

**Needs and Gaps in Services Provided for Children with Down Syndrome in
Yerevan, Armenia. Perspectives of Parents and Healthcare Providers:**

A Qualitative Research

Master of Public Health Integrating Experience Project

Professional Publication Framework

by

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List of abbreviations

DS	Down syndrome
Ts21	Trisomy 21
CDC	United States Centers for Disease Control and Prevention
USA	United States of America
AAP	American Academy of Pediatrics
CWD	Children with Down syndrome
UNICEF	United Nations Children's Fund
MOH	Ministry of Health of Armenia
PHC	Primary healthcare
IDI	In-depth interview
FGD	Focus group discussion
IRB	American University of Armenia Institutional Review Board
CHSR	AUA Center for Health Services Research and Development
BBP	Basic benefits package
NGO	Non-governmental organization

Abstract

Down syndrome (DS, trisomy 21, Ts21) is known as one of the most common causes of mental disability. The estimated worldwide incidence of DS is from 1 in 1,000 to 1 in 1,100 live births. Comprehensive health care and continuous medical supervision of children with DS (CWD) are the major factors influencing the health and developmental outcomes of these children.

Literature evidence suggests a lack of appropriate counselling, special healthcare, developmental and educational support, presence of economic/financial barriers, and stigmatization as factors which negatively influence CWD and their families' adjustment. There is no official published statistical information about the rates of DS in Armenia. DS's genetic diagnostics and counselling are only available at the Center of Medical Genetics and Primary Healthcare in Yerevan. According to the data obtained from this center, from 2013 to 2017, a total of 148 infants were diagnosed with DS through post-natal genetic testing. Unfortunately, available data do not reflect the real situation in terms of prevalence or care for CWD in Armenia.

Moreover, there is a significant gap in medical, sociodemographic, and disease burden data regarding CWD, a formidable barrier to informed decision making by stakeholders. This qualitative study aimed to explore the gaps in care, healthcare needs, and barriers to appropriate care provided to CWD from the perspectives of parents and healthcare providers of CWD in Yerevan, Armenia. Data was collected through a focus group discussion (FGD), semi-structured in-depth interviews (IDI), and key informant interviews. The study participants were selected by purposive sampling technique and included: primary care pediatricians from Yerevan polyclinics (specifically those who have at least one child with DS 1-17 years of age under their supervision), neonatologists from maternity hospitals, mothers of CWD, and field-experts (a developmental pediatrician and a pediatric health policymaker). Four IDI and one FGD field

guides were developed using the Socioecological Model of Health and based on literature review, then translated into Armenian. Data collection continued until the saturation was reached. Conventional content analysis was done using deductive approach. The study gave a comprehensive understanding of healthcare and social support needs of CWD and their families in Armenia. According to the study findings, initial reactions at the time of DS diagnosis disclosure, mostly defined as denial, stress, and shock experienced by mothers, were closely linked to the way by which the diagnosis was delivered to parents. Mothers reported insufficient and inadequate medical counselling provided to them. The current practices of healthcare and supervision of CWD in Armenia significantly differed from those internationally accepted. The study findings suggested a lack of coordinated and sustainable social support services and limited access to developmental and educational programs for CWD in Armenia. The role of government was perceived critical for future enhancement and provision of quality care for CWD. As a first step in this direction, it was recommended to obtain statistical data on the overall prevalence and incidence of DS in Armenia. Further, developing medical guidelines for health supervision of CWD and establishing national DS registry through the integration of international DS foundations was recommended. The need to organize trainings of first-contact providers (PHC pediatricians and neonatologists) on appropriate medical counselling of families of CWD was acknowledged. Finally, it was recommended to support CWD and their families via coordinated social support services tailored to the real needs of their beneficiaries.

1. Introduction

Down syndrome (DS) is a genetic, chromosomal disorder “caused by extra genetic material in chromosome 21.”¹ Chromosomes are the genetic "packages," which determine the growth, development, and functioning of the human body.² Typically, each cell has a nucleus which contains 23 pairs of chromosomes. In DS, a triplication (having an extra copy) of all or a part of the 21st chromosome occurs, which results in cognitive and physical abnormalities in affected individuals.² Down syndrome (DS, trisomy 21, Ts21) is known as the commonest cause of mental disability worldwide.³ According to the United States Centers for Disease Control and Prevention (CDC), about 6000 newborns with DS are born in The United States of America (USA) annually, which is approximately one in every 700 newborns.⁴ According to the United Nations organization, the worldwide incidence of DS is estimated from 1 in 1,000 to 1 in 1,100 live births.⁵ Individuals with DS have distinctive physical features that appear at birth along with cognitive disability, characterized by impaired language, memory, and global developmental delays, which result in difficulties with daily life.⁶ Besides the developmental and cognitive impairment, DS patients also typically have health-related risks and comorbidities, such as hearing impairment (up to 75%), congenital heart defects (50% of all DS cases), obstructive sleep apnea (up to 79%), ear infections (50 -70%), eye disease (up to 60%), and thyroid disease (up to 18%).^{2,7}

Comprehensive health care and continuous medical supervision of CWD are major factors influencing the health and developmental outcomes of these children. The American Academy of Pediatrics (AAP) clinical report⁷ of “Health Supervision for Children with DS” (published 2011, reaffirmed Jan 2018) provides a clinical guide for age-appropriate health supervision of CWD, including specific screenings and parental counselling.⁷ Unfortunately, there is increasing

evidence of frequent disparities between recommended and actual health care practices for CWD.⁸ A retrospective review of medical records of the primary care clinics included in the University of Wisconsin Health system revealed that most CWD do not receive appropriate age-specific health supervision.⁹ Further, there was a decrease in adherence to audiological and ophthalmological screening recommendations with increasing age of children. Low adherence was prevalent in specific ethnic groups, with males and among those who were receiving alternative medical care.⁹

Other studies have identified the impact of gaps in healthcare. A qualitative study in Ontario, Canada, reported limited ophthalmological services, inadequate care for thyroid problems, “diagnostic overshadowing” during the hospital stay as major concerns of parents of CWD.¹⁰

The impact of the implementation of specific recommendations for health supervision of CWD was studied for particular diseases among CWD. A large population-based retrospective cohort study among 1257 CWD aged 1-18 years old showed that after the AAP guidelines were released, during 11 years of follow-up, the incidence of successfully treated thyroid disease cases dramatically increased.¹¹

Parenting children with disabilities is a challenging task and significantly differs from regular parental care. From the moment parents are told about their child’s impairment, they typically experience conflicting emotions: disbelief, guilt, and denial. DS can be diagnosed prenatally. However, it is more often diagnosed at birth. In either case, proper counselling by professionals will play a key role in informed decision making and parents’ future adjustment. CWD have special needs, and their families will likely face stressful periods due to practical, financial and emotional challenges while providing care.^{12 13}

A large number of studies have assessed the experiences and perceptions of families caring for CWD. Studies conducted in North American and Western European countries have shown that families with CWD are often well adjusted to caring for the child and report nearly comparable experiences of overall quality of life compared with those not having CWD.^{14 15 16 17} On the other hand, the few available studies from low and middle-income countries have reported the lives of families with CWD as oppressive due to high stigmatization and unmet needs.^{18 19}

Despite between-country differences in the extent of adaptation of families to bringing up CWD, factors influencing adaptation of these families are typically the same and include not only inadequate health care services but also insufficient social and educational support, stigmatized cultural norms, and family beliefs, which remain the major factors influencing parental and family adaptation and attitudes.^{18 20 21 22}

In a qualitative study conducted in the State of Florida, USA, caregivers of CWD highlighted the need for consistent and appropriate family-centered services provided by healthcare systems.

Formal and informal support for both developmental and medical services for CWD were reported by families and care providers as a primary need.²¹ Another study investigated parents' experiences of having CWD from birth and beyond in Ecuador. According to the study authors, poor or stressful communications between medical professionals and parents, lack of social support, and stigmatization, all contributed to difficulties faced by CWD and their families.

These factors were indicated as major barriers to the development of CWD and prevented many positive adjustments within their families.¹² Appropriate medical counselling during both prenatal and postnatal diagnosis periods is a key factor influencing parents' adjustment and stress. A study conducted in Pakistan revealed that the lack of appropriate support from medical professionals together with widespread stigmatization and rejection by society and community

are the main contributors to parents' decision to terminate the pregnancy after prenatally diagnosing DS.²³ Another study reported results from a survey of 1250 American parents of CWD.²⁴ The majority reported their first reaction of knowing the child's diagnosis as "anxious and frightening." The way in which medical professionals informed parents about the diagnosis was mentioned as the most frequent cause of negative parental experience.²⁴

Lack of information and special education are also important causes of anxiety and stress among new parents of CWD.²⁵ Other studies have investigated internal (parental and family) factors and coping strategies influencing parental adaptation. Family belief models, uncertainty and hope, were identified as main themes in the adaptation process.^{22 26} In general, the overwhelming majority of parents of CWD face similar experiences and needs regarding their child's care, development, and future. Lack of appropriate counselling, special healthcare, developmental and educational support, presence of economic/financial barriers, and stigmatization are all factors which negatively influence DS children and their families' adjustment and are strongly associated with parents' worries about their DS children's future self-control and independence.²⁷

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1.1. Children with Down syndrome in Armenia

As of the 2011 census, the population of Armenia was 3,018,854 (NSS 2013). As of early 2016, 20.8 % of the permanent population was <15 years of age.²⁹ According to the 2009-2011 United Nation's information on Inclusive Education in Armenia, the registered number of children with disabilities (age 0-18) was 8113.³⁰

Unfortunately, available numbers do not reflect the real situation in terms of prevalence or care for children with disabilities, nor the actual situation is described from the perspectives of

children with disabilities, their families, or healthcare providers in Armenia. Moreover, there is a significant gap in medical, sociodemographic, and disease burden data regarding children with disabilities, a formidable barrier to informed decision making by stakeholders.

A survey conducted by UNICEF Armenia among 5707 children with disabilities (most of them living in families) in Armenia ("It's About Inclusion" report in 2012)³¹ investigated the level of access to health care, social protection and education in this particular population, and identified barriers to access and satisfaction with services. According to the reported results, about 1% of the total child population was registered as having disabilities (age 0-18), and of those registered, 13% were under the care of residential institutions (orphanages and special schools). Further, only 23% of registered children with disabilities received individualized rehabilitation care. About 18% of the surveyed children were not in any education program. Parents of those children reported learning difficulties, poor health condition of the child, and lack of appropriate accommodations at school as the main reasons for low attendance at educational institutions. Of families of children with disabilities, 81% mentioned that they did not receive any social protection services, indicating lack of awareness of existing services as the main reason, though 97% were receiving a disability pension. Of children with disabilities in the surveyed families, 19% were not receiving any pediatric follow-up care, and parents reported financial barriers, limited access and lack of awareness as the main factors for not being under medical supervision. Especially in rural communities, disability was typically perceived as a disease rather than a life condition.³¹

Unfortunately, there is no official published statistical information about DS in Armenia. DS's genetic diagnostics and counselling are only available at one genetic laboratory in Armenia, Yerevan Center of Medical Genetics and Primary Healthcare. According to the data obtained

from this center, from 2013 to 2017, a total of 148 infants were diagnosed with DS through post-natal genetic testing. It is known that many of these children are now under the care of residential institutions.³¹

To the best of our knowledge, CWD receives disability pension only if they are registered as having a disability group. Based on the information from personal communications with an official from the RA Ministry of Labour and Social Affairs, the criteria for recognizing a child as disabled, defining disability category, terms of disability, privileges, and pension size are the same for CWD and those not having DS.³²

There is only one, relatively newly established non-governmental organization (NGO), which specifically supports CWD and their families (“Sun children” NGO). It was founded by parents of CWD. During in-person communications with the representatives of this NGO, we were informed that the mentioned NGO, together with few field-experts, is working on the development of parental information leaflets for DS. Another source from the Ministry of Health of Armenia (MOH) confirmed this information.

Given the limited information and lack of substantial research on the study topic, a qualitative study was conducted focusing on mothers’ and healthcare providers’ experiences of caring for CWD in Armenia. Mothers are the key information source for assessing the real-life needs of CWD and their families.^{24 33} In addition, taking into consideration that DS is most frequently diagnosed postnatally, experiences of neonatologists regarding medical counselling for parents of CWD added valuable information to this exploratory study. Further, since CWD require special health supervision by primary healthcare (PHC) pediatricians due to frequent

comorbidities associated with Ts21³⁴, PHC pediatricians are a key source of information about the existing situation and barriers in providing adequate health care to CWD.

This study aimed to explore the gaps in care, healthcare needs, and barriers to appropriate care provided to CWD from the perspectives of parents and healthcare providers of CWD in Yerevan.

The study research questions were the following:

- What are the experiences of parents/ mothers raising CWD and needs of CWD from the parental perspectives in Yerevan?
- What are the current healthcare delivery practices of CWD, and what are the barriers to providing appropriate health care for CWD in Yerevan from the perspectives of healthcare providers?

The findings of this study can be used to address the healthcare needs of DS children in Armenia better, to develop health and social services for them and to improve the quality of life of both CWD and their families. Further, we foresee to use the study findings for making recommendations on future research needs among this vulnerable population.

2. Methods

2.1. Study design

A qualitative study was conducted using in-depth interviews (IDI) with parents and providers (PHC pediatricians, neonatologists), focus group discussions (FGD) with PHC pediatricians, and key-informant interviews with field experts (pediatrician-policy makers and developmental pediatricians). Given the limited research on the study topic, qualitative research design allows obtaining a basic understanding of barriers, needs, and gaps in delivering care for CWD from

different perspectives.^{10 35 33} Multiple data collection methods (method triangulation) were used to support the study creditability.^{36 37}

2.2. Data collection: Study participants and settings

Convenience sampling method with the purposive technique was utilized to recruit primary pediatricians from Yerevan polyclinics (specifically those who had at least one child with DS 1-17 years of age under their supervision) and neonatologists from maternity hospitals. To achieve heterogeneity among participants, mothers were recruited through PHC pediatricians and from NGOs. Field experts were recruited from “ArBes” Health Center and MOH. After an approval was received from the American University of Armenia Institutional Review Board (IRB), mothers/primary caregivers were first contacted by their PHC pediatrician or an NGO, and agreed to be contacted by the research team through telephone calls to schedule for IDI at the time and setting convenient for them (Appendix 1, Appendix 2). Providers and key-informants were approached directly at their work settings and were informed about the study.

Further, for each potential participant, an appropriate time and place were identified for the interview. Permission of participants was obtained for audio recording of the interviews. In those cases when the audio-recording was refused by the participant, note-taking was done by the student-investigator. Only three participants refused to be recorded. Each participant was assigned an ID number, and no personal identifiers were used. The data transcription was done in the original language (Armenian) to avoid real content changes and missing of any valuable information provided by the study participants.

2.3. Study guide

One FGD field guide was developed for discussions with PHC pediatricians, and four IDI guides were developed specifically for mothers, providers (neonatologists and PHC pediatricians), experts (developmental pediatrician), and policy-makers in the pediatric healthcare field (Appendices 3-12). The field guides were developed using Socio-ecological model of health and, also, based on formative discussions with the field experts and literature review. Socio-ecological model has been widely used in qualitative research exploring healthcare utilization, needs, barriers, and experiences of marginalized populations (Figure 1).^{38 39} This model provides a general framework for different levels, such as individual, interpersonal, community, organizational, and policy; therefore supports the understanding and explanation of needs, barriers and gaps in delivering care for CWD.⁴⁰

The main domains of the semi-structured interview guides were the following:

- Medical counselling and parental reactions at first exposure
- Gaps in health services for CWD
- Social acceptance and support
- Educational/developmental needs
- Daily challenges and experiences
- Suggestions for improvements

Each guide consisted of 8 to 15 open-ended questions. The study guides have not been modified during the study process. The guides were developed in English, then translated into Armenian and discussed within the research team to ensure that questions are meaningfully addressing their intended content and do not overlap. A short socio-demographic questionnaire adapted from

prior studies conducted at the AUA Center for Health Services Research and Development (CHSR) was also used (Appendix 13, Appendix 14).

2.4. Data analysis

Conventional content analysis was done utilizing deductive approach.⁴¹ Based on the literature review, seven predetermined themes were identified. Within each of these themes, coding of the text data was done manually in the original language of interviews not to lose any important piece of information and avoid meaning and real-content changes during the analysis.

Meaningful phrases and sentences were coded. Categories were derived by grouping codes that shared common patterns throughout the data and were translated into English.^{41 42}

Several methods were used to guarantee the study rigor. To ensure the trustworthiness and confirmability of this study, data relevancy to the study framework was discussed within the research team.^{43 44} The creditability of the study was maintained by triangulation of data collected from different categories of participants (data-source triangulation).⁴⁵ Another method to strengthen the trustworthiness of the study was participant validation, also known as member check on spot method when the information provided by the participants was rephrased and returned to them to ensure the accuracy of the reflected meanings of their ideas.⁴⁶

2.5. Ethical considerations

The study protocol was approved by the American University of Armenia Institutional Review Board (IRB) before the data collection started. Oral informed consent forms were developed and approved by the IRB. The forms included a detailed description of the study in an understandable language for the study participants to guarantee the confidentiality of the information, and to inform about the right to refuse participation in the study. Prior to the

interview, each participant was informed about her right of withdrawal from the study at any time-point. A short informing form for the study enrollment was provided to the participants through telephone calls. At the beginning of the interview, the oral informed consent was read for each participant, and a copy of it was left with them. The interviews were recorded after receiving oral consent from the participants. (Appendices 15-18).

3. Results

3.1. Sociodemographic characteristics of participants

Overall, one FGD and 16 IDIs were conducted with a total of 19 participants. The FGD was conducted with three PHC pediatricians. Additionally, four PHC pediatricians participated in IDIs. Of other participant categories, four neonatologists, six mothers of CWD, and two key-informants (developmental pediatrician and MOH specialist) participated in IDIs. All interviews with mothers were conducted at sites based on the mother's convenience. Interviews with the remaining participants were conducted at their workplaces (polyclinics and maternity hospitals, MOH office). The mean duration of IDIs was 35 minutes. The mean age of providers was 45 years, with the youngest 29 and the oldest 53. The mean duration of their professional experience was 19.5 years. None of the interviewed providers had received training/educational course about health supervision for children with disabilities, including CWD, during the past five years. The mean age of mothers was 43 years, ranging from 34 to 54, with the age of their CWD ranged between 3 and 15 years. All mothers had at least an undergraduate degree of education and family's socioeconomic status was reported as "middle" by all mothers except one who reported "high" socioeconomic status.

Seven main themes predefined based on the literature review were the following:

- First exposure and medical counselling
- Experiences and daily challenges of parents raising CWD
- Healthcare gaps and needs of CWD
- Social support services
- Social acceptance and stigmatization
- Educational and developmental needs
- Suggestions for improvement

3.2. First exposure and medical counselling

3.2.1. Initial reaction to the birth of a child with DS

Each of the interviewed mothers shared unique experiences and feelings when first informed about the diagnosis of their child. The most common reactions included lack of acceptance and denial, to the extent, that for some of the mothers it took quite long to accept the diagnosis of DS, even after confirmation with genetic testing results. Medical professionals verified this observation, also reporting a lack of acceptance and denial as the most common parental reaction to the birth of a child with DS. Further, even mothers who were aware of the diagnosis during the pregnancy and made a conscious decision to not terminate the pregnancy were severely frustrated when the diagnosis was confirmed after birth. Commonly experienced feelings included fear for the future, hopelessness, loneliness, and devastation when realizing that the child will have a lifelong mental disability. The feeling of loneliness was commonly linked to a lack of support from close family members and relatives. Some mothers were still experiencing those feelings and became emotional during the interview; while others refused to even talk about "those horrible and shocking" days.

- *Until the last moment, I kept a hope that the diagnosis wouldn't be confirmed and my child would be born healthy... (Mother, 42y.o.)*
- *Even after the genetic testing, parents were trying to deny the diagnosis. They were saying, "I can't see any problems with my child; she just looks like me..." (PHC pediatrician, 47y.o.)*
- *It was really hard at the beginning; I was hopeless, felt alone, and could not find any solution. I could not understand the reason we were punished; I was crying all the time. (Mother, 41y.o.)*
- *Forty days after the birth, we obtained the results of genetic testing, but even then I could not believe it... (Mother, 42y.o.)*

3.2.2. *First-time disclosure of the diagnosis of DS*

Consistency was observed across categories with how DS diagnosis was delivered to parents. In most of the interviewed cases, fathers were informed first by the neonatologist about the suspicion that their child could have a DS. Mothers reported that they were told by relatives, but few of them were informed by the neonatologist. All the mothers shared similar experiences at the time of the first disclosure of the child's diagnosis, indicating that the approach of their doctor was very unsupportive and discouraging.

- *When she was just born, I was not allowed to breastfeed; they didn't bring my child to me saying: "decide first [whether you will take her home], then [we will bring the child to you], so that you are not getting bounded with her..." (Mother 42 y.o.)*
- *Initially, we inform it [the diagnosis] as a suspicion. No final diagnosis is made without genetic testing. [We do this] also considering the psycho-emotional status of the parents so that they do not get shocked. (Neonatologist 53 y.o.)*
- *Parents are told [by doctors], "you know, your child is ill, and his care will take a lot of time." Hence, the parents think that they would better devote their time to their healthy children rather than being overwhelmed with the burden of caring for the ill child. (Mother 41y.o.)*

However, concerns shared by providers about the first parental reaction to the diagnosis of DS differed from those that mother-participants shared. Most providers thought they did their best to convince parents to take the child home. However, a common statement was that “every 2nd child with DS is left in the orphanage.”

- *It is very common when parents leave the child even without waiting for the genetic test results. In such cases, mothers even refuse to breastfeed, in order not to get attached [to the child]. (Neonatologist, 50y.o.)*
- *There have been parents whom we were able to convince to take the child, but the next day their relatives came and told that the family decided to leave the child, because they did not want this to have a negative impact on the healthy siblings, because of feeling shame for having disabled child... Older members of the family have a huge influence, if they say – take the child, parents would take. (Neonatologist, 53y.o.)*

Frequently, providers stated that there was a strong association between the decision of leaving the child and the family beliefs and stereotypes, such as “fear of the negative impact on healthy siblings,” “feeling shame for having a mentally disabled child,” “fear of future difficulties that young parents would face.” Further, most of the providers highlighted the powerful influence of older family members on parental decision-making.

3.2.3. Lack of appropriate medical counselling

All mothers thought that they received either insufficient or inadequate information about the child’s condition and DS in general. They felt that they were not counseled sufficiently on DS-associated health complications and mental problems, and the information they were provided was restricted to the medical term of the disorder. Mothers reported the internet, relatives with medical education, and social media were their primary information sources. Parents contacted multiple medical professionals seeking guidance yet still indicated a feeling of “unanswered questions.” For those looking to providers for answers, some mothers felt ignored and described

their experience as rather oppressive.

- *When the child was one year old, we applied to XXX doctor, and he told: "You know, if you train a parrot, it talks, if you train a dog, it becomes a friend. Go try to train her; maybe you will have some success." (Mother, 34y.o.)*
- *I used to approach different professionals for help, but instead of giving directions, they were telling me to leave the child in the orphanage. (Mother 34 y.o.)*
- *The XXX doctors said: "The child has DS." They left us to find out what does it mean or what to expect. We did not receive any information; the XXX doctor told us: "Well, this is not a fatal diagnosis; the only thing is that if you say something to an ordinary child once, you need to say the same thing to this child five times [to make her understand]. Just this much." (Mother, 34y.o.)*
- *My questions were left unanswered...and I started exploring information myself to meet my child's needs. (Mother, 42y.o.)*

Among providers, we observed similar perceptions regarding the medical counselling provided to the families of CWD. All neonatologists found that most of the information related to DS and special needs of CWD should be provided by the PHC pediatricians. They justified this point of view, saying that they are not engaged in the further supervision of CWD. Few neonatologists thought that CWD do not significantly differ from healthy neonates in terms of routine care, so there is no need for providing special counselling to mothers of CWD. They said that mostly the information provided to parents was related to the necessary screening tests, such as cardiological and audiological check-ups. Still, PHC pediatricians expressed concerns regarding the lack or inadequacy of the information provided to parents at the first exposure. Few of them felt that parents did not have at least a basic knowledge about the child's condition at the first visit to the policlinic. A common perception was that in the maternity hospitals, the information provided to parents was restricted to the medical term of the disease only. All pediatricians shared a perception that what parents get from counselling depends on their level of understanding and attitudes.

- *Main information [provided to parents of CWD] is related to non-urgent but necessary tests to be done, e.g. screening for hearing impairment, cardiological tests; this is for those cases when we haven't been encountered with any obvious problem [health issues]. (Neonatologist, 50y.o.)*
- *Of course, parents are being explained in details about the DS specifications, about what to expect in terms of mental development, etc. From other perspectives, their (neonates with DS) care does not differ from that of healthy neonates, and no need for additional advice [parental counselling about the needs and care of CWD]. Mostly we leave the detailed information to be provided by PHC pediatricians, because that is not related to us [neonatologists], I mean the older-age specifications. (Neonatologist, 47y.o.)*
- *Basically, in the maternity hospital, only the diagnosis is told [by medical professionals to parents], and they [medical professionals at maternity hospital] note to approach the PHC pediatrician with the remaining questions. (PHC pediatrician, 29y.o.)*

3.3. Experiences and daily challenges of parents raising CWD

3.3.1. Life after having a child with disability and parental concerns

All participants experienced challenging and stressful changes in their life after having a child with DS. A common statement was that they had to leave their job and carrier dreams because of raising a child with DS, as he/she required a lot of time and emotional resources. The majority of mothers indicated the importance of family members' being supportive and encouraging, while a few mothers experienced conflicts with their partners, the stress of being blamed and loneliness because of lack of support from their family. Financial issues were also commonly mentioned, with a lack of financial resources indicated as contributing to the feeling of being "unable to meet the child's special needs." All participants realized the DS-related limitations of their child and perceived themselves as the main, if not the only, caregiver of their child, resulting in many mothers experiencing fear of "not being able to be

near the child all the time," which caused anxiety for the future of their child.

- *I can say from my example that I forgot my profession, my job, and completely devoted myself to my child. We live with [disability] allowance and with the help of relatives. Now could you tell me how I can provide adequate care to my child? (Mother, 54y.o.)*
- *I don't know whether it is because of the fact of having the 3rd child, or specifically because of having a child with DS, but the daily life became more complicated and stressful. (Mothers 42y.o.)*
- *My child has a severe mental problem, and he even can't find the way from the yard to home, but I can't be next to him all the time. (Mothers 54 y.o.)*

3.4. Healthcare gaps and needs of CWD

3.4.1. Importance of the special medical guidelines

There were contradicting findings regarding the importance and necessity of special medical guidelines for the healthcare and supervision of CWD, with different perspectives and attitudes identified between providers and mothers. Most of the interviewed mothers were well informed about the special healthcare needs of their children and stated that there is a strong need for formal medical guidelines for CWD. Mothers shared similar experiences while trying to get specific screening tests for their children (mostly, the screening test for hypothyreosis) when pediatricians refused to prescribe the needed test. It was thought that the barrier to testing is largely due to a lack of awareness and clear guidelines that the test is indicated. Mothers felt that the lack of special guidelines for the medical management of CWD causes severe problems for their child's health and introduces significant stress in the lives of their families.

Field-experts confirmed the urgent need for special guidelines for medical management of CWD but stated that the process of guideline development and subsequent confirmation by the MOH is complicated and requires extensive time and resources.

- *Almost 90% of PHC pediatricians have no idea on what is required to do, neither regarding the screenings nor about the special healthcare needs. The lack of medical guidelines results in serious shortcomings in their work, which causes serious problems and a lot of stress for our children and families. (Mother, 42y.o.)*
- *I went to the PHC pediatrician to ask for a referral to check my child for hypothyreosis, and only then she got aware of that special screening requirement. (Mother, 41y.o.)*

In contrast to parental perceptions, a common statement of providers was that specific guidelines for medical management of CWD are not very important, justifying that CWD do not significantly differ from non-CWD children in terms of healthcare or supervision requirements. In the absence of formal guidelines, interviewed PHC pediatricians primarily used general medical knowledge, or turned to international guidelines during their clinical practice. Few pediatricians mentioned a need for medical guidelines, especially for health supervision and specific screenings. All participants felt that the small estimated number of CWD in Armenia made specific medical guidelines unnecessary. Further, field-experts confirmed that there is no comprehensive statistical data available for CWD in Armenia.

- *There is no need for any special guideline for them. These children are similar to all other children in terms of pediatric healthcare. Besides, they are so few; the condition is so rare that there is no meaning to develop a special guideline for 1-2 children diagnosed [with DS] annually. (PHC pediatrician, 51y.o.)*
- *As to the guidelines for recommended screenings, yes, there is a need for those. (PHC pediatrician, 51y.o.)*
- *Unfortunately, there are no specific guidelines, and our decisions are based on general knowledge. There is a small number of CWD, might be that's the reason that the ministry. (PHC pediatrician 47y.o.)*

3.4.2. Current practices of healthcare and supervision of CWD

The most commonly observed practice in the supervision of CWD was referring the child to a pediatric neuro-psychological assessment dispensary, mentioned as a standard procedure by

field-experts as well. All pediatricians reported that CWD should receive their primary supervision and special healthcare in specialized follow-up clinics, especially highlighting that most of CWD who have congenital heart diseases should be under the supervision of a specialized cardiological clinic. Hence, they perceived their role as “more for the referral.” All pediatricians thought that "DS is predominantly a social issue, rather than a healthcare problem." Few pediatricians mentioned difficulties while providing healthcare to CWD, such as "impossible to perform a simple physical examination" due to the special behavioral characteristics of CWD.

- *I think that neuro-psychological dispensary is a better choice [for health supervision of these children]. Now the psychologist and neurologist are supervising her development. (PHC pediatrician 47y.o.)*
- *Finally, I think that in the case of children with these types of problems, PHC pediatrician's function [CWD] is more referring to them rather than providing direct care. (PHC pediatrician 51y.o.)*
- *It is almost impossible to conduct a physical examination of this child, even measuring weight and height is impossible, as s/he is severely mentally impaired. (PHC pediatrician 53y.o.)*

3.4.3. Communications between medical professionals and parents

All mothers found their relationship with PHC pediatricians mostly served to provide referrals to specialized hospitals and rehabilitation centers. This point of view was commonly observed among pediatricians as well. Most mothers perceived their relationships with PHC pediatricians as positive, although some were indifferent and, others felt ignored by their pediatrician. Generally, mothers avoided blaming or giving negative opinions about their PHC pediatrician, but in the majority of cases, there was a lack of trust between mothers and PHC pediatricians, prompting them to seek pediatric care in specialized pediatric

inpatient clinics. One of the commonly mentioned reasons was the perception of inadequate knowledge on the part of the PHC pediatrician.

- *We make contact with the PHC pediatrician solely for obtaining referral letters, but for routine healthcare, we apply to our pediatrician who is very knowledgeable, a true professional. (Mother, 54y.o.)*
- *I don't want to tell anything bad, but there is an extreme indifference in the polyclinic, sometimes even ignorance. (Mother, 34y.o.)*
- *The PHC pediatrician is nice, though we haven't visited the polyclinic for a year, and she even didn't contact us to ask whether the child is alive or not. (Mother, 41y.o.)*
- *I almost never see these patients (CWD), [usually,] they don't come, as parents don't want to make frequent visits to polyclinic, they often take a referral letter to the rehabilitation center. In most cases, the contact with them is for getting referral letters... (PHC pediatrician, 46y.o.)*

3.4.4. Resources

All pediatricians mentioned that limited state order and lack of training or educational programs targeting advances in the healthcare of CWD were the primary barriers to providing sufficient care for CWD. Also, all pediatricians stated that the services included in the basic benefits package (BBP) for children under the age of 7 years old are not enough to meet the healthcare needs of CWD. Particularly, they highlighted the limited number of rehabilitation services included in the BBP for 0-7 years old children. Both mothers and providers found that the services provided by the available rehabilitation centers are good, but not enough for achieving significant improvements in the child's condition. Another commonly observed concern was regarding the healthcare expenses of those CWD who were not registered as having a disability and were above the age of 7 years old. Both mothers and pediatricians stated that most of the screening tests and specialized health services were obtained through out-of-pocket payments. Owing to the physiological and anatomical

characteristics of CWD, these children require frequent hospitalizations and pharmacological treatment, causing an additional financial burden.

- *These children are getting sick very frequently. They are more prone to complicated respiratory illnesses, gastrointestinal diseases, such as biliary tract inflammations, and congenital heart diseases, and consequently, they need a number of laboratory tests and additional medical expenses, which put a continuous financial burden on the government as well. (PHC pediatrician 47 y.o.)*
- *Mother was referred for an audiological check-up for her child, but using her own financial means, as the BBP didn't cover such test. (PHC pediatrician 47 y.o.)*
- *When they get older and the BBP for 0-7 years old doesn't cover their health expenses anymore, their healthcare becomes more complicated in terms of financial expenses. (PHC pediatrician 47 y.o.)*

3.5. Social support services

All mothers felt desperate for any positive changes of formal support services for CWD in Armenia. Further, all were convinced that they were alone in solving the problems of their CWD.

- *I am hopeless that some positive change will take place in Armenia. We are alone with our problem, and probably this will be the case always. (Mother, 41y.o.)*

3.5.1. Lack of awareness about the existing social support services

Almost all providers were unaware of the existing social support services for CWD and their families. Few pediatricians mentioned that providing disability allowance to those CWD having disability status was the only formal social support service for them in the country. In contrast, mothers were better aware of the informal social support services, though, they also mentioned having disability status as the only means for receiving formal social support service in Armenia.

- *I am not aware of any social support services for CWD. I know only that their families receive some allowance. (Neonatologist, 50y.o.)*

3.5.2. *Lack of coordinated and sustainable social support*

As mentioned above, all mothers were well informed about social support programs but thought that services were not well organized and required more resources. A common statement was that the support provided by NGOs was either for a short period or did not target the real needs of CWD and their families. Some mothers had a feeling of injustice towards the existing forms of governmental support, highlighting that the families of CWD should get the same social support benefits as getting those adopting a child with a disability from residential institutions. Among the providers, those who were aware of the existing situation with social support for CWD and their families had similar thoughts and concerns regarding the lack of coordination and sustainability of the existing social support programs.

- *Commonly, the charitable organizations even do not know about these children, so that they could help them. There is a lack of a coordinated system for social support and charitable organizations' work. This is a real problem. (PHC pediatrician 59 y.o.)*
- *I wonder why does the government provide financial support every month to those families who are adopting CWD? Why are we treated differently? Does that mean that we should leave the child in the residential institution and later adopt him to get the same support? (Mother, 41y.o.)*
- *As a parent of CWD, we need adequate and targeted support; this is not that someone takes care of the child instead of us, but we need to get feedback when applying with an issue, or at least to have a place to apply and get responses to our questions. (Mother, 41y.o.)*
- *There are many financial problems... Of course, there are programs and organizations that provide some help, but typically for a short period. At least the government could have solved the transportation issue for these children. (Mother 54y.o.)*

3.5.3. *The barriers to obtaining a disability group*

All mothers interviewed were unhappy with the procedure for obtaining disability status for their CWD. Most of them indicated that their children were given disability status only because the child also suffered from congenital heart disease. All families shared a similar experience of being on the waiting list for a long time to get disability status. They unanimously described the procedure as "affecting self-esteem," "overwhelmed with the paperwork" and "oppressive." All of the participants, both mothers, and providers, were concerned about the criteria, based on which CWD is classified into disability group, feeling "injustice" that only children with severe mental impairment and those with surgically treated congenital heart disease were eligible for obtaining a disability group.

- *We are not receiving a disability pension because DS alone is not enough for receiving a disability status. The child should have some heart defect or be registered in the neuro-psychological dispensary for severe mental retardation to receive it [disability status]. (Mother, 54y.o.)*

3.6. Social acceptance and stigmatization

Almost all participants in both categories, mothers and providers, had similar perceptions of the root cause of non-acceptance and stigmatization of DS: specific cultural mentality and inadequate knowledge about the nature of the condition.

3.6.1. *Cultural stereotypes and beliefs*

As mentioned previously, all participants found cultural stereotypes and beliefs to be stigmatizing and oppressive. A common statement was that although there were some positive changes in people's attitudes and behavior towards DS, the parents still felt embarrassment and uncertainty while being in public places with their children. Few mothers described their

perceptions of public reactions as "injustice," "artificial empathy," and "uncertainty getting attention." All providers and mothers highlighted that being labeled by society were one of the commonly faced challenges of CWD and their families. Labeling, together with insufficient social support, was mentioned as the leading cause for the social isolation of the families of CWD. Moreover, almost all providers found that the above mentioned social attitudes and cultural stereotypes were accountable for the parent's decisions of leaving the child in the residential institutions.

- *It is a matter of local mentality that the families of these children are getting isolated; it is like being labeled for having a sick child, especially if the disease is of genetic nature... (Mother, 34y.o.)*
- *The public attitude has been changed. Before, there was more mocking, while now they show more compassion... yield sit in the public transport, are chary of giving offense... (Mother, 54y.o.)*
- *When I asked [a mother] how her first child [with DS] feels, she cried and told that they were keeping him isolated at home, so that no one would come to know about it [child's disease] ... This is to say; our system allows that you keep the child locked at home and nobody knows or asks questions... (Neonatologist, 45y.o.)*
- *The cultural mentality is predominant in our country: what if the neighbors come to know that they have a child with a congenital disorder, and they don't like to marry their daughter... (Neonatologist, 47y.o.)*

3.6.2. Social awareness

The majority of participants, both mothers, and providers indicated that stigmatizing attitudes are partially predetermined by people's inadequate or insufficient knowledge of DS. Particularly, mothers experienced such situations, when people confessed they had different, more dramatic perceptions about what is DS and about the severity of the impairment. Besides, few providers thought that social media is the most reliable source for maintaining public awareness.

- *I think that television has a significant role. Nowadays, there are many TV-shows about children and adults with DS and their achievements. Might be the social acceptance [of CWD] somewhat increased due to this. (PHC pediatrician, 47y.o.)*
- *There were cases when my neighbors came, inquired about [the health of the child] and got surprised saying: "... we used to think that they [CWD] were much more severely impaired." (Mother, 34y.o.)*
- *In my opinion, the negative attitudes are mostly determined by the lack of information or inadequate information [of people]. (Neonatologist, 53y.o.)*

3.7. Educational and developmental needs

Considering that mental impairment is the most characteristic feature of DS, all participants stated the importance of providing special education to CWD and developing targeted programs for them.

3.7.1. Practical and financial barriers to access to developmental services

Although mothers were aware of services that developmental pediatricians and speech-training programs provide, they mentioned financial issues as the predominant factor preventing the utilization of those services. In contrast, providers were not much aware of available options of developmental programs and services. The majority of mothers mentioned that because of unemployment and substantial medical and care expenses, they could not completely meet the developmental needs of their child. As an available alternative, they were seeking for special developmental programs which didn't require payment and are mostly provided by NGOs or other charitable organizations. Besides, mothers thought that those programs were good, though not sustainable. All participants reported that developmental programs included within BBP for 0-7 years old children were limited to 2-3 annual visits to the particular rehabilitation centers. In addition to the financial barrier, some mothers indicated a lack of time as another reason for not attending any developmental program. Field-experts also confirmed that there is a gap in the

developmental services for children with mental disabilities, particularly highlighting the financial barriers and the limited number of qualified specialists in this field.

- *There is a lot to do in the field of developmental programs for CWD, at least to help these children to develop normal speech instead of communicating with unintelligible sounds. But those services are not covered by BBP. (PHC pediatrician 40y.o.)*
- *We couldn't meet our child's developmental and rehabilitation needs because of financial, family related, and time issues. We used to visit physiotherapy courses covered with BBP 2-3 times per year, went to the speech therapist for a period, and then had to stop it because of [lack of] finances. (Mother, 54y.o.)*
- *Currently, the child is not included in any program. One of the reasons is the financial issue: all institutions providing special programs are for a fee. (PHC pediatrician 47 y.o.)*

3.7.2. Educational needs

All participants were well informed about the lack of inclusive education in Armenia. Mothers found that existing educational institutions were not able to meet the special needs of their children, mentioning the lack of required accommodation and equipment and lack of specialized professionals as the main gaps in those services. A joint statement was that CWD attend schools with inclusive education programs mostly for socialization purposes, rather than for education itself. Similarly, pediatricians thought that available inclusive education institutions should require trained professionals to meet the educational needs of CWD. Some mothers were concerned about the scarcity of available educational opportunities for their children, highlighting that because of mental impairment, their children were not able to get on track at school and they were forced to seek for alternative options, such as specialized schools for mentally impaired children.

- *My child attends school with inclusive education but, I don't know why, a CWD cannot attend the school without a parent because the school lacks elementary conditions [for children with disabilities], e.g., the toilet equipment is not adjusted for the needs of a child with a muscular problem. (Mother, 54y.o.)*
There is a huge gap also in involving these children in educational programs, as no inclusive education program that currently exists meets the special needs of these children. At least the basic education should be accessible for everyone. (Mother, 42y.o.)

3.8. Suggestions for improvement

To improve healthcare services for CWD, all participants suggested developing guidelines for healthcare and medical management of CWD, especially highlighting the support from the government (MOH), emphasizing that the process of guideline development and approval is under the Ministry's jurisdiction. All participants in both categories mentioned the lack of knowledge of CWD among healthcare providers and suggested specialized training/educational programs for medical professionals, especially pediatricians, to address this gap. The providers also mentioned the need for strengthening prenatal screening of DS by raising awareness among women of reproductive age about the importance of prenatal follow-up. The suggestions for improvements in social services were related to the development of coordinated social support programs and were addressed to both formal support from the government and informal support from donor agencies. Participants in different categories suggested the creation of a specialized referral center for CWD and their families, where they could receive appropriate counselling related to health and social services. Moreover, one of the common suggestions to improve social support for CWD and their families was to engage international organizations targeting needs of CWD. Similarly, the center would have explicit information about the needs of CWD and their families, thus would facilitate the coordination of available support services. Lack of statistical data regarding CWD was mentioned as a barrier to sufficient functioning and coverage

of support services. Other suggestions were improving access to particular developmental services by providing financial support to families, using either governmental resources or donations from funding agencies. Considering limited financial and specialist resources, few providers suggested creating special programs which will train mothers on basic developmental and rehabilitation skills, thus giving an opportunity to train their children at home. The field expert in the developmental pediatrics mentioned the existing problems with inclusive education and suggested to start inclusive education from preschool institutions rather than from schools. This suggestion was supported by the perception that it would be more feasible in terms of resources and time, and that social integration will be easier to achieve among younger children.

- *Another option to help these children is trying to integrate in Armenia international organizations which target particular problems of CWD, and there are many of those [international organizations] worldwide. (Key-informant)*
- *The most important is to inform young families to attend women health counselling center right at the beginning of pregnancy, to be under medical supervision, thus making possible early diagnosing in order not to face the fact at the end. (Neonatologist 53y.o.)*
- *For example, at least there could be special training programs for parents [developmental and rehabilitation skills], so the parents can train children at home. (Neonatologist, 45y.o.)*
- *In my opinion, it is a priority to create sufficient conditions for our children to receive at least a mid-level education, at least to give them an opportunity to do some activities, e.g., create some crafting center, where they will get socialized with each other and learn something as well. (Mother, 54y.o.)*

4. Discussion

This study demonstrated that initial reactions at the time of DS diagnosis disclosure, mostly defined as denial, stress, and shock experienced by mothers, were closely linked to the way by which the diagnosis was delivered to parents. Interestingly, our findings on this issue were

almost similar to those found in lower-middle income countries with specific social and cultural values, as well as in Western European and North American countries.^{12 23 24 47} Studies from these countries described that according to mothers of CWD, they got inadequate support from medical personnel at the time of the first exposure, which was the case in our study as well. As in this study, studies from other countries also found a relation between the initial reaction of parents at the time of the first exposure and the way the diagnosis of DS was delivered, or between the extent of adaptation achieved by parents and the cultural stereotypes and mentality in the given society. Lack of adequate medical counselling was one of the important findings of this study, and was commonly reported in other studies as well.^{12 47} Despite the differences in individual experiences, all mothers mentioned the fact of seeking answers for their questions from different sources, such as internet, social media and relatives. In the meantime, mothers perceived the counselling provided by medical professionals as inadequate, rude, and, sometimes, lacking any content but just telling the medical term of the disorder. The research evidence supports the finding of this study that lack of social support, lack of appropriate knowledge among healthcare professionals and unfavorable cultural mentality are factors preventing healthcare professionals from providing DS-counselling to parents in an appropriate manner.^{17 25 47} We found that the main concerns of families of CWD were related to the future of their child and exacerbated by the feeling of not being able to meet their child's need because of financial barriers. Parental fear of future and feeling of guilt for not being able to meet all the required needs of CWD were commonly reported by studies from low and middle countries as well^{15 16}, while research from western countries reported better adjustment and nearly comparable overall quality of life of families of CWD compared with those not having a CWD.¹⁸²⁰

Further, the study findings showed a lack of knowledge on the part of healthcare providers in the field of healthcare of CWD. Majority of healthcare providers (neonatologists and PHC pediatricians) were not aware of existing international guidelines (particularly AAP guideline for CWD) for healthcare and supervision of CWD. Moreover, they showed an indifferent attitude towards the need for developing or using a special medical guideline for CWD management. Considering the fact of not having any officially recognized guideline for the healthcare of CWD in Armenia, it was difficult to make comparisons between Armenia and other countries concerning the extent of applicability and usage of such guidelines by providers. However, several studies from countries that adopted DS medical management guidelines for more than a decade demonstrated that there were low compliance and awareness about these guidelines among general pediatricians.^{48,49} A study conducted in the USA in 2016 showed that 72% of the surveyed pediatricians provided incorrect answers to the questions related to the content of AAP DS-guidelines, though 80% self-reported as being comfortable with those.⁵⁰ These findings demonstrate that merely adopting a guideline is not enough for improving pediatric healthcare of CWD and underscore the importance of conducting provider training on these guidelines.

This study results showed that current practices of healthcare and supervision of CWD in Armenia significantly differ from those internationally accepted. The most common practice reported by the pediatricians was referring CWD to neuro-psychological assessment dispensary for further follow-up. Although none of the interviewed pediatricians could explicitly describe the functions of that dispensary, the general idea about the purpose of the dispensary was conducting primary follow-up of CWD by the neurologist and the pediatric psychologist. No literature was found supporting this practice. In contrast, the world's leading pediatric associations recommended the follow-up and supervision of CWD to be conducted by general

pediatricians, and neurological or psychological care to be symptom-based rather than routine. ⁷

⁵¹ From parental perceptions observed in this study, lack of knowledge among medical professionals, and the absence of special guidelines for the management of DS caused insufficient and inadequate healthcare provided to CWD. Particularly, insufficient screening for DS-specific comorbidities was one of the common parental concerns. We found echocardiography being reported by the providers and mothers as the main screening universally applied to CWD, while screenings for other common DS-specific comorbidities (hypothyreosis, hearing and vision impairment, etc.) were not reported by the pediatricians as a routine practice. Low compliance with the necessary screenings was reported by other research as well. A retrospective study conducted in Jamaica in 2018 reported low adherence to AAP guidelines, as evaluations for DS-specific health conditions were not carried out promptly for the majority of children.⁵² Another retrospective analysis of medical records obtained from primary healthcare providers in Oklahoma and Nebraska revealed only 34% and 45% of required screenings for thyroid disease performed for the period of 2001-2004.⁵³

In the current study, the interviewed mothers also reported lack of trust in relationships with their PHC pediatrician, mostly because of the perception of lack of knowledge on the part of the pediatrician and his/her indifferent attitude. Similarly, PHC pediatricians reported communication gaps with CWD and their families while providing primary healthcare to those. Particularly, they perceived the difficulty caused by the specific behavior in CWD as a common barrier to providing necessary healthcare to them. This was consistent with other studies, such as the qualitative study in Canada, 2008, where mothers of CWD found that primary physicians' attitudes were indifferent, characterizing those as "not interested in the child at all" and "diagnostic overshadowing". ¹⁰ According to our results, another barrier to adequate and

sufficient healthcare for CWD in Armenia was the lack of financial resources. The latter, combined with the limited number of rehabilitation services available for CWD as a part of BBP and the coverage of BBP limited to only children aged 0-7 y.o., were the main concerns expressed by both parents and providers. Despite the economic differences at country-level, findings of studies from higher income level countries were consistent with those in this study. A qualitative assessment of services and support to CWD conducted in Florida, the USA in 2014, reported common concerns of parents and pediatricians related to the limited insurance coverage for therapy services and lack of awareness of available resources. ²¹

Our findings suggested a lack of coordinated and sustainable social support services to families of CWD in Armenia and lack of awareness of the existing support services as the major gaps in this sphere. Evidence from the literature supports our findings. Studies conducted in the USA and Canada indicated service-coordination and real-needs-based support as the main gaps in social support services from parental perspectives. ^{21 22} One of the interesting findings of this study was the difficulty of obtaining disability status for CWD, as reported by mothers.

However, this finding was not discussed in other studies on the issue. One of the possible reasons for this could be the fact that the procedure of obtaining disability status is very specific for each country, and also might be defined by other terminology. We found high stigmatization level and lack of social acceptance of DS being linked to the cultural stereotypes and beliefs, as well as inadequate and insufficient public awareness of the condition. Interestingly, studies conducted in countries known as having relatively open-minded and less conservative societies report results similar to ours and the findings of other studies conducted in more culturally-restricted areas.^{19 54 55} The scarcity of developmental and educational programs for CWD and their families was another concern reported by mothers. In this study, the majority of mothers

perceived special educational programs as a better alternative to inclusive education. A survey conducted in 2012 in Armenia also pointed out that approximately 27% of the surveyed children with a mental and motor disability were left out of any educational program, while another 12% with auditory and mental disabilities were attending special schools rather than inclusive.³¹ Moreover, families mentioned lack of appropriate accommodations at inclusive schools and the inability of those programs to meet the individual needs of children with disabilities.³¹ However, there is evidence from western studies for high satisfaction and high utilization of inclusive educational programs in countries such as the USA, Israel, and the Netherlands.^{56 57 58} Additionally, the importance of early interventional programs and their role in long-term intellectual development and social adaptation of CWD was supported by evidence from literature.^{58 59}

This study gave a comprehensive understanding of healthcare and social support needs of CWD and their families in Armenia. Moreover, the gaps in the provided services were identified from different perspectives. The role of government was perceived critical for the future enhancement and provision of quality care for CWD.

4.1. Study strengths and limitations

This study explored the needs and gaps of healthcare and social services provided to CWD from the perspectives of both parents and service providers, and to our knowledge, was the first study conducted in Armenia. The study allowed a deeper understanding of the existing situation by integrating the experiences and perceptions of primary caregivers, service-providers, and mothers of CWD. The findings of the study pointed out not only the existing gaps and needs in this field but also identified barriers to meet those needs and barriers to the social adaptation of CWD and their families.

The use of focus group discussion, in-depth interviews, and key-informant interviews for collecting data from mothers of CWD, PHC pediatricians, neonatologists and field experts, helped to ensure triangulation (data-source and method triangulation) and thus enhanced the rigor of the study. Moreover, enrolling participants from different PHC clinics and maternity hospitals allowed increasing the generalizability of the findings. Transcription and analysis conducted in the original language allowed to keep the original meaning of data and avoid real-content changes during the analysis. Data were collected from 19 participants, and the saturation was reached after the 15th interview. However, this study had several limitations. Firstly, the study covered only participants from Yerevan, and therefore, no information was received from the rural areas.

Additionally, because of lack of time and resources, we did not approach residential institutions and pediatricians from specialized inpatient clinics. In qualitative research, the possible participant bias and researcher bias are of special consideration. Although the bias of leading questions was minimized in this study by formulating open-ended and neutral questions, the social desirability bias on the part of providers (PHC pediatricians and neonatologists) could not be ruled out. Considering the nature of qualitative design, when the researcher is the main instrument of the study, researcher bias related to reflexivity issues should also be taken into account.

4.2. Recommendations

Based on the study findings and the evidence from literature, several recommendations were developed, which were considered as potential tips for having achievable results:

- As a first step for the provision and enhancement of services for CWD, it is recommended to obtain statistical data on the overall prevalence and incidence of DS in Armenia. We suggest the government to establish a procedure for data collection on CWD from the Genetic Center and policlinics throughout Armenia to make the statistical data collection process continuous and sustainable.
- We recommend creating a national DS registry. As the governmental support is limited because of scarce financial resources, we suggest relevant governmental institutions (MOH and the Ministry of Labour and Social Affairs) to focus on the integration of international DS foundations, such as Global DS foundation, DS International organization, and others in Armenia.
- There is an emergent need to develop medical guidelines for healthcare and supervision of CWD. The government is a single instance that is responsible for that. To make the guideline development as feasible as possible, we suggest adapting and adopting of already existing international AAP guidelines on the subject.
- The medical professionals who are at first contact with families of CWD, as of PHC pediatricians and neonatologists, should be trained on providing appropriate medical counselling to families of CWD in terms of the content and the ways of delivering the information. Medical professionals should be ethical and unbiased with individual perceptions while providing the diagnosis and information on the spectrum of medical conditions (comorbidities) occurring with DS in an understandable language for parents.
- We suggest governmental social support services provided to CWD to be revised in terms of being more coordinated and tailored to the needs of CWD and their families. Considering that most mothers reported a lack of support for obtaining appropriate

developmental services for CWD, we suggest relocation of financial resources to the field of developmental programs for CWD.

- Based on the study findings, it was concluded that the developmental needs of CWD are not met because of two major barriers: limited financial resources and lack of qualified professionals. Thus, we suggest the government to support the education and training of medical personnel in the field of developmental pediatrics abroad (as there are no educational opportunities available in Armenia).
- Finally, there is a need for future research in the field of health and social services for CWD. We believe that a deeper understanding of international practices and experiences will facilitate the complicated process of improvements in the field.

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Figure 1. The Socioecological Model of Health



Appendix 1

American University of Armenia

Turpanjian School of Public Health

Institutional Review Board # 1

Interviewer Script for The Recruitment of mothers/primary caregivers

Hello, my name is Arpine. I am a pediatrician and a second-year master student in the Turpanjian School of Public Health at the American University of Armenia. As a part of my thesis project, I with my advising team members are conducting a study, which aims to explore the needs and gaps in healthcare provided to children with Down syndrome from perspectives of parents and healthcare providers. Your phone number was provided by your child's PHC pediatrician or by NGOs and is one of approximately 10 phone numbers. You are invited to participate in an interview that will last 30 minutes, at a convenient time and settings for you (PHC setting and American University of Armenia are the available options). Your participation or refusal will not affect the treatment that your child receives and/or will receive in the future. If you agree to participate, we can schedule a convenient time and place for the interview.

Appendix 2

Հայաստանի Ամերիկյան Համալսարան

Թրպանճեան Հանրային առողջապահության բաժին

Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով

Հեռախոսագանգերի միջոցով մայրերին/հիմնական խնամողների հավաքագրման ձեռնարկ

Բարեւ Ձեզ, ես Արփինեն եմ. ես մանկաբույժ եմ և, համատեղությամբ, Հայաստանի ամերիկյան համալսարանի (ՀԱՀ) Թրպանճեան Հանրային Առողջապահության բաժնի ավարտական կուրսի ուսանող: Այժմ մենք հետազոտություն ենք իրականացնում, որի նպատակն է գնահատել Հայաստանում Դաունի համախտանիշով երեխաներին մատուցվող ծառայությունների բացթողումներն ու կարիքները: Ձեր հեռախոսահամարը մեկն է այն 10-ից, որ ինձ է տրամադրել Ձարգացման հապաղման խնդիրներ ունեցող երեխաների հարցերով զբաղվող հասարական կազմակերպությունը (ՏԱրև երեխաներ՝ ՀԿ, Արբես ԲԿ) կամ պոլիկլինիկան, որտեղ հսկվում է Ձեր երեխան: Ձեր մասնակցությունն այս հետազոտությանը լիովին կամավոր է և սահմանափակվում է հարցազրույցով, որը կտևի մոտ 30 րոպեից 1 ժամ՝ Ձեզ հարմար վայրում և ժամի: Ձեր երեխայի ստացած բուժօգնությունը ներկայումս և հետագայում չի տուժի հետազոտությանը մասնակցելու կամ չմասնակցելու հետևանքով: Եթե համաձայն եք մասնակցել, մենք կարող ենք պայմանավորվել հարցազրույցի վայրի և ժամի մասին:

Appendix 3

Focus group field guide

(PHC pediatricians)

Date: _____

Time: _____

Place: _____

Good afternoon, and first of all - thank you very much for coming. My name is Arpine. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, we conduct a study to explore the existing needs and gaps in care delivery for children with Down syndrome (CWD), to identify the main problems and concerns from different perspectives. We have invited you here to ask you to share with us your approaches towards healthcare and supervision of CWD and to tell us about your experience in delivering care to CWD in general. Your frank answers will be very helpful for us in selecting the right issues to address in the future development of services provided to this special pediatric population. I will just suggest you topics of discussion and will ask all of you to express your opinions on those topics. Our discussion will take approximately 30 minutes to 1 hour. It would be better if the discussion will pass as a free conversation, and everybody will participate in it without waiting to his turn. I ask you only do not speak simultaneously, to make it easier for us to listen carefully to all of you. Please, express your ideas freely, having in mind that there are no wrong or right answers here. We are interested in all opinions equally, and all opinions are equally valuable for us. Be informed also that the information you will give us will remain confidential, and your names will not be mentioned with that information. Please, let us begin now.

Medical counselling and parental awareness at first exposure

1. How many children with DS do you have under your supervision? How old they are?
2. How would you define the level of awareness of parents/family about the condition of their child at your first visit and in general?
3. What do you know about the medical counselling provided to parents of CWD in the maternity hospitals in general?

Gaps in health services for CWD

4. How is it providing healthcare to a CWD? What challenges have you faced during healthcare co-ordination process of CWD?
5. How would you define the availability of reference information assisting healthcare of CWD? Do you use any literature or other sources of information for your reference?

What reference sources/guideline do you use in your current practice?

6. Which additional screenings do you perform among CWD? Do you use any international guidelines for the follow-up of CWD?

Educational/developmental needs

7. Do you have access to developmental pediatric services for the referral of CWD under your supervision? What are the barriers that prevent and/or facilitating factors to the access and utilization of developmental-pediatric services?
8. Are CWD under your supervision included in any educational institution (kindergarten, day-care centers, school)? What do you know about the inclusive education for CWD available in Armenia? What are the barriers to access to education for CWD in your opinion?

Social acceptance and support

9. What are the social support sources for families of CWD that you are aware of?
10. How do you feel about the general social acceptance of DS in Armenia? Do you feel public awareness of DS is adequate? Are CWD marginalized in the community in your opinion? How do you perceive the situation of DS stigmatization in Armenia?

Suggestions

11. What changes do you perceive as necessary for enhancing the healthcare and social services provided to CWD and their families?
12. Would you like to add any topic or issue, other than discussed, that is important in your opinion?

Thank you very much for your time and contribution, which we highly appreciate!

Appendix 4

Խմբային քննարկման ուղեցույց

(Առաջնային բուժապասարկման օդակի մանկաբույժների համար)

Ամսաթիվ _____

Ժամ _____

Վայր _____

Բարև Ձեզ: Նախ և առաջ, շնորհակալություն գալու համար: Իմ անունն է Արփիինե: Ես մանկաբույժ եմ, և համատեղությամբ սովորում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետում: Այժմ մենք հետազոտություն ենք իրականացնում, որի նպատակն է բացահայտել Դաունի համախտանիշով (ԴՀ) երեխաների կարիքները և նրանց մատուցվող ծառայությունների բացթողումները, այս ասպարեզում առկա հիմնական խնդիրները և մտահոգությունները՝ տարբեր տեսանկյուններից: Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, որպեսզի կիսեք Ձեր փորձը և մտածումները ԴՀ երեխաների բուժօգնության և հսկողության վերաբերյալ: Ձեր անկեղծ պատասխանները կօգնեն մեզ վեր հանել գոյություն ունեցող խնդիրներն ու կարիքները, դրանով իսկ նպաստելով այս հատուկ խմբի երեխաներին մատուցվող ծառայությունների բարելավմանը: Ես կառաջարկեմ թեմաներ, և կխնդրեմ յուրաքանչյուրին արտահայտել իր կարծիքը դրանց վերաբերյալ: Մեր հարցազրույցը կտևի մոտ 30 րոպեից 1 ժամ: Ցանկալի է, որ հարցազրույցն ընթանա անկեղծ միջավայրում, և յուրաքանչյուրը մասնակցի՝ իր կարծիքն ազատորեն հայտնելով՝ առանց իր հերթին սպասելու: Ես միայն կխնդրեմ, որ խոսեք ոչ միաժամանակ՝ հնարավորություն տալով մեզ ամբողջությամբ լսել յուրաքանչյուրիդ: Խնդրում եմ, ազատ և անկաշկանդ արտահայտեք Ձեր մտքերը, հիշելով, որ այստեղ չկան ճիշտ կամ սխալ պատասխաններ: Մեզ համար հավասարաչափ կարևոր և արժեքավոր են յուրաքանչյուրիդ կարծիքն ու մտքերը: Եթե դեմ չեք, ես կձայնագրեմ մեր հարցազրույցը, որպեսզի ոչ մի կարևոր ինֆորմացիա բաց չթողնենք: Եվս մեկ անգամ կցանկանայի նշել, որ այս հարցազրույցի ընթացքում արտահայտած ողջ ինֆորմացիան խիստ գաղտնի է լինելու: Այժմ, խնդրում եմ, սկսենք.

Բժշկական խորհրդատվությունը և տեղեկացվածությունը

1. Քանի՞ ԴՀ երեխա է ներկայումս գտնվում Ձեր հսկողության տակ: Քանի՞ տարեկան են նրանք:
2. Ընդհանուր առմամբ, ինչպե՞ս կգնահատեք այդ երեխաների ծնողների

տեղեկացվածության աստիճանն իրենց երեխայի՝ ԴՀ ախտորոշմամբ պայմանավորված վիճակի վերաբերյալ: Ինչպիսի՞ն էր նրանց տեղեկացվածության աստիճանը Ձեր առաջին այցի ժամանակ:

3. Ի՞նչ գիտեք ծննդատներում ԴՀ երեխաների ծնողներին տրամադրվող բժշկական խորհրդատվության մասին:

Առողջապահական ծառայություններում տոկա թերություններ/բացթողումներ

4. Կպատմե՞ք ԴՀ երեխաներին առողջապահական ծառայություններ մատուցելու Ձեր անձնական փորձից: Ի՞նչ խոչընդոտների էք հաճախ հանդիպում ԴՀ երեխաների առողջապահական ծառայությունների համակարգման/ուղղորդման գործընթացում:
5. Ի՞նչ կասեք ԴՀ երեխաների բժշկական հսկողության ու բուժման ուղեցույցների և այս թեմայով այլ ինֆորմացիայի հասանելիության մասին: Ի՞նչ ուղեցույցներ կամ այլ տեղեկատվական աղբյուրներ էք օգտագործում Ձեր ներկայիս աշխատանքի ընթացքում:
6. Ի՞նչ լրացուցիչ սկրինինգային հետազոտություններ էք իրականացնում Ձեր հսկողության տակ գտնվող ԴՀ երեխաների համար: Արդյո՞ք կիրառում էք ԴՀ երեխաների առողջության հսկողության որևէ միջազգային ուղեցույց:

Կրթական և ընդհանուր զարգացման կարիքները

7. Որքանո՞վ են հասանելի զարգացման մանկաբույժի ծառայությունները Ձեր հիվանդների համար: Արդյոք ունե՞ք հնարավորություն՝ ուղեգրելու երեխաներին զարգացման մանկաբույժի խորհրդատվության: Ձեր կարծիքով, ի՞նչն է նպաստում կամ, հակառակը, խոչընդոտում այդ ծառայությունների հասանելիությանն ու մատչելիությանը:
8. Ձեր հսկողության տակ գտնվող ԴՀ երեխաները ընդգրկվա՞ծ են որևէ կրթական ծրագրում կամ կառույցներում: Ընդհանուր առմամբ, ի՞նչ գիտեք Հայաստանում ԴՀ երեխաների համար նախատեսված ներառական կրթության մասին: Ձեր կարծիքով, որո՞նք են ԴՀ երեխաների՝ կրթական կառույցներում և ծրագրերում ընդգրկվելու խոչընդոտները:

Հասարակական ընդունում և սոցիալական աջակցություն

9. Ծանո՞թ էք ԴՀ երեխաներին և նրանց ընտանիքներին սոցիալական աջակցություն տրամադրող ծառայություններին:
10. Ընդհանուր առմամբ, ինչպե՞ս կգնահատեք ԴՀ հանդեպ հասարակության վերաբերմունքը Հայաստանում: Կարծո՞ւմ էք, որ մեր հասարակությունը բավարար չափով է տեղեկացված ԴՀ մասին: Ձեր կարծիքով, ԴՀ

երեխաները մեկուսացված են հասարակությունից: Ինչպե՞ս կրնա գրեթե ԴՀ-ի ստիգմատիզացիայով (խարանով) պայմանավորված իրավիճակը Հայաստանում:

Առաջարկներ

11. Ձեր պատկերացմամբ, ի՞նչ կարևոր փոփոխություններ են անհրաժեշտ Դաունի համախտանիշով երեխաներին և նրանց ընտանիքներին մատուցվող առողջապահական և սոցիալական ծառայությունների բարելավման համար:
12. Կցանկանա՞ք ավելացնել այլ մտքեր կամ հարցեր, որոնք կարևոր եք համարում, սակայն չքննարկվեցին մեր զրույցի ընթացքում:

Շնորհակալություն Ձեր ժամանակի և մասնակցության համար, որը մենք շատ ենք կարևորում:

Appendix 5

In-depth interview guide (Neonatologists)

Date: _____

Time: _____

Place: _____

Good afternoon, and first of all - thank you very much for coming. My name is Arpine. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, we conduct a study to explore the existing needs and gaps in care delivery for children with Down syndrome (CWD), to identify the main problems and concerns from different perspectives. We have invited you here to ask you to share with us your approaches towards healthcare and supervision of CWD and to tell us about your experience in delivering care to CWD in general. Your frank answers will be very helpful for us in selecting the right issues to address in the future development of services provided to this special pediatric population. I will just suggest you topics of discussion and will ask you to express your opinion on those topics. Our discussion will take approximately 30 minutes. If you don't mind, I will tape-record our conversation so that no important piece of it is lost. Please, express your ideas freely, having in mind that your responses will be fully confidential and anonymous. If you don't mind, please, let us begin now.

Medical counselling and parental awareness at first exposure

1. How are parents being informed about their child's diagnosis? Who (obstetrician, neonatologist, other) does inform parents about the diagnosis? What kind of counselling do they get at birth and/or prenatal period?
2. What are the factors influencing parental reactions on their child's diagnosis in your opinion? What do you feel about medical professionals'/ maternity staff' role in this?

Gaps in health services for CWD

3. How would you define the availability of reference information assisting healthcare of CWD?
4. What reference sources/guideline do you use in your current practice for neonatal screenings for CWD?
5. Describe the process of referring newborns with DS to special hospitals based on existing comorbidities (e.g. congenital heart defects, thyroid disease, etc.)?

Educational/developmental needs

6. What are the social support sources for families of CWD that you are aware of?
7. How do you feel about the general social acceptance of DS in Armenia? How do you

perceive the situation of DS stigmatization in Armenia?

Suggestions

8. What changes do you perceive are needed for enhancing the healthcare and social services provided to CWD and their families?
9. Would you like to add any topic or issue, other than discussed, that is important in your opinion?

Thank you very much for your time and contribution, which we highly appreciate!

Appendix 6

Անհատական հարցազրույցի ուղեցույց (Նեոնատոլոգների համար)

Ամսաթիվ _____

Ժամ _____

Վայր _____

Բարև Ձեզ: Նախ և առաջ, շնորհակալություն գալու համար: Իմ անունն է Արփիինե: Ես մանկաբույժ եմ և համատեղությամբ սովորում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետում: Այժմ մենք հետազոտություն ենք իրականացնում, որի նպատակն է բացահայտել Դաունի համախտանիշով (ԴՀ) երեխաների կարիքները և նրանց մատուցվող ծառայությունների բացթողումները, այս ասպարեզում առկա հիմնական խնդիրները և մտահոգությունները՝ տարբեր տեսանկյուններից: Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, որպեսզի կիսեք Ձեր փորձը և մտեցումները ԴՀ երեխաների բուժօգնության և հսկողության վերաբերյալ: Ձեր անկեղծ պատասխանները կօգնեն մեզ վեր հանել գոյություն ունեցող խնդիրներն ու կարիքները, դրանով իսկ նպաստելով այս հաստուկ խմբի երեխաներին մատուցվող ծառայությունների բարելավմանը: Ես կառաջարկեմ թեմաներ, և կխնդրեմ արտահայտել Ձեր կարծիքը դրանց վերաբերյալ: Մեր հարցազրույցը կտևի մոտ 30 րոպե: Եթե դեմ չեք, ես կձայնագրեմ մեր հարցազրույցը, որպեսզի ոչ մի կարևոր ինֆորմացիա բաց չթողնենք: Եվս մեկ անգամ կցանկանայի նշել, որ այս հարցազրույցի ընթացքում արտահայտած ողջ ինֆորմացիան խիստ գաղտնի է լինելու: Այժմ, խնդրում եմ, սկսենք:

Բժշկական խորհրդատվությունը և տեղեկացվածությունը

1. Ինչպե՞ս են ծնողները տեղեկացվում ԴՀ երեխայի ախտորոշման մասին: Ե՞րբ և ու՞մ կողմից (մանկաբարձ-գինեկոլոգի, նեոնատոլոգի, այլ): Ի՞նչ խորհրդատվություն է կատարվում այդ ծնողների համար հղիության ընթացքում, նախաձննդյան շրջանում և երեխայի ծնվելուց հետո:
2. Ձեր կարծիքով, ո՞ր հանգամանքները կամ գործոններն են առավելապես ազդում նորածնի՝ ԴՀ ախտորոշմանը ծնողների տված արձագանքի վրա: Ի՞նչ կասեք ծննդատներում բժշկական անձնակազմի դերի վերաբերյալ՝ ծնողների առաջին արձագանքը ձևավորելու հարցում:

Առողջապահական ծառայություններում առկա թերություններ/բացթողումներ

3. Ի՞նչ կասեք ԴՀ երեխաների բշկական հսկողությանն ու բուժմանը օժանդակող և կարգավորող ուղեցույցների/այլ ինֆորմացիայի հասանելիության մասին:
4. ԴՀ նորածինների վարման ի՞նչ ուղեցույցներ կամ այլ տեղեկատվական աղբյուրներ եք օգտագործում Ձեր ներկայիս աշխատանքի ընթացքում:
5. Կարո՞ղ եք նկարագրել ԴՀ նորածիններին մասնագիտացված հիվանդանոցային բուժման կամ հետազոտության ուղեգրելու պրոցեսը (սրտի բնածին արատի, հիպոթիրեոզի կամ այլ համակցված հիվանդությունների առկայության կամ կասկածի դեպքում):

Կրթական և ընդհանուր զարգացման կարիքները

6. Ծանո՞թ եք ԴՀ երեխաներին և նրանց ընտանիքներին սոցիալական աջակցություն տրամադրող ծառայություններին:
7. Ինչպե՞ս կգնահատեք Հայաստանում ԴՀ հանդեպ հասարակության վերաբերմունքն ընդհանուր առմամբ: Կարծո՞ւմ եք, որ մեր հասարակությունը բավարար չափով տեղեկացված է ԴՀ մասին: Ինչպե՞ս կբնութագրեք ԴՀ-ի ստիգմատիզացիայով (խարանով) պայմանավորված իրավիճակը Հայաստանում:

Առաջարկներ

8. Ձեր պատկերացմամբ, ի՞նչ կարևոր փոփոխություններ են անհրաժեշտ Դաունի համախտանիշով երեխաներին և նրանց ընտանիքներին մատուցվող առողջապահական և սոցիալական ծառայությունների բարելավման համար:
9. Կցանկանա՞ք ավելացնել այլ մտքեր կամ հարցեր, որոնք կարևոր եք համարում, սակայն չքննարկվեցին մեր զրույցի ընթացքում:

Շնորհակալություն Ձեր ժամանակի և մասնակցության համար, որը մենք շատ ենք կարևորում:

Appendix 7

In depth interview field guide (Mothers/primary caregivers)

Date: _____

Time: _____

Place: _____

Good afternoon, and first of all - thank you very much for coming. My name is Arpine. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, we are conducting a study to explore the existing needs and gaps in care access for children with Down syndrome (CWD). We want to identify the main problems and concerns from several perspectives and have invited you here to share your experiences, concerns and perspectives to improve services for your children. The information you share with us will help us to identify needs and gaps and find ways to overcome the existing barriers to adequate social and health services delivery for your children.

I will suggest you the topics for discussion and will ask you to express your opinion on those topics. Our discussion will take approximately 30 minutes. I ask you only do not speak simultaneously so that we can listen carefully to all of you. If you don't mind, we would like to record our conversation so that no any important piece of it is lost. We are interested in all opinions equally and all opinions are equally valuable for us. Be informed also that the information you will give us will remain confidential and your names will not appear with that information. Please, let us begin now.

Introduction (Ice breaking questions)

1. How many children do you have? How old they are? How old is your child with special needs?

First exposure and reaction to the birth of CWD

2. How and when were you informed about your child's diagnosis? Who told you (e.g. maternity hospital staff member, neonatologist, genetics specialist, other)?
 - 2.1. How do you feel about the way the information was delivered? Could it have been delivered in a better way? How did you react to that information? Do you think that how you were told by the medical personnel affect your reaction?
3. Did they explain your child's condition to you at the time they told you about the diagnosis? Ideally, what would you have liked to have been told? Were some questions you had left unaddressed? Where you able to find answers to those?

Gaps in health services for CWD

4. How do you feel about the health services provided to your child? What are the most

serious and annoying gaps in healthcare services provided to your child in PHC settings and hospitals, in your opinion (if applicable)?

5. What kind of difficulties have you experienced in getting health services for your CWD at a hospital and/or PHC setting?
6. What do you know about the developmental-pediatric services for children with DS? What makes it difficult to use those services? What would help make it easier?

Social acceptance and support

7. What social support sources that you are aware of?
8. What kind of social services do you receive or have received for your CWD? How do you feel about the social support services that you have benefitted from?
9. How do you feel about the general social acceptance of DS in your community?

Educational/developmental needs

10. Does your child attend any of educational institutions, such as kindergarten, day-care setting, school, etc.?
 - If no, why not?
 - If yes, are they meeting your child's needs (developmental, educational etc.)?

Daily challenges and experiences

11. How has having a child with special needs changed your family's life?
12. Could you, please, tell how is it to care for a child with DS in the current circumstances?
13. What challenges do you or have you faced during your child's social integration process (attending public places, events, etc.)?

Suggestions

14. What changes are needed to improve healthcare and social services for CWD?
15. Would you like to add any topic or issue, other than discussed, that is important in your opinion?

Thank you very much for your time and contribution, which we highly appreciate!

Appendix 8

Անհատական հարցազրույցի ուղեցույց (Մայրերի կամ հիմնական խնամողների համար)

Ամսաթիվ _____

Ժամ _____

Վայր _____

Բարև Ձեզ: Նախ և առաջ, շնորհակալություն գալու համար: Իմ անունն է Արփիին: Ես մանկաբույժ եմ և համատեղությամբ սովորում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետում: Այժմ մենք հետազոտություն ենք իրականացնում, որի նպատակն է բացահայտել Դաունի համախտանիշով (ԴՀ) երեխաների կարիքները և նրանց մատուցվող ծառայությունների բացթողումները: Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, որպեսզի կիսեք Ձեր փորձը, մտահոգություններն ու Ձեր երեխաներին մատուցվող ծառայությունների բարելավման հնարավորությունների մասին պատկերացումները: Ձեր տրամադրած ինֆորմացիան կօգնի մեզ վեր հանել գոյություն ունեցող խնդիրներն ու կարիքները, դրանով իսկ կնպաստի դրանց հաղթահարման ուղիներ գտնելուն: Ես կնշեմ քննարկման թեմաները, և կխնդրեմ արտահայտել Ձեր կարծիքը դրանց վերաբերյալ: Մեր հարցազրույցը կտևի մոտ 30 րոպե: Եթե դեմ չեք, ես կձայնագրեմ մեր զրույցը՝ հետագայում ոչ մի միտք և կարծիք բաց չթողնելու նպատակով: Մեզ համար հավասարաչափ կարևոր և արժեքավոր են յուրաքանչյուրիդ կարծիքն ու մտքերը: Եվս մեկ անգամ կցանկանայի նշել, որ այս հարցազրույցի ընթացքում արտահայտած ողջ ինֆորմացիան խիստ գաղտնի է լինելու: Այժմ, խնդրում եմ, սկսենք.

Նախաբան

1. Քանի՞ երեխա ունեք: Քանի՞ տարեկան են նրանք: Քանի՞ տարեկան է Ձեր հատուկ կարիքներով երեխան:

Առաջին արձագանքը ախտորոշմանն ու երեխայի ծննդին

2. Ե՞րբ և ինչպե՞ս տեղեկացաք Ձեր երեխայի ախտորոշման մասին: Ո՞վ հայտնեց Ձեզ այդ տեղեկությունը: Ինչպե՞ս կգնահատեք այդ տեղեկության մատուցման ձևը: Արդյո՞ք հնարավոր էր այդ լուրը հայտնել այլ, ըստ Ձեզ, ավելի ճիշտ ձևով: Ինչպիսի՞ն էր Ձեր առաջին արձագանքն այդ տեղեկությանը: Բժշկական անձնակազմի կողմից տեղեկության մատուցման

ձևը որևէ կերպ ազդե՞ց Ձեր առաջին արձագանքի վրա:

3. Ախտորոշումը հայտնելուց հետո, Ձեզ բացատրեցի՞ն երեխայի վիճակը և կարիքները: Ինչի՞ մասին կցանկանայիք տեղեկացվել այդ ժամանակ և ինչպե՞ս: Կայի՞ն հարցեր, որոնց պատասխանները չեք ստացել այդ խորհրդատվության ընթացքում: Արդյո՞ք հետագայում կարողացաք այդ հարցերի պատասխանները գտնել:

Առողջապահական ծառայություններում առկա թերություններ/բացթողումներ

4. Ինչպե՞ս կգնահատեք Ձեր երեխային մատուցվող բժշկական ծառայությունների որակը: Ձեր կարծիքով, որո՞նք են հիվանդանոցում կամ տեղամասային պոլիկլինիկայում Ձեր երեխային մատուցված բժշկական ծառայությունների ամենակարևոր և անհանգստացնող բացթողումները կամ թերացումները (*եթե այդպիսիք կան*):
5. Ի՞նչ խնդիրների եք առնչվել հիվանդանոցում և/կամ պոլիկլինիկայում՝ Ձեր երեխայի համար բուժման դիմելիս կամ բուժման ընթացքում:
6. Որքանո՞վ եք տեղյակ Դաունի համախտանիշով (ԴՀ) երեխաներին սպասարկող զարգացման մանկաբույժի ծառայությունների մասին: Ձեր կարծիքով, որո՞նք են այդ ծառայությունների հասանելիությանը խոչընդոտող և նպաստող գործոնները:

Հասարակական ընդունում և սոցիալական աջակցություն

7. Ծանո՞թ եք սոցիալական աջակցություն տրամադրող ծառայություններին:
8. Ի՞նչ սոցիալական աջակցության ծառայություններ եք ստացել Ձեր երեխայի համար: Ինչպե՞ս կգնահատեք այդ ծառայությունների որակը:
9. Ինչպե՞ս կգնահատեք Ձեր շրջապատի մարդկանց և հասարակության ընդհանուր վերաբերմունքը Դաունի համախտանիշով երեխաների նկատմամբ: Կարծու՞մ եք, որ մարդիկ ըմբռնումով են մոտենում այդ երեխաների կարիքներին:

Կրթական և ընդհանուր զարգացման կարիքները

10. Ձեր երեխան հաճախու՞մ է որևէ կրթական հաստատություն, օրինակ՝ մանկապարտեզ, ցերեկային խնամքի կենտրոն, դպրոց կամ այլ հաստատություն:
 - Եթե ոչ, կասե՞ք ինչու:
 - Եթե այո, ապա արդյո՞ք այդ հաստատությունները բավարարում են Ձեր երեխայի կարիքները (կրթական, զարգացման, այլ):

Առօրյա խնդիրներն ու փորձառությունները

11. Ինչպե՞ս փոխվեց Ձեր և Ձեր ընտանիքի կյանքը հատուկ կարիքներ ունեցող երեխայի ծննդից հետո:
12. Ինչպե՞ս կրնաթագրեք մեր իրականությունում ԴՀ երեխային խնամելը և մեծացնելը:
13. Ի՞նչ խնդիրների եք հանդիպել Ձեր երեխայի հասարակական ինտեգրման/ ներգրավման պրոցեսում, օրինակ՝ հասարակական վայրեր այցելելիս, միջոցառումների մասնակցելիս, և այլն:

Առաջարկներ

14. Ձեր պատկերացմամբ, ի՞նչ կարևոր փոփոխություններ են անհրաժեշտ ԴՀ երեխաներին մատուցվող առողջապահական և սոցիալական ծառայությունների բարելավման համար:
15. Կցանկանա՞ք ավելացնել այլ մտքեր կամ հարցեր, որոնք կարևոր եք համարում, սակայն չբնարկվեցին մեր գրույցի ընթացքում:
Շնորհակալություն Ձեր ժամանակի և մասնակցության համար, որը մենք շատ ենք կարևորում:

Appendix 9

Key-informant interview guide (Developmental pediatrician)

Date: _____

Time: _____

Place: _____

Recorder: _____

Good afternoon, and first of all - thank you very much for coming. My name is Arpine. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, we conduct a study to explore the existing needs and gaps in care delivery for children with Down syndrome (CWD), to identify the main problems and concerns from different perspectives. We have invited you here to ask you to share with us your approaches towards healthcare and supervision of CWD and to tell us about your experience in the delivering care to CWD in general. Your frank answers will be very helpful for us in selecting the right issues to address in the future development of services provided to this special pediatric population. I will just suggest you topics of discussion, and will ask you to express your opinion on those topics. Our discussion will take approximately 30 minutes. If you don't mind, I will tape-record our conversation so that no any important piece of it is lost. Please, express your ideas freely, having in mind that your responses will be fully confidential and anonymous. If you don't mind, please, let us begin now.

Medical counselling and parental awareness at first exposure

1. How many children with DS do you have under your supervision?
2. How would you define the level of awareness of parents/family about the condition of their child at your first visit?

Gaps in health services for CWD

3. How would you define the availability of reference information assisting healthcare of CWD? What reference sources/guidelines are available/used in current healthcare practices?
4. Which additional screenings are performed among CWD in Armenia?

Educational/developmental needs

5. Describe the most prevalent ways by which CWD are referred to your developmental center. Do you think it could have been organized in better way? Does government support developmental and special educational programs for CWD in your knowledge?
6. What are the barriers that prevent and/or facilitating factors to the access and utilization of developmental-pediatric services in your opinion?
7. How do you perceive the situation with inclusive education for CWD available in

Armenia?

Social acceptance and support

8. What are the social support sources for families of CWD that are currently available in Armenia? How would you define the accessibility to those services for families of CWD?
9. How do you feel about the general social acceptance of DS in Armenia? How do you perceive the situation of DS stigmatization in Armenia?

Suggestions

10. What changes do you perceive are necessary for enhancing the healthcare and social services provided to CWD and their families? What changes do you perceive are the most important for enhancing access to special educational and developmental services for CWD in Armenia in your opinion?
11. Would you like to add any topic or issue, other than discussed, that is important in your opinion?

Thank you very much for your time and contribution, which we highly appreciate!

Appendix 10

Խորացված հարցազրույցի ուղեցույց (Զարգացման մանկաբույժի համար)

Ամսաթիվ _____

Ժամ _____

Վայր _____

Բարև Ձեզ: Նախ և առաջ, շնորհակալություն մասնակցելու համար: Իմ անունն է Արփիինե: Ես մանկաբույժ եմ, և համատեղությամբ սովորում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետում: Այժմ մենք հետազոտություն ենք իրականացնում, որի նպատակն է բացահայտել Դաունի համախտանիշով (ԴՀ) երեխաների կարիքները և նրանց մատուցվող ծառայությունների բացերը, այս ասպարեզում առկա հիմնական խնդիրները և մտահոգությունները տարբեր տեսանկյուններից: Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, որպեսզի կիսեք Ձեր փորձը և մտեցումները ԴՀ երեխաների բուօգնության և հսկողության վերաբերյալ: Ձեր անկեղծ պատասխանները կօգնեն մեզ վեր հանել գոյություն ունեցող խնդիրներն ու կարիքները, դրանով իսկ նպաստելով այս հատուկ խմբի երեխաներին մատուցվող ծառայությունների բարելավմանը: Ես կառաջարկեմ թեմաներ, և կխնդրեմ արտահայտել Ձեր կարծիքը դրանց վերաբերյալ: Մեր հարցազրույցը կտևի մոտ 30 րոպե: Եթե դեմ չեք, ես կձայնագրեմ մեր հարցազրույցը, որպեսզի ոչ մի կարևոր ինֆորմացիա բաց չթողնենք: Եվս մեկ անգամ կցանկանայի նշել, որ այս հարցազրույցի ընթացքում Ձեր հայտնած ողջ ինֆորմացիան խիստ գաղտնի է լինելու: Այժմ, խնդրում եմ, սկսենք:

Բժշկական խորհրդատվությունը և տեղեկացվածությունը

1. Քանի՞ ԴՀ-ով երեխա է գտնվում Ձեր հսկողության տակ:
2. Ընդհանուր առմամբ, ինչպե՞ս կգնահատեք այդ երեխաների ծնողների տեղեկացվածության աստիճանն իրենց երեխայի վիճակի վերաբերյալ: Ինչպիսի՞ն էր նրանց տեղեկացվածության աստիճանը Ձեր առաջին հանդիպման ժամանակ:

Առողջապահական ծառայություններում առկա թերություններ/բացթողումներ

3. Ի՞նչ կասեք ԴՀ երեխաների բժշկական հսկողության ու բուժման ուղեցույցների/այլ ինֆորմացիայի հասանելիության մասին:
4. Ի՞նչ ինֆորմացիայի աղբյուրներ կամ ուղեցույցեր են ներկայումս կիրառվում ԴՀ երեխաների բժշկական հսկողության համար:

5. Ի՞նչ լրացուցիչ սկրինինգային հետազոտություններ են կատարվում ԴՀ երեխաների համար Հայաստանում:

Կրթական և ընդհանուր զարգացման կարիքները

6. Կարո՞ղ եք նշել, ինչպե՞ս են ԴՀ երեխաները հայտվում Ձեր կենտրոնում (ուղեգրվում են մանկաբույժի կողմից, սեփական նախաձեռնությամբ): Արդյո՞ք հնարավոր է ԴՀ երեխաների ուղեգրումը զարգացման մանկաբույժի խորհրդատվության կազմակերպել այլ՝ ավելի լավ, տարբերակով:
7. Ձեր կարծիքով, ի՞նչն է նպաստում կամ, հակառակը, խոչընդոտում զարգացման մանկաբույժի ծառայությունների հասանելիությանն ու մատչելիությանը: Ի՞նչ կասեք Հայաստանում ԴՀ երեխաներ համար նախատեսված ներառական կրթության վերաբերյալ:

Հասարակական ընդունում և աջակցություն

8. Ծանո՞թ եք Հայաստանում ԴՀ երեխաներին և նրանց ընտանիքներին սոցիալական աջակցություն տրամադրող ծառայություններին: Որքանո՞վ են դրանք հասանելի Ձեր կարծիքով:
9. Ընդհանուր առմամբ, ինչպե՞ս կգնահատեք Հայաստանում ԴՀ հանդեպ հասարակության վերաբերմունքը: Կարծու՞մ եք, որ մեր հասարակությունը բավարար չափով տեղեկացված է ԴՀ մասին: Ինչպե՞ս կբնութագրեք ԴՀ-ի ստիգմատիզացիայով (խարանով) պայմանավորված իրավիճակը:

Առաջարկներ

10. Ձեր պատկերացմամբ, ի՞նչ կարևոր փոփոխություններ են անհրաժեշտ Դաունի համախտանիշով երեխաներին և նրանց ընտանիքներին մատուցվող առողջապահական և սոցիալական ծառայությունների բարելավման համար:
11. Կցանկանա՞ք ավելացնել այլ մտքեր կամ հարցեր, որոնք կարևոր եք համարում, սակայն չքննարկվեցին մեր զրույցի ընթացքում:

Շնորհակալություն Ձեր ժամանակի և մասնակցության համար, որը մենք շատ ենք կարևորում:

Appendix 11

Key-informant interview guide (Ministry of Health of Armenia)

Date: _____

Time: _____

Place: _____

Recorder: _____

Good afternoon, and first of all - thank you very much for coming. My name is Arpine. I represent the School of Public Health of the American University of Armenia. As mentioned in the informed consent form you have read, we conduct a study to explore the existing needs and gaps in care delivery for children with Down syndrome (CWD), to identify the main problems and concerns from different perspectives. We have invited you here to ask you to share with us your approaches towards healthcare and supervision of CWD. Your frank answers will be very helpful for us in selecting the right issues to address in the future development of services provided to this special pediatric population. If you don't mind, I will tape-record our conversation so that no any important piece of it is lost. Please, express your ideas freely, having in mind that your responses will be fully confidential and anonymous. If you don't mind, please, let us begin now.

Medical counselling at first exposure

1. In your knowledge, is any statistical data available about the prevalence/incidence of CWD in Armenia? Who should be responsible for providing such data (medical professionals, institutions, other sources)?
2. Are there any guidelines for the initial medical counselling for parents of CWD at birth and/or at first exposure to the diagnosis, including prenatal counselling? Who is responsible for referring families to genetic-medical counselling for DS?

Gaps in health services for CWD

3. How would you define the availability of reference information assisting healthcare of CWD? What reference sources/guidelines are available/used in current healthcare practices in Armenia?
4. Which additional screenings are performed among CWD in Armenia?

Educational/developmental needs

5. How is the situation with developmental-pediatric services for CWD in Armenia? Are those supported by the government? What are the barriers that prevent and/or facilitating factors to the access and utilization of developmental-pediatric services in your opinion?
6. How do you perceive the situation with inclusive education for CWD available in Armenia?

Suggestions

7. What changes do you perceive are necessary for enhancing the healthcare and social services provided to CWD and their families?
8. Would you like to add any topic or issue, other than discussed, that is important in your opinion?

Thank you very much for your time and contribution, which we highly appreciate!

Appendix 12

Խորացված հարցազրույցի ուղեցույց (Առողջապահության նախարարության մասնագետի համար)

Ամսաթիվ _____

Ժամ _____

Վայր _____

Բարև Ձեզ: Նախ և առաջ, շնորհակալություն գալու համար: Իմ անունն է Արփիինե: Ես մանկաբույժ եմ և համատեղությամբ սովորում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետում: Այժմ մենք հետազոտություն ենք իրականացնում, որի նպատակն է բացահայտել Դաունի համախտանիշով (ԴՀ) երեխաների կարիքները և նրանց մատուցվող ծառայությունների բացթողումները, այս ասպարեզում առկա հիմնական խնդիրները և մտահոգությունները տարբեր տեսանկյուններից: Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, որպեսզի կիսեք Ձեր մտեցումները ԴՀ երեխաների բուօգնության և հսկողության վերաբերյալ: Ձեր անկեղծ պատասխանները կօգնեն մեզ վեր հանել գոյություն ունեցող խնդիրներն ու կարիքները, դրանով իսկ նպաստելով այս հատուկ խմբի երեխաներին մատուցվող ծառայությունների զարգացմանն ապագայում: Ես կառաջարկեմ թեմաներ, և կխնդրեմ արտահայտել Ձեր կարծիքը դրանց վերաբերյալ: Մեր հարցազրույցը կտևի մոտ 30 րոպե: Եթե դեմ չեք, ես կձայնագրեմ մեր հարցազրույցը, որպեսզի ոչ մի կարևոր ինֆորմացիա բաց չթողնենք: Եվս մեկ անգամ կցանկանայի նշել, որ այս հարցազրույցի ընթացքում Ձեր հայտնած ողջ ինֆորմացիան խիստ գաղտնի է լինելու: Այժմ, խնդրում եմ, սկսենք:

Բժշկական խորհրդատվությունը և տեղեկացվածությունը

1. Արդյոք տեղյակ եք Հայաստանում ԴՀ երեխաների վերաբերյալ վիճակագրական տվյալների առկայության մասին: Ըստ Ձեզ, ո՞վ պետք է պատասխանատու լինի նման վիճակագրական տվյալների հավաքման և վերլուծության համար:
2. Արդյո՞ք գոյություն ունի ԴՀ երեխաների ծնողներին առաջնային բժշկական խորհրդատվություն տրամադրելու ուղեցույց (հղիության ընթացքում և հետծննդյան շրջանում): Ո՞վ է պատասխանատու ԴՀ երեխաներին գենետիկական հետազոտության և բժշկական-գենետիկական

խորհրդատվության ուղեգրելու համար:

Առողջապահական ծառայություններում առկա թերություններ/բացթողումներ

3. Ի՞նչ կասեք ԴՀ երեխաների բժշկական հսկողության ու բուժման ուղեցույցների և այլ ինֆորմացիայի աղբյուրների հասանելիության մասին: Ի՞նչ ինֆորմացիայի աղբյուրներ կամ ուղեցույցներ են ներկայումս կիրառվում ԴՀ երեխաների բժշկական հսկողության համար:
4. Ի՞նչ լրացուցիչ սկրինինգային հետազոտություններ են կատարվում ԴՀ երեխաների համար Հայաստանում:

Կրթական և ընդհանուր զարգացման կարիքները

5. Ի՞նչ կասեք զարգացման մանկաբույժի ծառայությունների վերաբերյալ Հայաստանում: Որքանո՞վ են դրանք հասանելի: Արդյո՞ք այդ ծառայությունները ստանում են պետական աջակցություն (ֆինանսավորվում են պետության կողմից): Ձեր կարծիքով, ի՞նչն է նպաստում կամ, հակառակը, խոչընդոտում այդ ծառայությունների հասանելիությանն ու մատչելիությանը:
6. Ի՞նչ կասեք Հայաստանում ԴՀ երեխաների համար նախատեսված ներառական կրթության վերաբերյալ:

Առաջարկներ

7. Ձեր պատկերացմամբ, ի՞նչ կարևոր փոփոխություններ են անհրաժեշտ Դաունի համախտանիշով երեխաներին և նրանց ընտանիքներին մատուցվող առողջապահական և սոցիալական ծառայությունների բարելավման համար:
8. Կցանկանա՞ք ավելացնել այլ մտքեր կամ հարցեր, որոնք կարևոր եք համարում, սակայն չքննարկվեցին մեր զրույցի ընթացքում:

Շնորհակալություն Ձեր ժամանակի և մասնակցության համար, որը մենք շատ ենք կարևորում:

Appendix 13

Sociodemographic questionnaires for study participants

Healthcare providers

1. Age (years) _____

2. Gender:

1. Male 2. Female

3. Specialization:

1. Primary healthcare pediatrician

2. Neonatologist

3. Developmental pediatrician

4. Other _____

4. How many years of clinical practice do you have? _____

5. During last 5 years did you receive any training/educational course about health supervision for children with disabilities, including CWD?

1. Yes

2. No

Sociodemographic questionnaires for study participants

Mothers/primary caregivers of CWD

1. How old is your child with DS? _____ years _____ months

Please, respond the questions below concerning your:

2. Age (completed years)_____

3. Marital status:

1. Married

2. Single

3. Divorced

4. Widowed

4. Education:

1. School/lower

2. Undergraduate

3. Graduate/higher

5. How would you rate your family's socioeconomic status:

1. Low

2. Middle

3. High

Sociodemographic questionnaires for study participants

Key informants (field experts)

Please, fill in Your:

1. Age (completed years)_____

2. Gender:

1. Male 2. Female

3. Specialty: _____

4. **Years of experience in the current field:** _____ *years*

Appendix 14

Ժողովրդագրական հարցաթերթիկ մասնակցի համար

Բուժաշխատողներ

Լրացրեք, խնդրեմ, Ձեր.

1. Տարիքը (լրացրած տարիները) _____ տարի
2. Սեռը
 1. Արական 2. Իգական
3. Մասնագիտությունը.
 1. Առաջնային օդակի մանկաբույժ
 2. Նեոնատոլոգ
 3. Զարգացման մանկաբույժ
 4. Այլ _____
4. Աշխատանքային փորձը տվյալ մասնագիտությամբ. _____ տարի
5. Վերջին 5 տարվա ընթացքում մասնակցե՞լ եք ԴՀ-ով երեխաների կամ, ընդհանրապես, հաշմանդանությամբ երեխաների առողջապահական ինսամբի վերաբերյալ կրթական կամ վերապատրաստման ծրագրերի:
 1. Այո
 2. Ոչ

Ժողովրդագրական հարցաթերթիկ մասնակցի համար

Մայրեր կամ հիմնական խնամողներ

1. Քանի՞ տարեկան է Դաունի համախտանիշով Ձեր երեխան.
___ տարի ___ ամիս

Լրացրեք, խնդրեմ, Ձեր.

2. Տարիքը (լրացրած տարիները) _____ տարի
3. Ամուսնական կարգավիճակը.
 1. Ամուսնացած
 2. Չամուսնացած

3. Ամուսնալուծված

4. Այրի

4. Կրթությունը.

1. Միջնակարգ (դպրոց) կամ պակաս

2. Միջին մասնագիտական կամ բակալավրի աստիճան

3. Բարձրագույն կամ հետդիպլոմային

5. Ինչպե՞ս կգնահատեիք Ձեր ընտանիքի կենսամակարդակը.

1. Միջինից ցածր

2. Միջին

3. Միջինից բարձր

Ժողովրդագրական հարցաթերթիկ մասնակցի համար

Հիմնական տեղեկատուներ (փորձագետներ)

Լրացրեք, խնդրեմ, Ձեր.

1. Տարիքը (լրացրած տարիները). _____ տարի

2. Սեռը.

1. Արական 2. Իգական

3. Մասնագիտությունը _____

4. Աշխատանքային փորձը տվյալ բնագավառում. _____ տարի

Appendix 15

American University Of Armenia
Turpanjian School of Public Health
Institutional Review Board # 1
Oral Consent Form

(Pediatricians, Neonatologists, Developmental Pediatricians, Experts from the Ministry of Health and Ministry of Social Affairs and Labour of Armenia)

Hello, my name is Arpine. I am a pediatrician and a second year master student in the Turpanjian School of Public Health at the American University of Armenia. As a part of my thesis project we are conducting a study, which aims to explore the needs and gaps in healthcare provided to children with Down syndrome. You are invited to participate in this study as you are a professional who have experience of providing care to children with Down syndrome. You are one of 10 professionals who were selected based on the fact of having children with Down syndrome under their supervision. The discussion will take about 30 minutes to 1 hour and will include only this interview today. I want to inform you that participation in this study is voluntary, without any consequences. It is your right to refuse to answer any question you will not want to answer and even to stop the interview. I assure the confidentiality of the information provided by you. All study data will be locked in a secure location, on a password protected computer and your name will not be attached to the data, until destroyed by me. With your permission, I will use an audio recording to ensure that we will not miss any information that you will share with us. Please remember that it is within your right to ask to turn off the recorder at any time during the interview, whenever you find it necessary. My notes and recording will be stored without any information that can identify you. Audio tapes will be transcribed by me and then the audio tape will be destroyed at the end of the data analysis process. At the conclusion of this study, the findings may be published. There will be a thesis of this project held on line at the AUA website. Statements which you have made may be included in publications and in the thesis. However, in any publication and in the thesis, your name and identifying information will not be used so that your confidentiality will be protected.

While you may not directly benefit from this research, your participation may contribute to the improvement of healthcare and social services provided to children with Down syndrome.

Before we will proceed, do you have any other question about your participation? If you have any questions regarding this study, contact the Principle Investigator Dr. Anahit Demirchyan, Gerald and Patricia Turpanjian School of Public Health, American University of Armenia 060 61 25 62. If you feel you have not been treated fairly or think joining the study has hurt you should contact Varduhi Hayrumyan, the Human Protections Administrator of the American University

of Armenia 060 61 25 61.

Do you agree to participate? Can I turn on the recorder? If NO, I will take notes if you do not mind. Can we start?

Appendix 16

Հայաստանի Ամերիկյան Համալսարան

Թրփանձեան Հանրային Առողջապահության բաժին

Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով

Իրազեկ համաձայնության ձև

(Մանկաբույժների, նեոնատոլոգների, զարգացման մանկաբույժների, առողջապահության նախարարության և աշխատանքի ու սոցիալական հարցերով նախարարության աշխատակիցների համար)

Բարև Ձեզ, ես Արփինեն եմ. ես մանկաբույժ եմ և, համատեղության կարգով, Հայաստանի ամերիկյան համալսարանի Թրփանձեան Հանրային Առողջապահության բաժնի ավարտական կուրսի ուսանող: Այժմ իմ ավարտական թեզի շրջանակներում մենք իրականացնում ենք հետազոտություն, որի նպատակն է գնահատել Հայաստանում Դաունի համախտանիշով երեխաներին մատուցվող ծառայությունների ոլորտում առկա բացթողումներն ու կարիքները: Դուք մեկն եք 10-15 բժիշկներից, և հրավիրված եք մասնակցելու այս հետազոտությանը, քանի որ ունեք Դաունի համախտանիշով երեխաներին ծառայություններ տրամադրելու կամ դրանք կազմակերպելու փորձ: Ձեր մասնակցությունն այս հետազոտությանը սահմանափակվում է այս միակ հարցազրույցով, որը կտևի մոտ 30 րոպեից 1 ժամ: Հարցազրույցը ներառելու է հարցեր Ձեր փորձի, ԴՀ երեխաներին ուղղված ծառայությունների և դրանց բարելավման Ձեր տեսակետների մասին: Ձեր մասնակցությունն այս հետազոտությանը կամավոր է: Դուք պարտավոր չեք մասնակցել, եթե չեք ցանկանում: Եթե համաձայնել եք մասնակցել հետազոտությանը, բայց հարցազրույցի ընթացքում մտափոխվել եք, կարող եք ցանկացած պահի հրաժարվել մասնակցությունից՝ առանց որևէ բացասական հետևանքների: Ես երաշխավորում եմ Ձեր հաղորդած տեղեկությունների գաղտնիությունը: Հետազոտության ընթացքում ձեռք բերված ողջ տեղեկությունները կպահվեն ծածկագրով պաշտպանված համակարգում, և Ձեր անունը չի կցվի ձեր հաղորդած տեղեկություններին: Հարցազրույցը գրի կառնվի, կամ, Ձեր թույլտվության դեպքում, կձայնագրվի՝ որևէ կարևոր ինֆորմացիա բաց չթողնելու նպատակով: Ցանկանում եմ տեղեկացնել, որ Ձեր իրավունքն է հարցազրույցի ցանկացած պահին պահանջել՝

անջատել ձայնագրիչը: Ձայնագրությունը գրավոր կերպով կարձանագրվի իմ կողմից, սակայն տվյալների վերլուծությունից հետո բոլոր ձայնագրությունները կոչնչացվեն: Հետազոտությունն ամփոփելուց հետո ընդհանրացված արդյունքները կներկայացվեն իմ թեզում, որը կտեղակայվի առցանց ՀԱՀ կայքում: Հետազոտության արդյունքները կարող են նաև հրատարակվել: Ձեր կողմից արված որոշակի արտահայտություններ կարող են տեղ գտնել թեզի և հրատարակության մեջ, սակայն դրանք կլինեն անանուն:

Այս հետազոտությանը մասնակցության արդյունքում Դուք չեք ունենա որևէ անմիջական շահ, սակայն, Ձեր մասնակցությունը կարող է նպաստել Հայաստանում Դաունի համախտանիշով երեխաներին մատուցվող սոցիալական և առողջապահական ծառայությունների զարգացմանն ու բարելավմանը:

Մինչև հարցազրույցը սկսելը, ուզում եմ ճշտել՝ կա՞ն արդյոք հարցեր՝ կապված հետազոտության հետ: Եթե այս հանցազրույցից հետո ունենաք հետազոտության հետ կապված որևէ հարց, կարող եք կապ հաստատել հետազոտական թիմի ղեկավար Անահիտ Դեմիրճյանի հետ՝ 060 61 25 62 հեռախոսահամարով: Եթե կմտածեք, որ Ձեզ հետ ճիշտ չեն վարվել կամ հարցազրույցի ընթացքում որևէ կերպ վիրավորել են Ձեզ, կարող եք դիմել Հայաստանի ամերիկյան համալսարանի գիտական էթիկայի հանձնաժողովի համակարգող Վարդուհի Հայրումյանին՝ 060 61 25 61 հեռախոսահամարով:

Դուք համաձայն եք մասնակցել հարցազրույցին: Եթե այո, կարո՞ղ ենք սկսել: Դուք համաձայն եք, որ հանցազրույցը ձայնագրվի: Եթե ԱՅՈ, ես կմիացնեմ ձայնագրիչը, իսկ եթե ոչ՝ գրի կառնեմ Ձեր պատասխանները: Եթե Դուք դեմ չեք, սկսենք:

Appendix 17

American University Of Armenia
Institutional Review Board # 1
Turpanjian School of Public Health
Oral Consent Form
(Mothers/primary caregivers)

Hello, my name is Arpine. I am a pediatrician and a second year master student in the Turpanjian School of Public Health at the American University of Armenia. As a part of my thesis project we are conducting a study, which aims to explore the needs and gaps in healthcare provided to children with Down syndrome (CWD). You are invited to participate in this study as you are experiencing parenting a child with a specific health condition. You are one of 10 parents who were recruited from either PHCs or from NGOs (“Sun children” NGO, Arbes MC). The discussion will take approximately 30 minutes and will include only this interview today. I want to inform you that participation in this study is voluntary. Your participation or refusal for participation will not have any consequences. Your participation or refusal will not have any effects on the treatment that your children receive and/or will receive in the future. It is your right to refuse to answer any question you will not want to answer and even to stop the interview. I assure the confidentiality of the information provided by you. All study data will be locked in a secure location, on a password protected computer and your name will not be attached to the data, until destroyed by me. With your permission, I will use an audio recording to ensure that we will not miss any information that you will share with us. Please remember that it is within your right to ask to turn off the recorder at any time during the interview, whenever you find it necessary. My notes and recording will be stored without any information that can identify you. Audio tapes will be transcribed by me and then the audio tape will be destroyed at the end of the data analysis process. At the conclusion of this study, the findings may be published. There will be a thesis of this project held on line at the AUA website. Statements which you have made may be included in publications and in the thesis. However, in any publication and in the thesis, your name and identifying information will not be used so that your confidentiality will be protected.

While you may not directly benefit from this research, your participation may contribute to the improvement of healthcare and social services provided to CWD. When we will finish the interview I will provide you contacts of NGOs, which you can use in case of seeking support. As I am a pediatrician, by the end of the study I will provide a short medical counselling in case if you have emerging questions regarding your child’s health.

Before we will proceed, do you have any other question about your participation? If you have

any questions regarding this study contact the Principle Investigator Dr. Anahit Demirchyan, Gerald and Patricia Turpanjian School of Public Health, American University of Armenia (060) 61 25 62. If you feel you have not been treated fairly or think joining the study has hurt you should contact Varduhi Hayrumyan, the Human Protections Administrator of the American University of Armenia (060) 61 25 61.

Do you agree to participate? Can I turn on the recorder? If NO, I will take notes if you do not mind. Can we start?

Appendix 18

Հայաստանի Ամերիկյան Համալսարան
Թրփանձեան Հանրային Առողջապահության Բաժին
Գիտահետազոտական Էթիկայի թիվ 1 հանձնաժողով
Իրազեկ համաձայնության ձև
(Օնոդների/հիմնական խնամողների համար)

Բարև Ձեզ, ես Արփինեն եմ. ես մանկաբույժ եմ և, համատեղության կարգով, Հայաստանի ամերիկյան համալսարանի Թրփանձեան Հանրային Առողջապահության Բաժնի ավարտական կուրսի ուսանող: Այժմ իմ ավարտական թեզի շրջանակներում մենք իրականացնում ենք հետազոտություն, որի նպատակն է գնահատել Հայաստանում Դաունի համախտանիշով երեխաներին մատուցվող ծառայությունների ոլորտում առկա բացթողումներն ու կարիքները: Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, քանի որ ունեք հատուկ կարիքներ ունեցող երեխային խնամելու փորձ: Դուք մեկն եք այն 10 ծնողներից, ում տվյալները տրամադրել է Ջարգացման հապաղման խնդիրներ ունեցող երեխաների հարցերով զբաղվող հասարակական կազմակերպությունը (ՏԱրև երեխաներ՝ ՀԿ, Արբես ԲԿ) կամ պոլիկլինիկական, որտեղ հսկվում է Ձեր երեխան: Ձեր մասնակցությունն այս հետազոտությանը սահմանափակվում է միայն այս հարցազրույցով, որը կտևի մոտ 30 րոպե: Հարցազրույցը ներառելու է հարցեր Ձեր փորձի, ԴՀ երեխաներին ուղղված ծառայությունների և դրանց բարելավման Ձեր տեսակետների մասին: Ձեր մասնակցությունն այս հետազոտությանը կամավոր է: Դուք պարտավոր չեք մասնակցել, եթե չեք ցանկանում: Եթե համաձայնել եք մասնակցել հետազոտությանը, բայց հարցազրույցի ընթացքում մտափոխվել եք, կարող եք ցանկացած պահի հրաժարվել մասնակցությունից՝ առանց որևէ հետևանքների: Ձեր երեխայի ստացած բուժօգնությունը 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 համակարգում, և Ձեր անունը չի կցվի տվյալներին: Հարցազրույցը գրի կառնվի, կամ, Ձեր թույլտվության դեպքում, կձայնագրվի՝ որևէ կարևոր ինֆորմացիա բաց չթողնելու նպատակով: Ցանկանում եմ տեղեկացնել, որ Ձեր իրավունքն է հարցազրույցի ցանկացած պահի պահանջել՝ անջատել ձայնագրիչը: Ձայնագրությունները գրավոր կերպով

կարձանագրվեն իմ կողմից, այնուհետև ձայնագրությունը կոչնչացվի տվյալների վերլուծությունից հետո: Հետազոտությունն ամփոփելուց հետո արդյունքները կարող են հրատարակվել: Այս հետազոտության թեզը առցանց կտեղակայվի ՀԱՀ կայքում: Ձեր կողմից արված որոշակի արտահայտություններ կարող են տեղ գտնել թեզի և հրապարակման մեջ: Այնուամենայնիվ, որևէ հրատարակման կամ թեզի մեջ Ձեր անունը կամ նույնականացվող որևէ տվյալ չի օգտագործվի՝ այդպիսով պաշտպանելով Ձեր տվյալների գաղտնիությունը: Չնայած որ հետազոտության արդյունքում Դուք չեք ունենա որևէ անմիջական շահ, Ձեր մասնակցությունը կարող է նպաստել Հայաստանում Դաունի համախտանիշով երեխաներին մատուցվող սոցիալական և առողջապահական ծառայությունների զարգացմանն ու բարելավմանը: Հարցազրույցի ավարտից հետո ես Ձեզ կտրամադրեմ հասարակական կազմակերպությունների տվյալներ, որոնք Դուք կարող եք օգտագործել աջակցություն ստանալու նպատակով: Քանի որ ես մանկաբույժ եմ, հարցազրույցի ավարտից հետո պատրաստ եմ տրամադրել Ձեզ հակիրճ խորհրդատվություն Ձեր երեխայի առողջական խնդիրների վերաբերյալ:

Մինչև հարցազրույցը սկսելը, ուզում եմ ճշտել՝ կա՞ն, արդյոք, հարցեր՝ կապված հետազոտության հետ: Եթե այս հանցազրույցից հետո ունենաք հետազոտության հետ կապված որևէ հարց, կարող եք կապ հաստատել հետազոտական թիմի ղեկավար Անահիտ Դեմիրճյանի հետ՝ 060 612562 հեռախոսահամարով: Եթե կմտածեք, որ Ձեզ հետ ճիշտ չեն վարվել կամ որևէ կերպ վիրավորել են Ձեզ հարցազրույցի ընթացքում, կարող եք դիմել Հայաստանի ամերիկյան համալսարանի գիտական էթիկայի հանձնաժողովի համակարգող Վարդուհի Հայրումյանին՝ 060 61 25 61 հեռախոսահամարով:

Դուք համաձայն եք մասնակցել հարցազրույցին: Եթե այո, կարո՞ղ ենք սկսել: Դուք համաձայն եք, որ հանցազրույցը ձայնագրվի: Եթե ԱՅՈ, ես կմիացնեմ ձայնագրիչը, իսկ եթե ոչ՝ գրի կառնեմ Ձեր պատասխանները: Եթե Դուք դեմ չեք, սկսենք: