թրփանճեան առողջապահական գիտությունների ֆակուլտետի մագիստրատուրայի ավարտական կուրսում: Ես բարձր եմ գնահատում, որ համաձայնեցիք մասնակցել այս հարցազրույցին: Իմ ավարտական թեզի շրջանակում ես նյարդաբանական զարգացման հապաղում (ՆՁՀ) ունեցող երեխաների կարիքների և նրանց մատուցվող կրթական և բուժական ծառայություններում առկա բացերի վերաբերյալ հետազոտություն եմ անցկացնում: Ինձ հետաքրքիր է Ձեր կարծիքը ՆՁՀ ունեցող երեխաների կրթության վերաբերյալ և Ձեր փորձառությունն այս ոլորտում: Հարցազրույցը կտևի մոտ 40-60 րոպե: Ձեր անկեղծ պատասխանները շատ կարևոր են այս հետազոտության համար: Ձեր կողմից տրամադրված տեղեկությունները գաղտնի են պահվելու, և հավաքագրված տվյալները ընդհանրացված կերպով օգտագործվելու են միայն հետազոտական նպատակներով՝ առանց նույնականացնող տվյալներ նշելու:

Ներածական հարց: Կպատմե՞ք մի փոքր Ձեր մասին, օրինակ ի՞նչ կրթություն ունեք և քանի՞ տարի է, որ աշխատում եք այս դպրոցում:

1. Ո՞րն է Ձեր դերը՝ որպես դպրոցի տնօրեն/ ուսուցիչ/ հոգեբան/ լոգոպեդ՝ ՆՁՀ ունեցող երեխաներին աջակցելու գործում:
Probe: Ինչպիսի՞ աշխատանքային փորձ ունեք ՆՁՀ ունեցող երեխաների հետ:
2. Ըստ Ձեր փորձի՝ ինչպիսի՞ն է ՆՁՀ ունեցող երեխաների նկատմամբ շրջապատի մոտեցումն՝ ընդհանուր առմամբ:
Probe: Ինչպե՞ս են նրանց ընդունում դպրոցում:
Ի՞նչ կասեք հասակակիցների վերաբերմունքի մասին:
Ի՞նչ կասեք այլ երեխաների ծնողների վերաբերմունքի մասին:

3. Կարո՞ղ եք նկարագրել ՆԶՀ ունեցող երեխայի դպրոց ընդունվելու գործընթացը և թե ինչպես է երեխան ներառվում դպրոցում:
Probe: Ի՞նչ դժվարություններ եք ունենում, երբ փորձում եք երեխային ներառել դասարանական աշխատանքներում:

4. Ձեր կարծիքով, որո՞նք են Հայաստանում նյարդաբանական զարգացման հապաղում ունեցող երեխաների կարիքները:
Probe: Որո՞նք են նրանց հատուկ կարիքները կրթության ոլորտում:
 Որո՞նք են նրանց հատուկ կարիքները սոցիալականացման ոլորտում:
 Որո՞նք են նրանց հատուկ կարիքները առողջապահության ոլորտում:

5. Ինչպե՞ս եք փորձում բավարարել նյարդաբանական զարգացման հապաղում ունեցող երեխաների կրթության առանձնահատուկ կարիքները:
Probe: Ի՞նչ միջոցներ եք ձեռնարկում:
 Ի՞նչ խոչընդոտներ եք ունենում այս կարիքները հոգալիս:
 Կարո՞ղ եք մի քանի օրինակ բերել:

6. Ինչպիսի՞ աջակցություն եք Դուք, Ձեր դպրոցը կամ համայնքը տրամադրում ՆԶՀ ունեցող երեխային և նրա ընտանիքին:
Probe: Ի՞նչ կասեք ֆինանսական, նյութական և մասնագիտական աջակցության վերաբերյալ:

7. Ինչպիսի՞ միջոցներ են անհրաժեշտ ՆԶՀ ունեցող երեխաներին և նրանց ծնողներին աջակցելու համար:
Probe: Մտածեք ֆինանսական, նյութական, հոգեբանական և մասնագիտական աջակցության մասին:

8. Նկարագրեք, խնդրեմ, Ձեր համագործակցությունը առողջապահական ոլորտի հետ՝ ՆԶՀ ունեցող երեխաներին դպրոց ընդունելու և կրթության մեջ ներառելու գործընթացում:
Probe: Ինչպե՞ս եք աշխատում առողջապահական ոլորտի մասնագետների հետ:
 Ո՞ր մասնագետների հետ եք համագործակցում:
 Նկարագրեք, խնդրեմ, այդ համագործակցության գործընթացը:

9. Ինչպե՞ս կնկարագրեք Ձեր աշխատանքը ՆՁՀ ունեցող երեխայի ծնողների հետ՝ երեխաներին դպրոցական կյանքում ներգրավելիս:
Probe: Ինչպե՞ս կարելի է բարելավել այդ աշխատանքը:
10. Ինչպիսի՞ փոփոխություններ կառաջարկեք՝ ՆՁՀ ունեցող երեխաների կրթությունը և սոցիալական ինտեգրումը բարելավելու համար:
11. Կա՞ ինչ-որ բան, որ մենք չքննարկեցինք, բայց դուք կարծում եք, որ կարևոր է և կցանկանայիք ավելացնել:

Ժողովրդագրական տվյալներ

Ձեր տարիքը	_____
Ձեր սեռը՝ (այս հարցը չկարդալ և լրացնել ինքնուրույն)	5. Արական 6. Իգական
Քանի՞ տարի եք աշխատել ձեր մասնագիտությամբ:	_____
Ավարտ	____:____

Շնորհակալություն մասնակցության և Ձեր մտքերն ինձ հետ կիսելու համար:

Appendix 9

In-depth Interview Guide with Healthcare Professionals (English Version)

Interview date: ____ / ____ / ____ (DD/MM/YY)

ID: _____

Start time: ____:____ (HH:MM)

Hello, my name is Lilit, I am a graduate student of the AUA Turpanjian College of Health Sciences. I highly appreciate that you agreed to participate in this interview. In the scope of my MPH thesis, I am doing a research on the needs and gaps in healthcare and education of children with neurodevelopmental delays (NDDs). Would you, please, share with me your opinion about the education of children with NDDs and your experience in this sphere? The interview will last approximately 40-60 minutes. I am interested in your frank answers as they are highly valuable for this study. Whatever you share here with me, will be kept confidential, no identifying information will be provided with that information and it will be used solely for this study purposes.

Introductory question: Would you please tell me little bit about yourself, for instance, how many years you are working in this sphere and what is your background?

1. What is your role as a Rehabilitation Doctor/ pediatrician/ neurologist supporting children with NDDs?
Probe: What kind of work experience do you have with children with NDDs?
2. Can you describe the diagnostic process of a child with NDD?
Probe: What stages does the child undergo before being diagnosed a child with NDD?
At what age and how is NDD discovered and diagnosed in Armenia?
What are the difficulties in the diagnostic process?
3. How do the parents or other family members respond to the diagnosis of NDD?
Probe: How do they admit the professional conclusion?
Based on your experience, can you share with us a few examples?
4. How the treatment process of a child with NDD is organized in Armenia?
Probe: When does the treatment process start and what does it include?
Who implements it and how?
What kind of specialists do you refer the child with NDD to?

What are the gaps and obstacles in the treatment process?

5. In your opinion, what are the main needs of children with NDDs in healthcare in Armenia?

Probe: Which services are available and accessible?

What other specific services are necessary?

6. How does the healthcare system satisfy the above mentioned healthcare needs? What services/support are provided to children with NDDs and their families in Armenia?

Probe: What about pharmacological/psychological and professional support?

What healthcare/ social services does a child with NDD receive during the treatment process?

7. What resources do you need to support the children with NDDs and their parents?

Probe: Think of financial/material/psychological/professional support.

8. How would you describe your collaboration with the education system when children with NDDs are admitted and integrated to school?

Probe: How do you work with school staff members?

With what kind of staff members do you collaborate (if any)?

Would you please describe what the process looks like?

9. How would you suggest improving the healthcare system to better address the needs of children with NDDs?

10. Is there any other information that you think is important and you would like to add?

Demographic Data:

Your age	_____
Your sex (Don't read this question aloud)	7. Male 8. Female
How many years have you worked by your profession?	_____
End time	____:____

Thank you for participating and sharing your thoughts with me.

Appendix 10

In-depth Interview Guide with Healthcare Professionals (Armenian Version)

Ամսաթիվ՝ ____/____/____

ID՝ _____

Մկիզբ՝ _____:

Բարև Ձեզ, իմ անունը Լիլիթ է: Ես սովորում եմ Հայաստանի ամերիկյան համալսարանի Թրփանճեան առողջապահական գիտությունների ֆակուլտետի մագիստրատուրայի ավարտական կուրսում: Ես բարձր եմ գնահատում, որ համաձայնեցիք մասնակցել այս հարցազրույցին: Իմ ավարտական թեզի շրջանակում ես նյարդաբանական զարգացման հապաղում (ՆՁՀ) ունեցող երեխաների կարիքների և նրանց մատուցվող բուժական և կրթական ծառայություններում առկա բացերի վերաբերյալ հետազոտություն եմ անցկացնում: Ինձ հետաքրքիր է Ձեր կարծիքը ՆՁՀ ունեցող երեխաների բուժապասարկման կազմակերպման վերաբերյալ և Ձեր փորձառությունն այս ոլորտում: Հարցազրույցը կտևի մոտ 40-60 րոպե: Ձեր անկեղծ պատասխանները շատ կարևոր են այս հետազոտության համար: Ձեր կողմից տրամադրված տեղեկությունները գաղտնի են պահվելու, և հավաքագրված տվյալներն ընդհանրացված կերպով օգտագործվելու են միայն հետազոտական նպատակներով՝ առանց նույնականացնող տվյալներ նշելու:

Ներածական հարց: Կպատմե՞ք մի փոքր Ձեր մասին, օրինակ ի՞նչ կրթություն ունեք և քանի՞ տարի է, որ աշխատում եք այս ոլորտում:

1. Ո՞րն է ձեր դերը՝ որպես վերականգնող բժիշկ/մանկաբույժ/նյարդաբան, ՆՁՀ ունեցող երեխաների ախտորոշման և բուժման գործընթացում:
 - a. *Probe:* Ինչպիսի՞ աշխատանքային փորձ ունեք ՆՁՀ ունեցող երեխաների հետ:
2. Նկարագրեք, ինչպե՞ս, ՆՁՀ ունեցող երեխաների ախտորոշման գործընթացը:
 - a. *Probe:* Ի՞նչ փուլեր է անցնում երեխան՝ նախքան ՆՁՀ ախտորոշում ստանալը:

- i. Ո՞ր տարիքում և ինչպե՞ս է հայտնաբերվում ու ախտորոշվում ՆԶՀ Հայաստանում:
 - ii. Ի՞նչ դժվարություններ են լինում ախտորոշման կազմակերպման գործընթացում:
- 3. Ինչպե՞ս են արձագանքում երեխայի ծնողները կամ ընտանիքի անդամները ՆԶՀ ախտորոշմանը:
 - a. *Probe:* Ինչպե՞ս են ընդունում մասնագիտական եզրակացությունը:
 - i. Խնդրում եմ կիսվել օրինակներով՝ Ձեր փորձից:
- 4. Ինչպե՞ս է իրականացվում ՆԶՀ ունեցող երեխաների բուժումը Հայաստանում:
 - a. *Probe:* Ե՞րբ է սկսվում բուժումը և ի՞նչ է ներառում:
 - i. Ինչպե՞ս և ու՞մ կողմից է իրականացվում:
 - ii. Ի՞նչ մասնագետների մոտ էք ուղղորդում նրանց:
 - iii. Ի՞նչ բացեր և դժվարություններ կան բուժման գործընթացում:
- 5. Ձեր կարծիքով, որո՞նք են ՆԶՀ ունեցող երեխաների կարիքները առողջապահության ոլորտում Հայաստանում:
 - a. *Probe:* Ո՞ր ծառայություններն են մատչելի և հասանելի:
 - i. Ի՞նչ այլ ծառայությունների կարիք կա:
- 6. Որքանո՞վ կամ ինչպե՞ս է ներկա համակարգը կարողանում բավարարել նշված առողջապահական կարիքները: Ի՞նչ աջակցություն կամ ծառայություններ են տրամադրվում ՆԶՀ ունեցող երեխային և նրա ծնողներին Հայաստանում:

Probe: Ի՞նչ կասեք դեղորայքային, հոգեբանական և մասնագիտական

 - i. աջակցության վերաբերյալ:
 - ii. Ո՞ր առողջապահական/սոցիալական ծառայություններից է օգտվում
 - iii. ՆԶՀ ունեցող երեխան բուժման ընթացքում:
- 7. Ի՞նչ ռեսուրսներ են անհրաժեշտ ՆԶՀ ունեցող երեխաներին և նրանց ծնողներին աջակցելու համար:

Probe: Մտածեք ֆինանսական/ նյութական/ հոգեբանական/ մասնագիտական

 - i. աջակցության մասին:

8. Նկարագրեք, ինդրեմ, ձեր համագործակցությունը կրթական ոլորտի մասնագետների հետ՝ ՆԶՀ ունեցող երեխաների դպրոց ընդունվելու և կրթության մեջ ներառելու գործընթացում:
- Probe:* Ինչպե՞ս եք աշխատում կրթական ոլորտի մասնագետների հետ:
- i. Ո՞ր մասնագետների հետ եք համագործակցում:
 - ii. Նկարագրեք, ինդրեմ, համագործակցության գործընթացը:
9. Ինչպիսի՞ փոփոխություններ կառաջարկեք իրականացնել, որպեսզի առողջապահական համակարգն ավելի նպատակային արձագանքի ՆԶՀ ունեցող երեխաների կարիքներին:
10. Կա՞ ինչ-որ բան, որ մենք չքննարկեցինք, բայց Դուք կարծում եք, որ կարևոր է և կցանկանայիք ավելացնել:

Ժողովրդագրական տվյալներ

Ձեր տարիքը	_____
Ձեր սեռը (այս հարցը չկարդալ և լրացնել ինքնուրույն)	1. Արական 2. Իգական
Քանի՞ տարի եք աշխատել Ձեր մասնագիտությամբ:	_____
Ավարտ	_____ : _____

Շնորհակալություն ձեր մասնակցության և ձեր մտքերն ինձ հետ կիսելու համար:

Appendix 11

Interview Guide with TPPSC Staff Members (English Version)

Interview date: ____ / ____ / ____ (DD/MM/YY)

ID: _____

Start time: ____:____ (HH:MM)

Hello, my name is Lilit, I am a graduate student of the AUA Turpanjian College of Health Sciences. I highly appreciate that you agreed to participate in this interview. In the scope of my MPH thesis, I am doing a research on the needs and gaps in healthcare and education of children with neurodevelopmental delays (NDDs). Would you, please, share with me your opinion about the education of children with NDDs and your experience in this sphere? The interview will last approximately 40-60 minutes. I am interested in your frank answers as they are highly valuable for this study. Whatever you share here with me, will be kept confidential, no identifying information will be provided with that information and it will be used solely for this study purposes.

Introductory question: Would you please tell me little bit about yourself, for instance, how many years you are working in this school and what is your background?

1. What is your role as a school principal/ teacher/psychologist/speech therapist in supporting children with NDDs?
Probe: What kind of work experience do you have with children with NDDs?
2. Based on your experience, what is the general approach towards children with NDDs?
Probe: How are they viewed and accepted at school?
What about the attitude of the peers?
What about the attitude of the parents of other children?
3. Can you describe the process of admission of a child with NDD to school and how the child is integrated to school?
Probe: What kind of difficulties do you face when trying to involve the child in the classroom activities?
4. In your opinion, what are the main needs of children with NDDs in Armenia?
Probe: What are their specific needs in education?
What are their specific needs in socialization?
What are their specific needs in healthcare?

5. How do you try to address the specific educational needs of children with NDDs?
Probe: What measures do you take?
 What obstacles do you face in meeting those needs?
 Can you share with us a few examples?
6. What support do you/your school or community provide to children with NDDs and their family?
Probe: What about financial support, material support, professional support?
7. What resources do you need to support the children with NDDs and their parents?
Probe: Think of financial/material/psychological/professional support.
8. How would you describe your collaboration with healthcare system when admitting and integrating children with NDDs to school?
Probe: How do you work with healthcare providers?
 With what kind of providers do you collaborate (if any)?
 Would you please describe what the process looks like?
9. How would you describe your work with parents of children with NDD when integrating children to school?
Probe: How could the work with parents be improved?
10. How would you suggest improving the education and social integration of children with NDDs in Armenia?
11. Is there any other information that you think is important and you would like to add?

Demographic Data:

Your age	_____
Your sex (Don't read this question aloud)	9. Male 10. Female
How many years have you worked by your profession?	_____
End time	____:____

Thank you for participating and sharing your thoughts with me.

Appendix 12

Interview Guide with TPPSC Staff Members (Armenian Version)

Ամսաթիվ՝ _____ / _____ / _____

ID՝ _____

Սկիզբ՝ _____: _____

Բարև Ձեզ, իմ անունը Լիլիթ է: Ես սովորում եմ Հայաստանի ամերիկյան համալսարանի Թրփանձեան առողջապահական գիտությունների ֆակուլտետի մագիստրատուրայի ավարտական կուրսում: Ես բարձր եմ գնահատում, որ համաձայնեցիք մասնակցել այս հարցազրույցին: Իմ ավարտական թեզի շրջանակում ես նյարդաբանական զարգացման հապաղում (ՆՁՀ) ունեցող երեխաների կարիքների և նրանց մատուցվող կրթական և բուժական ծառայություններում առկա բացերի վերաբերյալ հետազոտություն եմ անցկացնում: Ինձ հետաքրքիր է Ձեր կարծիքը ՆՁՀ ունեցող երեխաների կրթության վերաբերյալ և Ձեր փորձառությունն այս ոլորտում: Հարցազրույցը կտևի մոտ 40-60 րոպե: Ձեր անկեղծ պատասխանները շատ կարևոր են այս հետազոտության համար: Ձեր կողմից տրամադրված տեղեկությունները գաղտնի են պահվելու, և հավաքագրված տվյալները ընդհանրացված կերպով օգտագործվելու են միայն հետազոտական նպատակներով՝ առանց նույնականացնող տվյալներ նշելու:

Ներածական հարց: Կպատմե՞ք մի փոքր Ձեր մասին, օրինակ ի՞նչ կրթություն ունեք և քանի՞ տարի է, որ աշխատում եք ՏՄԱԿում:

1. Ո՞րն է Ձեր դերը՝ որպես ՏՄԱԿ-ի ներկայացուցիչ՝ ՆՁՀ ունեցող երեխաներին աջակցելու գործում:
Probe: Ինչպիսի՞ աշխատանքային փորձ ունեք ՆՁՀ ունեցող երեխաների հետ:
2. Ըստ Ձեր փորձի՝ ինչպիսի՞ն է ՆՁՀ ունեցող երեխաների նկատմամբ շրջապատի մոտեցումն՝ ընդհանուր առմամբ:
Probe: Ինչպե՞ս են նրանց ընդունում դպրոցում:
Ի՞նչ կասեք հասակակիցների վերաբերմունքի մասին:
Ի՞նչ կասեք այլ երեխաների ծնողների վերաբերմունքի մասին:

3. Կարո՞ղ եք նկարագրել ՆԶՀ ունեցող երեխայի դպրոց ընդունվելու գործընթացը և թե ինչպես է երեխան ներառվում դպրոցում:
4. Ձեր կարծիքով, որո՞նք են Հայաստանում նյարդաբանական զարգացման հապաղում ունեցող երեխաների կարիքները:
Probe: Որո՞նք են նրանց հատուկ կարիքները կրթության ոլորտում:
 Որո՞նք են նրանց հատուկ կարիքները սոցիալականացման ոլորտում:
 Որո՞նք են նրանց հատուկ կարիքները առողջապահության ոլորտում:
5. Ինչպե՞ս եք փորձում բավարարել նյարդաբանական զարգացման հապաղում ունեցող երեխաների կրթության առանձնահատուկ կարիքները:
Probe: Ի՞նչ միջոցներ եք ձեռնարկում:
 Ի՞նչ խոչընդոտներ եք ունենում այս կարիքները հոգալիս:
 Կարո՞ղ եք մի քանի օրինակ բերել:
6. Ինչպիսի՞ աջակցություն եք Դուք, որպես ՏՄԱԿ-ի ներկայացուցիչ, տրամադրում ՆԶՀ ունեցող երեխային և նրա ընտանիքին:
Probe: Ի՞նչ կասեք ֆինանսական, նյութական և մասնագիտական աջակցության վերաբերյալ:
7. Ինչպիսի՞ միջոցներ են անհրաժեշտ ՆԶՀ ունեցող երեխաներին և նրանց ծնողներին աջակցելու համար:
Probe: Մտածեք ֆինանսական, նյութական, հոգեբանական և մասնագիտական աջակցության մասին:
8. Նկարագրեք, ինդրեմ, Ձեր համագործակցությունը առողջապահական ոլորտի հետ՝ ՆԶՀ ունեցող երեխաներին դպրոց ընդունելու և կրթության մեջ ներառելու գործընթացում:
Probe: Ինչպե՞ս եք աշխատում առողջապահական ոլորտի մասնագետների հետ:
 Ինչպե՞ս եք համագործակցում դպրոցների մասնագետների հետ:
 Ո՞ր մասնագետների հետ եք համագործակցում:
 Նկարագրեք, ինդրեմ, այդ համագործակցության գործընթացը:
9. Ինչպե՞ս կնկարագրեք Ձեր աշխատանքը ՆԶՀ ունեցող երեխայի ծնողների հետ՝ երեխաներին դպրոցական կյանքում ներգրավելիս:

Probe: Ինչպե՞ս կարելի է բարելավել այդ աշխատանքը:

10. Ինչպիսի՞ փոփոխություններ կառաջարկեք՝ ՆՁՀ ունեցող երեխաների կրթությունը և սոցիալական ինտեգրումը բարելավելու համար:
11. Կա՞ ինչ-որ բան, որ մենք չքննարկեցինք, բայց դուք կարծում եք, որ կարևոր է և կցանկանայիք ավելացնել:

Ժողովրդագրական տվյալներ

Ձեր տարիքը	_____
Ձեր սեռը՝ (այս հարցը չկարդալ և լրացնել ինքնուրույն)	11. Արական 12. Իգական
Քանի՞ տարի եք աշխատել ձեր մասնագիտությամբ:	_____
Ավարտ	____:____

Շնորհակալություն մասնակցության և Ձեր մտքերն ինձ հետ կիսելու համար:

List of Appropriate Journals

BMJ Global Health

SAGE Journals

The Lancet

Public Health Reports

Qualitative Research Journal

Brain Sciences

J Glob Health

Dev Med Child Neurol

Research in Developmental Disabilities

Social Science & Medicine