ASSESSMENT OF THE IMPACT OF SOCIAL ALLOWANCES ON the QUALITY OF LIFE OF CHILDREN LIVING WITH HIV

Study report



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IMPACT OF SOCIAL ALLOWANCES ON THE QUALITY OF LIFE OF CHILDREN LIVING WITH HIV IN TAJIKISTAN

STUDY REPORT

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Every effort has been made to ensure that the information in this report is correct. Any factual errors that may appear are unintended and are the responsibility of the author alone. The report solely represents the views of the author and does not necessarily represent the views of UNICEF.

ACRONYMS

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AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
BMI	Body mass index
GBAO	Gorno-Badakhshan Autonomous Oblast
HIV	Human immunodeficiency virus
MoHSP	Ministry of Health and Social Protection of the Republic of Tajikistan
RAC	Republican AIDs Centre
NGO	Non-Governmental Organization
PMTCT	Prevention of mother-to-child-transmission
RRS	Regions of Republican Subordination
SD	Standard deviation
UNICEF	United Nations Children's Fund
USD	United States dollar
WHO	World Health Organization

EXECUTIVE SUMMARY

This report presents the results of a study commissioned by UNICEF Tajikistan in collaboration with the Republican AIDS Centre and the NGO Guli Surkh to evaluate the impact of social allowances on the treatment outcomes of children living with HIV in Tajikistan. Of the 7,552 persons living with HIV in Tajikistan today, 10.2 per cent are children under the age of 18. As of December 2017, 90.5 per cent of these children were covered with antiretroviral therapy.

In order to support families with children living with HIV, the Government issued a Decree 232 of 3 May 2010 to allocate social allowances for children living with HIV. According to the Republican AIDS Centre, 556 children were receiving social benefits at the government-mandated level of 350 somoni in 2017.

The goal of the study is to assess the impact of social benefit on the ART adherence and health outcomes of children living with HIV in Tajikistan.

The objectives of the study were as follows:

- Determine the socio-demographic profile of families with children living with HIV;
- Study the barriers that families face when seeking to access social benefits;
- Analyse child development;
- Identify if there is a difference in viral load between children receiving social benefits and those that do not receive them;
- Identify if any gender disparities in access by boys and girls living with HIV to social benefit;
- Other benefits for children living with HIV.

The study had a non-experimental, correlational design and applied both quantitative and qualitative methods. Quantitative methods were applied to collect and analyse data from primary sources, directly from family members of children living with HIV. Qualitative information was collected through individual interviews with representatives of various agencies – including health and social protection authorities, local authorities, banks and other stakeholders – to complement the quantitative findings and reflect on the context.

In total, the families of 465 children participated in this study, and it was reported that 74.8 per cent of the children (194 boys and 154 girls) were receiving social benefits. The vast majority of the parents of recipients (95.1 per cent) reported receiving the social benefit on a quarterly basis, as is mandated in law. The minimum amount received was 200 somoni and the maximum 1,050 somoni (compared to the designated amount of 350 somoni). This was confusing as the social benefit is set as 350 somoni per child paid on quarterly basis.

interview with parents some mentioned that they don't look at papers they sign and receive what the bank cashier hands them, although, the paying of 200 somoni was dismissed by bank personnel during the interview. In line with this the parents requested to look at the possibility of receiving the payment through debit card.

Almost three quarters (74.4 per cent) of the parents reported using the social benefit to provide for the nutrition of the child/children living with HIV. The next most common responses were other needs (41.4 per cent) and food for the whole family (15.0 per cent).

Although the size of the social benefit is not large, parents reported that they felt cared for (63.8 per cent) and had hope for the future (54.0 per cent). At the same time the parents requested an increase the amount of the benefit, as 350 somoni is not sufficient.

While urban residents were found to be more likely to receive the benefit in cash, in rural areas, most received it through a bank transfer. Almost a third of the respondents (29.0 per cent) reported facing difficulties obtaining the social benefit, with no significant difference between rural and urban areas for this figure. Respondents reported most frequently facing difficulties in the financial and banking sector, with a total of 59.7 per cent of respondents who had faced difficulties selecting that option (other options were social services and medical services.

Despite concern about the low level of the social benefit, parents reported several positive effects of it. Nearly two-thirds (63.8 per cent) felt cared for, while it gave 54.0 per cent hope for the future. Parents believed that if the benefit was terminated this would lead to deterioration in the child's health (54.6 per cent), a decline in the family's socioeconomic conditions (51.7 per cent), a lack of belief in the future (38.5 per cent) and (the least selected option) disappointment (37.1 per cent).

It is important to highlight that the social benefit calculation indicator is not adjusted for the inflation and the purchasing power of the allocated amount decreases over time with the rise of inflation. The calculation shows that the purchasing power of the allocated amount (280 somoni) in 2010 reduced by 32.7 per cent by 2016. The real value of the allocated amount in 2010 (280 somoni) after adjusting for inflation is worth 416 somoni and the revised amount of social benefit (350 somoni) is less than allocated in 2010 after adjustment of inflation.

Of 465 children who participated in the study, only three (0.6 per cent) were not on antiretroviral therapy. Most of the children in the survey (86.6 per cent) had been on antiretroviral therapy for over a year.

The study found that children who receive social benefits are much more likely to have lower quantities of HIV in their blood (expressed in medical terms as viral load). Of the children receiving social benefits, 80.3 per cent had a viral load of less than 1,000 copies/ml, compared with just 19.2 per cent of those who were

not receiving benefits. Other factors that correlated with reduced viral load include parental participation in various trainings including training on adherence and longer time on antiretroviral therapy: 82.7 per cent of children whose parents had participated in adherence training had viral loads of less than 1,000 copies/ml compared with 67.7 per cent of children whose parents had not participated in the training. Nearly a third of the children (31.4 per cent) had had interruptions to their antiretroviral therapy and 47.1 per cent of these children had viral loads of more than 1,000 copies/ml, significantly higher than for children who did not had interruptions to their intake of ARV drugs.

Children with HIV require enough nutrients for their growth and development, but also to have enough energy to respond to their illness. Of the children whose families took part in the survey, over half (58.7 per cent) were of normal weight, 10.2 per cent were overweight or obese, and a total of 31.4 per cent were underweight (including 6.7 per cent severely underweight, and 7.6 per cent very severely underweight). No significant differences were revealed by gender and food consumption.

A total of 43.3 per cent of the parents reported that they do face difficulties with their child's taking of ARV pills. A total of 25.5 per cent reported that the key difficulty is that children are tired of taking ARV medicines (this was also observed during the discussion with parents: one of their wishes was that their child could take a pill to be cured of HIV and never to have to take ARV pills again). The second most selected answer was keeping the tablets confidential (17.4 per cent) followed by being out overnight as guests (16.4 per cent) and too many pills to swallow (13.2 per cent). Also, during the interview parents, stated that they are very concerned that somebody will find out the child status of HIV and they are afraid to overnight in their extended family house as questions might come up about why the child is taking pills and for what treatment. They fear that families, friends, neighbours will know, and their family will be isolated.

Overall the finding suggests that social benefits have an impact on treatment outcomes as well as the duration on treatment and parental knowledge of ART adherence. It is important to note that the described factors are interlinked. The findings show that over half of the respondents are depending on remittance and salaries, which makes them economically vulnerable. The economic vulnerability may affect the food intake in families and eventually affect the health condition of the child as ARV therapy requires adequate care including nutrition care.

Key recommendation:

- Continue providing social benefit. The study shows that social benefit is having a positive impact on the children health. Children on ARV therapy and receiving social benefit have supressed viral load than other children in the study.
- The current research did not study the situation of children of 17 and 18 years, however, there was request for parents to increase the age limit of the provision of the social benefit up to 18 years old. This is the age

when children start stepping into early adulthood and it is quite important to analyse their situation and understand their needs.

- Adjustment for inflation is needed to keep the purchasing power of the social benefit. The study showed that the purchasing power of the social benefit reduced over time with the increase of inflation and there is a need for a policy in place to state how this could be adjusted periodically.
- Review the delivery mode of the social benefit to debit cards. The current prevailing method in cash from bank is not completely transparent as the minimum amount is reported given 200 somoni, when it is supposed to be 350 somoni and at the same time it is not convenient for the parents as they have to travel several time and sometime long distances just to find out if they can collect the benefit.
- Increase the knowledge of parents on HIV/AIDS, treatment adherence, nutrition, etc. The study revealed that there is strong relationship between the parents' knowledge and the viral load. Parents who attended a training had their child viral load suppressed. Educating parents can further improve the health of the child.
- It is quite important to provide mental and psychosocial support to children and adolescence as well as increase their knowledge about HIV, adherence, stigma, marriage etc. This could be done through summer camps with engagement of parents, doctors, social workers so that they can provide psychosocial support for the child or adolescent.
- The study revealed that 31 per cent of the children are underweight, however, it was not possible, within the current study, to thoroughly assess the nutrition status of HIV infected children as the level of measurement at which the data was collected limited it. It is recommended to study the micronutrient deficiency of the children living with HIV using integrated approached – patients' history, physical examination, anthropometrics (which provide information on body muscle mass and fat reserves), and laboratory studies. This approached would allow to capture the effect of social benefit support on children's nutrition condition.
- Prevention of stigma and discrimination at all structural level is needed. Parents have a fear of stigma and discrimination. They find it difficult keeping the intake of ARV tablets confidential. They also find it difficult to overnight in the house of their extended families. As they fear that families, friends, neighbours will know, and their family will be isolated.
- Gender awareness campaign and training is needed. The study revealed that gender stereotypes persist as the responded believe that the family life is more important for girls than for boys, the carrier growth is more important for boys than for girls, and girls are more likely to face life difficulties than boys. This type of perception could possibly lead to demotivation to continue ARV therapy and lack of virologic suppression.

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INTRODUCTION

According to the Republican AIDS Centre, an estimated 16,321 persons are living with HIV in Tajikistan. Between 1992, when the first case was registered, and the end of 2017 the cumulative number of registered people living with HIV reached 9,957, of whom 2,405 had died. Out of 7,552 alive HIV in Tajikistan 10.2% are children under 18 years old. Among persons living with HIV, 41 per cent (of whom 98 per cent were male) had a history of injecting drugs; 48 per cent (43.5 per cent male and 56.5 per cent female) had a history of unprotected sex; 3.51 per cent were infected by mother-to-child transmission; 0.1 per cent were infected by blood transfusions; and the mode of transmission for 7.21 per cent was unknown. These figures indicate that the HIV epidemic in Tajikistan is primarily driven by injecting drugs users.

Enormous progress has been made in the scaling up of antiretroviral treatment (ART). Between 2010 and 2017, the number of persons living with HIV on treatment increased by almost 1,000 per cent from 504 to 5,016 (including 2,248 females). The number of children under 18 years old on ART increased by over 33 times from 21 in 2010 to 695 in 2017 (see Chart 1: Trend in patients on ART in 2010-2016). The rate of enrolment in ART is high among children living with HIV, but low among adults. As of December 2017, 768 children under the age of 18 were registered with HIV, of whom 695 (90.5 per cent) were enrolled into ART (in 2013 the enrolment rate for children was reported as 62.3 per cent¹). In 2017, adult enrolment on ART was reported at 89 per cent.

The number of children on ART began increasing in 2012 following the adoption of two significant documents: Decree 232 of 3 May 2010 issued by the Government of Tajikistan and Order 451 of 18 August 2011. Decree 232 allocates state social benefits to children living with HIV, while Order 451 sets out indicators to test children with specific symptoms for HIV. The data show that a year after implementation of the orders, the number of children on ART increased by 260 per cent, from 50 children in 2011 to 133 in 2012.

2.1 Background Information

According to the RAC, approximately 10.2 per cent of persons living with HIV in Tajikistan are under the age of 18. Almost half of this children (48.3 per cent) have been infected through mother-to-child transmission, and their adherence to ART depends heavily on their parents' level of knowledge about HIV and AIDS.

¹ Ulrich L. J., Lali K. & others (2013). HIV/AIDS in Tajikistan. Mid-term review of The National AIDS Programme 2011-15, retrieved March 2018 from http://www.euro.who.int/en/health-topics/communicable-

diseases/hivaids/publications/2014/hivaids-in-tajikistan.-mid-term-review-of-the-national-aids-programme-2011-15-october-2013

The RAC places significant emphasis on consulting with the parents of children living with HIV about the benefits of ART for the child's health. The practical experience of the RAC shows that a large number of children living with HIV come from low- and middle-income families and are in great need of support. As a result, in 2010 the RAC and its partners successfully lobbied the Government to allocate state social benefit support to families with children living with HIV. According to the RAC, in 2017 556 HIV positive children were receiving social benefits with monthly amount of 350 somoni. In total, in 2017 the Government of Tajikistan gave 2,335,200 somoni of social benefit to families with HIV positive children. This study was commissioned by UNICEF in collaboration with the RAC and the Guli Surkh NGO to reveal the impact of public cash transfers on children living with HIV in Tajikistan. The subsequent sections of this report set out the goal and objectives of the study, the research methods, limitations and the findings, before discussing the results and making a conclusion.

2.2 Goal And Objectives

The goal of the study is to assess the impact of social benefit on the ART adherence and health outcomes of children living with HIV in Tajikistan.

The objectives of the study were as follows:

- Determine the socio-demographic profile of families with children living with HIV;
- Study the barriers that families face when seeking to access social benefits;
- Analyse child development;
- Identify if there is a difference in viral load between children receiving social benefits and those that do not receive them;
- Identify if any gender disparities in access by boys and girls living with HIV to social benefit;
- Other benefits for children living with HIV.

2.3 Methodology

The study had a non-experimental, correlational design and applied both quantitative and qualitative methods. Quantitative methods were applied to collect and analyse data from primary sources, directly from family members of children living with HIV. Qualitative information was collected through individual interviews with representatives of various agencies – including health and social protection authorities, local authorities, banks and other stakeholders – to complement the quantitative findings and reflect on the context.

Based on the proposed sampling methodology, of all the 768 children living with HIV in Tajikistan, 465 were selected for the study. The children included in the study were from all the geographical areas of Tajikistan. Parents or guardians

responded to the questions. The questionnaire was divided into several sections to collect demographic information, information about household socio-economic conditions, barriers to receiving social benefits and access to the benefits, as well as treatment, care and support questions covering issues including viral load and CD4 cell count collected directly from patients' medical cards.

Proportions were calculated for categorical variables, and medians and interquartile ranges (IQR) for continuous variables. We have determined the correlation between log_{10} viral load versus CD4 count, stratified by gender with least-squares line for children receiving and not receiving social benefit. Chi square (χ^2) tests were performed for viral load categories across different variables. "Virally suppressed" was defined as less than 1,000 copies per ml. The BMIs derived were categorized using WHO BMI Z-score tables for age standards for children and adolescents between 0 and 19 years of age (WHO Growth Reference Study Group 2006). The purchasing power was calculated for allocated social benefit using Consumer Price Index (CPI) for 2010 to 2016. All hypothesis testing used two-sided tests at 5% significance level using Stata 14.2 (StataCorp, College Station, USA).

2.4 Study Limitations

There were several limitations to the study, of which the key ones were sampling, lack of data (the data is not openly available), prior research studies on the topic, and measures used to collect data. Though there were enough participants in the study, when divided by age group there was less representation of children under 5 years and over 11 years of age. The same is true for ART duration, as over 80 per cent of the participants had been on treatment for over a year. This limitation could cause directional bias in our study. In other words, those who were receiving social benefits and had been on ART for over a year were more likely to have lower viral loads than those who had been receiving social benefit and been on ART for less than a year. This could lead to overestimation of the effect of social benefits on the size of the viral load.

RAC has disaggregated data about every person living with HIV in the country, including children, but the data is not openly available or published. There is enough data published on key populations – persons who inject drugs, sex workers, men who have sex with men, and prisoners – but there are very few publications about children living with HIV. Most of the publications are about HIV and AIDS in Tajikistan in general, with some focussing on prevention of mother-to-child transmission and they are not specifically focused on children and social benefits. This study is unique, as it does not only look at aspects of treatment but also into socio-demographic, educational, nutrition and developmental aspects of the child. The findings are also cross-analysed by gender and residence (urban/rural).

Another important limitation was the measures used to collect the data. Some variables were collected at a nominal or categorical level, but would have been more useful if they had been collected at a ratio level, for example with regard to

length of time on ART. It would have been better to collect the duration of ART as a date variable by indicating the date when the child's ART was initiated. This would allow to assess the effectiveness of ART over a period and perform other statistical tests if needed. There was a similar issue about allocations of social benefit. No specific question asked what the monthly/quarterly amount of social benefit allocated for a child is. This was later clarified through RAC and the data were cleaned accordingly. In addition, the stigma question section of the questionnaire did not include self-stigma, and the whole section was very much focused on gender rather than stigma. As a result, it was reported as a gender section. There was also lack of data on psychosocial/mental condition of a child on AVR therapy that would help to understand what kind of support the child needs beyond health support.

Most of the limitations were addressed by recoding the variables as nominal or categorical. For example, age was later categorized into three categories of children under five, primary school children, and post-primary adolescents. Viral load was categorized as those below and above the country's threshold of 1,000 copies/ml.

3.1 Socio-Demographic Profile Of The Respondents

Table 1 shows that a total of 465 children living with HIV participated in the study, of whom 47 per cent were from urban areas (n=219) and 53 per cent from rural areas (n=246). A total of 57 per cent of the children were boys (n=265) and 43 per cent were girls (n=200). The children who participated in the survey were not evenly distributed by oblast. The lowest proportions of participants were from GBAO (2 children; 0.4 per cent) and Sughd (9 children; 1.9 per cent), and the largest number from Dushanbe (162 children; 34.9 per cent).

Almost all the household heads had some educational attainment (95 per cent). Most of the parents had secondary education (35 per cent), 28.8 per cent had higher education, 15.5 per cent have professional primary/secondary education, 10 per cent had primary education and 5.8 per cent had general basic education.

The main sources of household income were remittances (28.9 per cent) followed by salaries (27.1 per cent), self-employment (19.7 per cent), farming (12.7 per cent) and pensions (9.8 per cent), while only five respondents chose the option of non-cash income.

Nearly three quarters of the respondents (72 per cent) have 1-4 children in their households, while 16.8 per cent reported 5-6 children and 11.2 per cent said that they had over 7 children in their household. The mean age of the children was 8.6 years old (SD=3.1). The minimum age was 0 and the maximum 16 years. Nearly all the respondents (91.3 per cent) reported having one child living with HIV in their household, 8.5 per cent reported two children in their households living with HIV, while one respondent reported having three children living with HIV in their household. See the table below for further information.

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Table 1. General demographic information

General information	n	%
Child's gender		/0
Boy	265	57.0
Girl	200	43.0
Residence		
Urban	246	52.9
Rural	219	47.1
Region		
Dushanbe	162	34.9
GBAO	2	0.4
Sughd	49	10.5
Khatlon	124	26.7
RRS	128	27.5
Household head education		
No education	20	4.3
Primary	47	10.1
General basic	27	5.8
General secondary	163	35.0
Professional primary	38	8.2
Professional middle	34	7.3
Higher	134	28.8
Don't know	2	0.5
Sources of income		
Remittances	132	28.9
Salary	124	27.1
Own business	90	19.7
Farming	58	12.7
Pension	45	9.8
Don't know	3	1.1
Non-cash income	5	0.7
Number of children in household		
1-2	143	30.7
3-4	192	41.3
5-6	78	16.8
7+	52	11.2
Number of children living with HIV in household		
One	417	91.3
Two	39	8.5
Three	1	0.2

3.2 Schooling

Of the 465 children discussed in the interviews, 355 (76.3 per cent) were going to school. However, 21 school-aged children (5.6 per cent of all school-aged children) did not go to school. Unfortunately, no variable was collected to analyse the reasons why school-aged children do not attend school. Three quarters of the children (74.62 per cent) studied in state-funded schools, 0.86 per cent (n=4) in private schools, and 0.86 per cent (n=4) in specialized schools. Nearly 77 per cent of the children enjoyed going to school. A higher proportion of girls (78.6 per cent) liked going to school than the proportion of boys (75.6 per cent), but the difference is only three percentage points. A greater gender difference was observed in "reading books", "learning the school programme" and the school "subject interest". A total of 75.3 per cent of girls enjoyed reading books, compared to 63.7 per cent of boys (a difference of 11.6 per cent). A total of 72.1 per cent of girls' parents and 61.7 per cent of boys' parents reported that their children are learning the school programme completely. Girls displayed more interest than boys in all subjects except for natural sciences, where the figures were 32.3 per cent for boys and 28.6 per cent for girls. This nuance has been observed in other research globally as well.

The data also revealed that boys and girls had different circles of friends. The data shows that boys are more likely to have friends with relatives (28.4 per cent) and schoolmates (37.3 per cent), while for girls these figures are 20.8 per cent and 34.4 per cent respectively. Girls are more likely to have friends among their neighbours (44.8 per cent, compared to only 34.3 per cent for boys).

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Table 2. School information by gender

School information	То	otal	М	ale	Female	
School Information	n	%	n	%	n	%
Type of school						
State-funded school	347	74.6	195	73.6	152	76.0
Private school	4	0.9	3	1.1	1	0.5
Specialized school	4	0.9	3	1.2	1	0.5
Does not study	64	23.6	64	24.1	46	23.0
School-aged children and school attendance						
Studies at school	355	94.4	201	94.8	154	93.9
Does not study	21	5.6	11	5.2	10	6.1
Likes going to school						
Yes	273	76.9	152	75.6	121	78.6
No	10	2.8	8	4.0	2	1.3
Sometimes	72	20.3	41	20.4	31	20.1
Likes reading books						
Yes	244	68.7	128	63.7	116	75.3
No	31	8.7	17	8.5	14	9.1
Sometimes	80	22.6	56	27.8	24	15.6
Learning the school programme						
Completely	235	66.2	124	61.7	111	72.1
Partly	63	17.7	40	19.9	23	15.0
Have difficulties	46	13.0	31	15.4	15	9.7
Does not learn	8	2.3	5	2.5	3	1.9
Don't know	3	0.8	1	0.5	2	1.3
Subjects your child are most interested in						
Humanitarian	195	41.94	107	53.2	88	57.1
Natural sciences	109	23.44	65	32.3	44	28.6
Technical	31	6.67	19	9.5	12	7.8
No interest	20	4.30	10	5	10	6.5
Child attendance at school						
Always participates	326	70.11	183	91.0	143	92.9
Sometimes misses	26	5.59	16	8.0	10	6.5
Misses every day	3	0.65	2	1.0	1	0.6
Activeness in extra-curricular activities						
Actively participates	146	31.40	77	38.3	69	44.8
Rarely participates	50	10.75	26	12.9	24	15.6
Does not participate	159	34.19	98	48.8	61	39.6
Your child's friends						
Relatives	89	19.14	57	28.4	32	20.8
Schoolmates	128	27.53	75	37.3	53	34.4
Neighbours	138	29.68	69	34.3	69	44.8

3.3 Access To Social Benefits And Usage

In May 2010, the Government of Tajikistan approved Decree 232 under which families with children living with HIV became eligible to receive governmentprovided social benefits. The size of the social benefit is calculated as a sevenfold calculation indicator. In 2016, the calculation indicator was 40 somoni and children were receiving 280 somoni per month as a social benefit. In 2016, the calculation indicator was revised and set 50 somoni, which increased the amount of the social benefit from 280 somoni to 350 somoni a month and since January 2017 families with children living with HIV start receiving 350 somoni (Ministry of Finance, 2016)². Although the amount provided is not great it is still a support for low-income families. The study findings revealed that 74.8 per cent of respondents (parents of 194 boys and 154 girls) reported that they receive social benefits for their child/children.

Nearly two thirds of the respondents (65.8 per cent) reported that they receive the social benefit in cash through local banks. Others receive bank transfers (30.5 per cent) and deposits into their debit cards (3.7 per cent). Most respondents who receive social benefits in cash live in urban areas (54.6 per cent, with the other 45.4 per cent in rural areas). Most respondents who receive social benefits by bank transfer live in rural areas (67.0 per cent). Of the 13 respondents who receive the benefit into a debit card, nine lived in rural areas and four in urban areas. During the in-depth interview with the parents, the means of receiving social benefits to be transferred to bank account so they could withdraw them from cash machines (debit card).

Most of the parents (95.1 per cent) reported that they received the social benefit on a quarterly basis. Only 11 parents (3.2 per cent) reported that the last time they received the social benefit it was for a month or two, while 6 parents reported receiving the benefit for four or more months. No major differences were observed between rural and urban answers, with 94.6 per cent of the rural respondents and 95.7 per cent of urban respondents reporting that the last time they received the social benefit it was for three months. The number of respondents who received the social benefit for one or two months was eight in rural areas and three for urban areas, but there were more respondents in urban areas for the over four months category.

Over two thirds of the parents (68.7 per cent) know that the social benefit is given to the family because a child/children is/are living with HIV, while 59.5 per cent also reported that it is given to them to improve the nutrition of the child living with HIV, and only 4.8 per cent reported that they receive the social benefit as state compensation for the harm to the health of their child.

² Ministry of Finance (2016) State budget of the republic of Tajikistan http://minfin.tj/index.php?do=static&page=budget

Almost three quarters (74.4 per cent) of the parents reported using the social benefit to provide for the nutrition of the child/children living with HIV. The next most common responses were other needs (41.4 per cent) and food for the whole family (15.0 per cent). A total of 4.9 per cent selected the option of family needs, while the least selected options were utility payments (1.2 per cent) and payments for rented accommodation (0.9 per cent). The distribution by gender shows that 80.5 per cent families with girls living with HIV mostly use the social benefit only for the nutrition of the child living with HIV whereas for boys the figure was 69.6 per cent.

	Тс	otal	M	ale	Fer	nale	Rı	Rural		ban
	n	%	n	%	n	%	n	%	n	%
Children receiving social benefit										
Yes	348	74.8	194	73.2	154	77.0	184	74.8	164	74.9
No	117	25.2	71	26.8	46	23.0	62	25.2	55	25.1
How did you receive the social benefit?										
Cash	229	65.8	126	65.0	103	66.9	104	56.5	125	76.2
Deposit card	13	3.7	7	3.6	6	3.9	9	4.9	4	2.5
Bank account	106	30.5	61	31.4	45	29.2	71	38.6	35	21.3
For what period was the social benefit given										
1-2 months	11	3.2	8	4.1	3	2.0	8	4.3	3	1.8
3 months	331	95.1	181	93.3	150	97.4	174	94.6	157	95.7
4+ months	6	1.7	5	2.6	1	0.6	2	1.1	4	2.5
Do you know the reason why your child is getting social benefit?										
Child is living with HIV	239	68.7	137	70.6	102	66.2	128	69.6	111	67.7
To increase immunity, through better nutrition State compensation for	207	59.5	113	58.3	94	61.0	106	57.6	101	61.6
harm to the health of my child	23	6.6	11	5.7	12	7.8	10	5.4	13	7.9
What do you use the social benefits for?										
Only for the nutrition of a child living with HIV	259	74.4	135	69.6	124	80.5	134	72.8	125	76.2
For other needs	144	41.4	86	44.3	58	37.6	57	30.4	87	41.2
Food for the whole family	78	22.4	50	25.8	28	18.2	46	25.0	32	19.5
Family needs	24	6.9	13	6.7	11	7.1	15	8.2	9	5.5
Payment of utility bills	4	1.2	2	1.0	2	1.3	2	1.1	2	1.2
Payment of rent for accommodation	3	0.9	1	0.5	2	1.3	2	1.1	1	0.6

Table 3. Access to social benefits and their utilization by gender of child and residence

The reported size of the social benefit varied from 200 somoni to 1,050 somoni (see Table 4). This was confusing as the social benefit is set as 350 somoni per child paid on quarterly basis. During the interview with parents some mentioned that they don't look at papers they sign and receive what the bank cashier hands them, although, the paying of 200 somoni was dismissed by bank personnel during the interview. In line with this the parents requested to look at the possibility of receiving the payment through ATM machines (debit card).

The mode and median are 350 somoni and the mean is 356.7 somoni (SD=84.9). The minimum and mean were higher for boys, at 250 somoni and 362.4 somoni respectively. The distribution by residence (rural/urban) does not vary significantly. These findings do not tally with the rate provided by the Government, which since 2017 is 350 somoni per child.

	Freq.	Min	Мах	Median	Mode	Mean	SD
Воу	194	250	1050	350	350	362.4	100.3
Girl	154	200	1040	350	350	349.5	59.6
Rural	184	200	1050	350	350	358.9	98.3
Urban	164	250	1040	350	350	354.3	66.9
Total	348	200	1050	350	350	356.7	84.9

Table 4. Distribution of social benefits in somoni by gender

To understand the distribution of social benefits further the responses were divided into three categories with the findings presented in Table 5. Table 5 indicates that 89.4 per cent of the families said they received 350 somoni, 6.6 per cent reported receiving under 350 somoni, and 4 per cent reported receiving over 350 sonomi. The findings are inconsistent with the Government Decree and the amount approved for quarterly payment by the Ministry of Health and Social Protection (MoHSP). Receiving less than 350 sonomi is often because some districts still continue paying families with the old tariff of 280 somoni, while some families report that that is what is given to them by bank. The amount higher than 350 somoni was not explained.

Table 5. Distribution of social benefits by categories

Social honofit distribution by astagorias	Tota	
	n	%
Under 350 somoni	23	6.6
350 somoni	311	89.4
Over 350 somoni	14	4.0

Table 6 shows challenges faced when seeking to receive social benefits. Almost a third of the respondents (29.0 per cent) reported facing difficulties obtaining the social benefit. Rural respondents are more likely to face difficulties (29.7 per cent) than their peers from urban areas (28.2 per cent), though the difference was not significant. Respondents from both rural and urban areas reported most frequently facing difficulties in the financial and banking sector, with a total of 59.7 per cent of respondents who had faced difficulties selecting that option. Over 41 per cent of the parents reported that they started receiving the social benefit within three months of submitting the paperwork, a further 27.8 per cent reported receiving it within six months, and 31 per cent reported that they began to receive it after six months or more. According to the National AIDS Centre (RAC) the amount should be distributed every quarter, as the RAC provides a list of children eligible for social benefit on a guarterly basis, but it is not clear why there is a delay of over six months. The Commissions on Child Rights also stated that they process social benefit claims in a timely fashion and that the parents should receive it within a month. Of 14 interviewed bank employees, 12 stated that the bank receives the social benefit in time and that the bank distributes it as soon as it is received.

Although the size of the social benefit is not large, parents reported that they felt cared for (63.8 per cent) and had hope for the future (54.0 per cent). At the same time the parents requested an increase in the social benefit, as 350 somoni is not sufficient. It is important to highlight that the social benefit calculation indicator is not adjusted for the inflation and the purchasing power of the allocated amount decreases overtime with the rise of inflation. The calculation shows that the purchasing power of the allocated amount (280 somoni) reduced by 32.7 per cent since 2010. In terms of somoni the purchasing power of 280 somoni in 2010 devalued to 188.5 somoni by 2016, after adjusting for inflation. Even the revised amount of the social benefit (350 somoni) in 2016 is less than the amount allocated in 2010 (280 somoni) if adjusted for inflation. Figure 1 shows the depreciation of the real value of the social benefit over time as well as it dynamic of increase if adjusted for inflation. Thus, in 2016 if the allocated amount would have been adjusted for inflation the value of the benefit should have been 416 somoni.



Figure 1. Social benefit adjusted for inflation

In the parents' response to the multiple-choice question about the consequences of *termination of the social benefit payment* demonstrates, the most selected choice was deterioration in the child's health (54.6 per cent) followed by a decline in the family's socioeconomic conditions (51.7 per cent), a lack of belief in the future (38.5 per cent) and (the least selected option) disappointment (37.1 per cent). It should be noted that the need to increase the amount of the social benefit for children with HIV is also supported by ILO as part of Assessment Based National Dialogue on Social Protection⁴ in Tajikistan in 2018.

Over two thirds of the parents (67.7 per cent) are concerned that the HIV status of their child will be disclosed when they receive the social benefit. This concern is higher among respondents in rural areas (71.0 per cent) than in urban areas (63.8 per cent). Respondents are more worried about their child's HIV status being disclosed among relatives and close ones when receiving social benefits (69.7 per cent). Rural respondents also had a higher concern than urban ones on this issue (72.2 per cent and 66.9 per cent respectively).

 $^{\scriptscriptstyle 3}$ The consumer price index is retrieved from The World Bank data site

https://data.worldbank.org/indicator/FP.CPI.TOTL?end=2016&locations=TJ&start=2010 and the calculation is performed by the author.

⁴ ILO (2018) Assessment Based National Dialogue on Social Protection Floors in the Republic of Tajikistan retrieved from: http://www.social-protection.org/gimi/ShowProject.action?id=3053

Challenges	Тс	Total		Rural		ban
Challenges	n	%	n	%	n	%
Are there any difficulties obtaining social benefits?						
Yes	105	29.0	57	29.7	48	28.2
No	255	70.4	133	69.3	122	71.8
No need for social benefits	2	0.6	2	1.0	0	0.0
At what stage of obtaining social benefits did you face difficulties?						
Social services	23	20.2	16	6.5	7	3.2
Medical services	7	6.1	1	0.4	6	2.7
Financial - banking services	68	59.7	39	15.9	29	13.2
Other	16	14.0	8	3.2	8	3.7
What changes did you feel from the moment of receiving the social benefit?						
Норе	132	37.9	76	30.9	56	25.6
Being cared for	222	63.8	117	63.6	105	64.0
Hope for a prosperous future	188	54.0	96	52.2	92	56.1
Stability	149	42.8	82	44.6	67	40.9
No change	30	8.6	17	9.2	13	7.9
How long after submitting the documents did you receive the social benefit?						
Within three months	142	41.2	92	50.3	50	30.3
Between three and six months	96	27.8	43	23.5	55	33.3
More than six months	107	31.0	48	26.2	60	36.4
If your child does not receive social benefits, do you have medical certificates?						
Yes	52	54.7	32	69.6	20	40.8
No	43	45.3	14	30.4	29	59.2
Did you provide a medical report to the child rights department at the local authority?						
Yes	122	67.4	72	69.9	50	64.1
No	59	32.6	31	30.1	28	35.9
Are you concerned that your child's HIV status will be disclosed when receiving social benefit?						
Yes	260	67.7	147	71.0	113	63.8
No	124	32.3	60	29.0	64	36.2

Table 6. Challenges to accessing social benefit by place of residence (rural/urban)

Are you concerned that your child's HIV status will be disclosed among your relatives when receiving social benefit?

•						
Yes	258	69.7	143	72.2	115	66.9
No	112	30.3	55	27.8	57	33.1
Are you worried about what will happen when the social benefits end?						
Yes	274	84.5	138	84.2	136	85.0
No	50	14.4	26	15.8	24	15.0
When the payment of social benefit ends what difficulties will you face?						
Deterioration of the child's health	190	54.6	103	56.0	87	53.0
Worsened socioeconomic conditions for the family	180	51.7	103	56.0	77	45.0
No belief in the future	134	38.5	73	39.7	61	37.2
Disappointment	129	37.1	69	37.5	60	36.6

3.4 Child growth and nutrition

Anthropometric indicators for young children based on weight (kg) and height/length (cm) were collected in this survey to provide outcome measures of nutritional status. The derived body mass index (BMI: the body mass divided by the square of the body height) was categorized by using z-score tables of WHO BMI-for-age standards for children and adolescents between 0 and 19 years (WHO Growth Reference Study Group, 2006). The underweight category is reported in three categories (z-score -1 to -3), normal is z-score 0, overweight z-score 1, and obese z-score 2. The results are provided in Table 7. The table also disaggregates by gender and mean BMI.

BMI categories	Total (N=405)		Male (n	=230)	Fema (n=1)	Mean BMI	
	n	%	n	%	n	%	
Very severely underweight	31	7.6	15	48.4	16	51.6	11.6
Severely underweight	27	6.7	19	70.4	8	29.6	13.5
Underweight	69	17.1	44	63.8	25	36.2	14.3
Normal weight	236	58.4	130	55.1	106	44.9	16.5
Overweight	17	4.1	5	29.4	12	70.6	19.8
Obese	25	6.1	17	68.0	8	32.0	27.5

Table 7. BMI-for-age (kg/m²) by gender

Over half of the children (58.7 per cent) have a normal weight, 10.2 per cent are overweight or obese, and a total of 31.4 per cent are underweight (including 6.7 per cent severely underweight, and 7.6 per cent very severely underweight). No significant differences were revealed by gender.

Good nutrition is important for everyone, and for persons living with HIV it is particularly important as they not only need to maintain their body weight, but also to have enough energy to respond to the illness (WHO, 2013).⁵ Children living with HIV deserve special attention because alongside their ongoing treatment they need enough nutrients for their growth and development. Their bodies are using up more energy to fight the HIV infection itself or other opportunistic infections. According to WHO, growth in numbers of children on antiretroviral therapy is a good indicator of response to treatment and ongoing adherence (WHO, 2009).⁶

The survey collected data on the number of times certain foodstuffs were consumed by children in the day or week before the interview. In particular, figures for meat, milk products, eggs and legumes consumption were collected for one day and fruit and herbs for a week and a daily. The variables were converted into dummy variables indicating children that consumed the food at least once a day/week or did not consume it at all. The findings are presented in Table 7. The table presents that animal sources of food in the form of meat/meat products/fish category were consumed by 54.4 per cent of children; 64.3 per cent consumed milk products including yogurt, churgot, and chakka; 42.4 per cent consumed eggs and 43.9 per cent legumes; consumption of fruit was the highest (94.2 per cent and consumption of herbs was 72.3 per cent), however, 3.6 per cent of families reported that their child is consuming fruit only once a week and 4.5 per cent of families reported that their child is consuming herbs once a week. Across all the categories boys were observed to consume more, but this is not statistically significant. The observation is statistically significant by rural and urban areas for meat ($\chi^2_{(1, N=465)}$ = 8.74, p>0.01) and legume ($\chi^2_{(1, N=465)}$ = 14.13, p>0.001) consumption. Urban children reportedly had higher consumption of meat (61.6 per cent) and rural children of legumes (52.0 per cent).

Patterns by oblast characteristics shows that consumption of meat products and fish was less in Khatlon (31.5 per cent; $\chi^2_{(3, N=465)} = 35.61$, p>0.001), and the proportion of milk product consumption is much lower in Sughd (48.9 per cent; $\chi^2_{(3, N=465)} = 8.45$, p>0.05) and Khatlon (60.5 per cent) than Dushanbe (67.3 per cent) and RRS (70.3 per cent). Children were least likely to have consumed eggs in Khatlon (36.3 per cent) than in Dushanbe (41.2 per cent), Sughd (44.9 per cent) and RRS (49.2 per cent), but this was not statistically significant. The proportion of legume consumption among children was lowest in Sughd (20.4 per cent; $\chi^2_{(3, N=463)} = 27.38$, p>0.001) and Dushanbe (34.5 per cent): in RRS (52.3

⁵WHO (2013) Essential nutrition actions: improving maternal, newborn, infant and young child health and nutrition. WHO Document Production Services, Geneva, Switzerland.

⁶WHO (2009) Guidelines for an integrated approach to the nutritional care of HIV-infected children (6 months-14 years). WHO Document Production Services, Geneva, Switzerland

per cent) and Khatlon (55.6 per cent) slightly over half of the children consumed legumes. Consumption of fruits was high in all the oblasts except for Khatlon (86.3 per cent), and consumption of herbs was lower in Dushanbe (67.9 per cent) than in all the other oblasts, in which over three quarters of children consumed herbs.

Table 8. Food consumption by background characteristic

Percentage of children who consumed meat, poultry, fish, milk product, eggs legumes at least once day, the week before the survey; and percentage of children who consumed fruit and herbs at least once a week, the week before the survey.

Background characteristic	N	%	Meat, poultry, fish	Dairy product s	Eggs	Legume s	Fruits	Herbs (dill, parsley, spring onion)
Child's gender								
Воу	265	57.0	55.1	66.4	43.4	42.3	95.1	75.8
Girl	200	43.0	53.5	61.5	41.0	46.0	93.0	67.5
Both genders	465	100.0	54.4	64.3	42.4	43.9	94.2	72.3
Residence								
Rural	246	52.9	48.0**	63.0	43.9	52.0	92.7	77.2
Urban	219	47.1	61.6	65.7	40.6	34.7***	95.9	66.7
Region								
Dushanbe	162	34.9	61.1	67.3	41.2	34.5	96.9	67.9
RRS	128	27.5	64.1	70.3	49.2	52.3	97.7	72.7
Sughd	49	10.5	63.3	48.9*	44.9	20.4***	95.9	75.5
Khatlon	124	26.7	31.5***	60.5	36.3	55.6	86.3	75.8
GBAO	2	0.4	100.0	50.0	0.0	100.0	100.0	100.0
Body mass index for	r age							
Underweight	127	31.4	57.5	69.3	45.7	48.0	92.9	71.6
Normal weight	236	58.4	55.9	67.8	42.4	44.5	95.6	72.5
Overweight	41	10.2	58.5	61.0	51.2	43.9	90.2	73.2
Age								
0 – 2 years	14	3.0	42.9	57.1	42.9	35.7	71.4	64.3
3 – 5 years	48	10.3	60.4	60.4	41.7	50.0	91.7	72.9
6 – 11 years	305	65.6	54.1	65.9	44.9	41.3	95.4	69.5
12 – 14 years	84	18.1	54.8	66.7	33.3	50.0	95.2	80.9
15 – 16 years	14	3.0	50.0	35.7	42.9	50.0	92.9	85.7
Viral load category								
> 1,000 copies/ml	150	34.5	58.7	68.7	40.7	42.7	91.3	69.3
≤ 1,000 copies/ml	285	65.5	53.0	64.5	42.8	45.3	95.1	73.7

***p>0.001; **p>0.01; *p>0.05

The proportion of child consumption by BMI for age categories, age categories, and viral load categories is not statistically different. Overall the study revealed that the proportion consuming meat products was the lowest and fruit consumption was the highest.

It was expected that the study would reveal relationship between consumption and BMI for age particularly among underweight children, however, table 8 shows that there is no relationship between these two variables. All the children are eating enough of the food; however, the collected data was about consumption of the above-mentioned products at least once a day/week, which does not give the true picture of the situation of why children are underweight. There could be many causes of weight loss including the effect of opportunistic infection on food intake, absorption, and metabolism (WHO 2010)⁷, which was not investigated in the current study. The finding suggest that children do consume, but it may be insufficient in quantity and quality. Other study suggest that ARV therapy can alter the concentration of micronutrient in the body⁸. It is recommended to further study this issue.

3.5 Treatment

Of the 465 children, only 3 were not on treatment, and the other 462 (99.4 per cent) were on treatment. Most of the children in the survey (86.6 per cent) had been on treatment for over a year. The proportion of children who had been on treatment for less than a year with viral load above 1000 copies/ml was significantly higher than that of children who had been over a year on treatment (49.1 per cent compared to 32.1 per cent; $\chi^2_{(1, N=433)} = 5.94$, p>0.01). The median viral load for children on treatment for over a year was lower, at 300 copies/ml (IQR: 55.5 – 2,523), compared to the 500 copies/ml for children on treatment for less than a year (IQR: 300 – 48,900).

The median viral load for both genders was 300 copies/ml and the CD4 count median was higher for females (706.5), but the difference was not statistically significant. The proportion of children under five years of age with a viral load of more than 1,000 copies/ml was significantly higher than that of older groups of children (53.6 per cent, compared to 34.0 per cent for 6-12 year olds and 24.2 per cent for 12-16 year olds; $\chi^2_{(1, N=435)} = 13.34$, p>0.001).

⁷ WHO (2010) Antiretroviral therapy of HIV infection in infants and children: towards universal access: recommendations for a public health approach - 2010 revision retrieved from:

https://www.ncbi.nlm.nih.gov/books/NBK138576/pdf/Bookshelf_NBK138576.pdf

⁸ Flax, V. L., Adair, L. S., Allen, L. H., Shahab-Ferdows, S., Hampel, D., Chasela, C. S., ... Bentley, M. E. (2015). Plasma Micronutrient Concentrations Are Altered by Antiretroviral Therapy and Lipid-Based Nutrient Supplements in Lactating HIV-Infected Malawian Women. The Journal of Nutrition, 145(8), 1950–1957. http://doi.org/10.3945/jn.115.212290



Figure 2. Correlation plot of log10 viral load and CD4 count, stratified by gender with least-squares line for children receiving and not receiving social benefit.

The result of the Pearson correlation is presented in Figure 1, and shows there is a weak negative correlation of r(431)=-0.19, p=0.001 between \log_{10} viral load and CD4 as well as weak negative correlation of r(431)=-0.17, p=0.001 between \log_{10} viral load and children receiving social benefit. Children receiving social benefit has a lower level of viral load and higher level of CD4 compare to those children who are not receiving social benefit. Nearly a third of the children (31.4 per cent) have had interruptions to their antiretroviral therapy and 47.1 per cent of these children had viral loads of more than 1,000 copies/ml, which is significantly higher than for children who did not had interruptions to their intake of ARV drugs (47.1 per cent compared to 28.8 per cent; $\chi^2_{(1, N=433)} = 14.62$, p>0.001). The median viral load was 500 copies/ml (IQR: 300 – 48,900) for children who had not had interruptions.

Overall, the health of 93.9 per cent of the children had improved after antiretroviral therapy was initiated, according to their parents. The proportion of parents who reported that their child's health improved after initiating of ART and had a viral load greater than 1,000 copies/ml was lower (33.5 per cent) in contract to 45.4 per cent who reported no improvement in health and had viral load greater than 1,000 copies/ml. Although, there is a difference, but it is not statistically significant. The median viral load for children whose health had improved was 300 (IQR: 60 - 3,020) compared to 500 among the others (IQR: 300 - 44,767.5).

The difference in the proportion of children with viral load of more than 1,000 copies/ml who were receiving social benefit and those who were not was statistically significant (69.0 per cent compared to 53.8 per cent; $\chi^2_{(1, N=435)} = 8.24$, p>0.01). Also, children who received social benefits had lower median viral load (300 copies/ml; IQR: 53 – 2,300) than those that did not (500 copies/ml; 170 – 26,573.5).

			Percentag		
Treatment and demographic characteristic	Fre q.	%	children with VL >1000 copies/ml	Median VL (IQR)	Median CD4 (IQR)
Child on ARV therapy					
Yes No Duration on ARV therapy	462 3	99.4 0.6	n/a n/a	n/a n/a	n/a n/a
Less than a year	61	13.2	49.1**	500 (300 -	527 (200 –
Over a year	401	86.8	32.1	48900) 300 (55.5 – 2523)	1059) 706.5 (432 – 989)
Child's gender					
Male	252	57.9	33.3	300 (67.5 – 3040)	697 (393 – 982)
Female	183	42.1	36.1	300 (81 – 5580)	706.5 (417.5– 1066.5)
Child's age				,	,
0 – 5 years old	56	12.9	53.6***	1292.5 (300 – 64621.5)	923 (485 – 1142)
6 – 12 years old	288	66.2	34.0	300 (109 – 5367)	741 (408.5 – 1031)
12 – 16 years old	91	20.9	24.2	300 (40 – 1000)	566 (300 – 741)
Interruption in ARV therap	у				695 (250
Yes	136	31.4	47.1***	8792) ⁵⁰⁰	965)
No	297	68.9	28.8	300 (52 – 2220)	703.5 (436 – 1021)
Child's health improved at	ter ini	tiating	ARV therapy	300 (60 -	700 (402 -
Yes	434	93.9	33.5	3020)	992)
No	28	6.1	45.4	500 (300 – 44767.5)	739 (383 – 965)
ARV intake					
Before meal	34	7.4	61.3	300 (52 – 2300)	642 (400 – 835) 702 (402
After meal	428	92.6	66.1	300 (75 – 3831)	703 (402 – 993)
Child receiving social ben	efit			,	
Yes	331	76.1	30.8**	300 (53 – 2300)	700 (432 – 988)
No	104	23.9	46.2	500 (170 – 26573.5)	702 (348 – 1085.5)
***p>0.001; **p>0.01; *p>0.0)5				

Table 9. Treatment, viral load, median viral load and CD4

When asked about difficulties, 43.3 per cent of the parents reported that they do face difficulties with their child's taking of ARV pills. A total of 25.5 per cent reported that the key difficulty is that children are tired of taking ARV medicines (this was also observed during the discussion with parents: one of their wishes was that their child could take a pill to be cured of HIV and never to have to take ARV pills again). The second most selected answer was keeping the tablets confidential (17.4 per cent) followed by being out overnight as guests (16.4 per cent) and too many pills to swallow (13.2 per cent). "Side effects" was selected less (for details see Table 10). Over half the parents (306 respondents) selected *improved health* and *reducing the viral load* as the key reason for a child to take ARV medicines. The third most selected option (200 respondents) was *all of the above* answers, which included *the child's life will be longer* (156 respondents).

According to parents there is enough treatment support to children in terms of treatment. This is provided by AIDS Centers and funded through The Global Fund across the country, however, there is limited mental, emotional and psychosocial support for HIV positive children. As demonstrated in Table 10 a guarter of the parents reports that the key challenges in regular intake is that children are tired of ARV therapy. This is alarming as without psychosocial support and enough knowledge of HIV and AIDS children, when grown and start making decision could stop taking ARV therapy and this will be an issue if they stop in early stage of adolescence. Adolescence (10-19 years) is a phase of physical growth and development accompanied by sexual maturation, often leading to intimate relationships. This is the age when they should be aware of their status and the risk of HIV transmission. According to NGO Guli Surkh working with HIV positive children and adolescent not many of them know their status. The experience of Guli Surkh shows that there is adolescent that are not aware of their HIV status and their parents told them that they are taking the medicine for other disease such as helminths⁹. Also, there are adolescents that are not guite aware of what to do next after they finish school and how to build a family as they are HIV positive. This is also the concern of the children's parents.

⁹ Authors discussion with the representative of Guli Surkh

Difficulties	Freq.	%
Are there any difficulties with regular intake of ARV drugs?		
Yes	186	40.3
No	276	59.7
If yes, what are they?		
Tired of taking ARV	129	25.5
Keeping the taking of the tablets confidential	88	17.4
Being away from the house	83	16.4
Too many tablets to swallow	67	13.2
Side effects	55	10.9
Forgetting to take ARVs	53	10.5
Lack or absence of ARV drugs	30	5.9
Why does your child need to take ARV drugs?		
To improve the health of the child	306	31.6
To reduce the viral load	306	31.6
The life of the child will be longer	156	16.1
All above	200	20.7

Table 10. What are the difficulties in intake of ARV drugs?

Another concern is the stigma and discrimination. Table 10 shows that two of the issues after *tired of taking ARV drugs* are issues related to confidentiality. Also, during the interview with parents, stated that they are very concerned that somebody will find out the child status of HIV and they are also afraid to overnight in their extended family house as questions might come up about why the child is taking pills and for what treatment. They fear that families, friends, neighbours will know, and their family will be isolated. Studies shows that stigma and discrimination may contribute to poor HIV treatment outcome¹⁰¹¹¹². Stigma and discrimination can affect child health and impede their opportunities to meet their potential. During the interview parents stressed that they do face the stigma and discrimination even when they go to bank to collect the social benefit. It is quite important to develop strategies and approaches on how to address the stigma and discrimination issues.

¹⁰ Nayar, U. S., Stangl, A. L., De Zalduondo, B., & Brady, L. M. (2014). Reducing Stigma and Discrimination to Improve Child Health and Survival in Low- and Middle-Income Countries: Promising Approaches and Implications for Future Research. Journal of Health Communication, 19(sup1), 142–163. http://doi.org/10.1080/10810730.2014.930213

¹¹ Rael, C. T., & Hampanda, K. (2016). Understanding Internalized HIV/AIDS-Related Stigmas in the Dominican Republic: A Short Report. AIDS Care, 28(3), 319–324. http://doi.org/10.1080/09540121.2015.1095277

¹² Chan, B. T., Pradeep, A., Prasad, L., Murugesan, V., Chandrasekaran, E., Kumarasamy, N., ... Tsai, A. C. (2017). Association between internalized stigma and depression among HIV-positive persons entering into care in Southern India. Journal of Global Health, 7(2), 020403. http://doi.org/10.7189/jogh.07.020403

Table 11 provides data on parents' participation in various training events. Over two thirds of the parents (64.5 per cent) had participated in *ARV adherence* training, followed by *psychological support for parents* (42.9 per cent), *disclosing HIV status* (39.5 per cent), *correctly using social benefits* (32.0 per cent), and *self-help groups* (31.2 per cent).

Table 11. Parental participation in training

Parental participation in training	Freq.	%
Adherence to ART	237	64.5
Psychological support for parents	126	42.9
Disclosing status	123	39.5
Correctly using the social benefits	87	32.0
Self-help groups	84	31.2

Of all the study participants (465 parents) over two thirds of them (65.2 per cent) attended at least one of the above-mentioned trainings. The median viral load was higher (500 copies/ml) for parents who did not participated in the training at all and lower for other parents (300 copies/ml) for details see table 12.

Table 12. Number of training attended by parents

Number of training attended	Freq.	%	Median VL
No training	162	39.3	500
One training	121	30.4	300
Two trainings	92	19.8	300
Three trainings	39	8.4	300
Four trainings	20	4.3	300
Five trainings	31	6.7	300

To see the effect of the training of the viral load a new dichotomous variable was created with the attributed of parents who participated in the training and parents that don't. A chi-square test of independence was performed to examine the relationship between these two variables. The relationship between these variables was significant, $\chi^2(1, N=435) = 6.78$, p>0.01. Parents who did not attended any training were more likely to have children with viral load >1000 copies/ml than those parents who attended at least one training.

	Viral Loa				
Variable	VL >1000 cc (n=28	pies/ml 5)	VL <1000 c (n=15	X ²	
	Ν	%	Ν	%	
Parents participated at least in one training					χ ² (1) =
Yes	199	69.8	86	30.2	6.78**
No	86	57.3	64	42.7	
***p>0.001; **p>0.01; *p>0.05					

Table 13. Chi-square result for parents that participated at least in one training and the VL of children

3.6 Gender

Table 14 provides data on parents' thoughts about persons living with HIV creating families. Almost 71 per cent of the respondents reported that a person living with HIV can create his/her own family. This shows that trainings and awareness raising campaigns carried out by national and international organisations have had their impact, but despite that there is almost a quarter of respondent (24.3 per cent) who don't know that PLHIV can create their family, which demonstrates a need for more awareness raising initiatives.

49.2 per cent reported that they could create families with other persons living with HIV, 11.6 per cent said they could create family with persons not living with HIV while only 10 per cent stated that the HIV status should not be a barrier to marriage.

Table 14. Respondents' thoughts on family creation

Respondents' thoughts on family creation	Freq.	%
Can a person living with HIV create a family?		
Yes	330	70.9
No	22	4.7
Don't know	113	24.3
If yes, then with whom?		
Another person living with HIV	229	49.2
Another person who is not living with HIV	54	11.6
HIV status should not be an obstacle	47	10.1

Overall the table shows that over three-fifths of the parents do agree that both gender should have equal opportunities, however, the pattern of gender differences could still be observed. Forty-eight point five (48.5) per cent of the parents reported that girls are more likely to face life difficulties than boys. The table also shows that over guarter (25.8 per cent) of the parents believe that boys have more opportunities to success in life then girls. 14.4 per cent of the parents reported that family life is important for girls than for boys (9.7 per cent). The similar tendency can also be observed in personal life where 14.6 per cent of the parents reported that it is important for boys than for girls. (8.2 per cent), and carrier growth 29.7 per cent of the parents believe that it is important for boys than for girls (7.1 per cent). These findings suggest that there are substantial number of families with perception that their HIV positive daughter might not be able to succeed in life, this type of perception could possibly lead to demotivation to continue ARV therapy and lack of virologic suppression. The table also presents data of rural respondents, which does not differ from urban respondents apart from the fact that there are more rural people who don't know.

Gender perceptions of respondents	Freq.	%	Percentage of Rural respondent responses
For whom is getting social benefits more important: girls or boys?			
For girls For boys Both Don't know	112 43 282 28	24.1 9.3 60.6 6.0	61.6 60.5 46.4 71.4
Who is more likely to face difficulties in life, girls or boys?			
Girls Boys Both Don't know	213 51 182 19	45.8 11.0 39.1 4.1	53.2 51.0 52.2 57.9
Who has more opportunities for success in life?			
Girls Boys Both Don't know	72 120 250 23	15.5 25.8 53.8 4.9	41.7 54.2 52.8 82.6
Is being educated more important for girls or boys?			
Girls Boys Both Don't know	45 87 327 6	9.68 18.71 70.32 1.29	60.0 56.3 50.5 83.3
Is family life more important for girls or boys?	· ·		
Girls Boys Both Don't know	67 45 343 10	14.41 9.68 73.76 2.15	46.3 48.9 54.2 70.0
Is being successful in one's personal life more important for girls or boys?			
Girls Boys Both Don't know	38 68 353 6	8.17 14.62 75.91 1.29	47.4 47.1 54.1 83.3
Is having a senior position (career growth) more important for girls or boys?			
Girls Boys Both Don't know	33 138 286 8	7.10 29.68 61.51 1.72	51.5 47.8 54.9 75.0
How should social benefits be allocated to girls and boys living with HIV in the same families?			
More for the girls More for the boys The same for both Don't know	36 13 402 14	7.74 2.80 86.45 3.01	50.0 53.8 52.7 64.3

Table 15. Gender perceptions of respondent

CONCLUSIONS AND RECOMMENDATIONS

The main purpose of the study was to evaluate the impact of state-allocated social benefits on the treatment outcomes of the social benefit recipients. Viral load was used as a proxy for measuring the effectiveness of the social benefit on the outcome of the treatment. Almost all the study participants (99.3 per cent) were on ARV and 74.8 per cent of them were receiving government social benefits. The viral load figure was available for 435 (93.5 per cent) of the children living with HIV that participated in the study.

The Government is allocating funding for families with children living with HIV so that they meet the basic needs of the children. Although the amount is not large families feel that the Government is providing them with care and support. The findings revealed that the social benefit is used for various needs, including utilities, rent, and other family needs. However, almost three quarters of the respondents (74.4 per cent) reported that they are using the social benefit for the nutritional needs of the child/children living with HIV. The study also observed that children living with HIV in families that receive social benefit have lower viral loads than children that do not receive the benefit. In the sample of 435 children, 80.3 per cent of those receiving social benefits had viral loads of less than 1,000 copies/ml compared with just 19.2 per cent of those who did not receive benefits (see Annex 1). The study also revealed that since 2010 the purchasing power of the social benefit was reduced by 32.7 per cent and the real value of the social benefit was reduced from 280 somoni in 2010 to 188.5 somoni, after adjusting for inflation. The real value of the allocated amount in 2010 (280 somoni) after adjusting for inflation is worth 416 somoni and the revised amount of social benefit (350 somoni) in 2017 is less than allocated in 2010, after adjusting of inflation. Other factors that have association with reductions in viral load included parental participation in trainings and duration of ART: 69.8 per cent of children whose parents participated in training had viral load less than 1,000 copies/ml compared with 30.2 per cent of children whose parents did not participate in a training. The median viral load was lower (300 copies/ml) for children who had been on ART for over a year than for children on ART for less than a year (500 copies/ml).

The finding suggests that social benefits have an impact on treatment outcomes as well as the duration on treatment and parental knowledge of ART adherence. It is important to note that the described factors are interlinked. The findings show that over half of the respondents are depending on remittance and salaries, which makes them economically vulnerable. The economic vulnerability may affect the food intake in families and eventually affect the health condition of the child as ARV therapy requires adequate care including nutrition care. Key recommendation:

- Continue providing social benefit. The study shows that social benefit is having a positive impact on the children health. Children on ARV therapy and receiving social benefit have supressed viral load than other children in the study.
- The current research did not study the situation of children of 17 and 18 years, however, there was request for parents to increase the age limit of the provision of the social benefit up to 18 years old. This is the age when children start stepping into early adulthood and it is quite important to analyse their situation and understand their needs.
- Adjustment for inflation is needed to keep the purchasing power of the social benefit. The study showed that the purchasing power of the social benefit reduced over time with the increase of inflation and there is a need for a policy in place to state how this could be adjusted periodically.
- Review the delivery mode of the social benefit to debit cards. The current prevailing method in cash from bank is not completely transparent as the minimum amount is reported given 200 somoni, when it is supposed to be 350 somoni and at the same time it is not convenient for the parents as they have to travel several time and sometime long distances just to find out if they can collect the benefit.
- Increase the knowledge of parents on HIV/AIDS, treatment adherence, nutrition, etc. The study revealed that there is strong relationship between the parents' knowledge and the viral load. Parents who attended a training had their child viral load suppressed. Educating parents can further improve the health of the child.
- It is quite important to provide mental and psychosocial support to children and adolescence as well as increase their knowledge about HIV, adherence, stigma, marriage etc. This could be done through summer camps with engagement of parents, doctors, social workers so that they can provide psychosocial support for the child or adolescent.
- The study revealed that 31 per cent of the children are underweight, however, it was not possible, within the current study, to thoroughly assess the nutrition status of HIV infected children as the level of measurement at which the data was collected limited it. It is recommended to study the micronutrient deficiency of the children living with HIV using integrated approached – patients' history, physical examination, anthropometrics (which provide information on body muscle mass and fat reserves), and laboratory studies. This approached would allow to capture the effect of social benefit support on children's nutrition condition.
- Prevention of stigma and discrimination at all structural level is needed.
 Parents have a fear of stigma and discrimination. They find it difficult keeping the intake of ARV tablets confidential. They also find it difficult to overnight in the house of their extended families. As they fear that families, friends, neighbours will know, and their family will be isolated.

 Gender awareness campaign and training is needed. The study revealed that gender stereotypes persist as the responded believe that the family life is more important for girls than for boys, the carrier growth is more important for boys than for girls, and girls are more likely to face life difficulties than boys. This type of perception could possibly lead to demotivation to continue ARV therapy and lack of virologic suppression.

LIST OF ANNEXES

Annex 1. The result of chi²

	Ch				
Variable	Yes (n	No (n=117)		χ2	
	Ν	%	Ν	%	
Viral Load Level <1000 copies/ml					v2 (1) = 0 04**
VL <1000 copies/ml	228	80.3	56	19.2	$\chi^{2}(1) = 8.24$
VL >1001 copies/ml	103	68.2	48	31.9	
Over a year on ART					
Over a year	337	84.0	64	16.0	χ2 (1) =
Less than a year	11	18.0	50	82.0	124.1***
***p>0.001; **p>0.01; *p>0.05					

