Improving Quality of Life and Support to Children Living with HIV in Tajikistan
This report documents an intervention by UNICEF, the Ministry of Health and Social Protection and the NGO Guli Surkh in Tajikistan to improve the quality of life of children living with HIV in the country by introducing a multi-disciplinary support team and a peer support system. The intervention took place between December 2013 and May 2015 in the 10 local government areas that had the highest number of children registered as living with HIV.

The need for the project arose from the current state of the healthcare system in Tajikistan. Since 2012, there has been a significant increase in the number of children in the country registered as living with HIV. However, a 2013 WHO evaluation found that 38.3 per cent of registered children were not receiving antiretroviral therapy. Therefore, a need was identified to improve the coverage of children with ARV, and to ensure that their families had access to social services and benefits.

As part of the project a multidisciplinary mobile team was formed, which included a social worker, a psychologist, a lawyer and three doctors: a paediatrician, an infectious diseases specialist, and a tuberculosis specialist. The doctors examined children for co-infections, reviewed the assistance they were receiving, and provided mentoring support to healthcare professionals. At the same time, the team provided psychological support and assistance with understanding the social assistance the families were entitled to, as well as the legal rights of children and their families, particularly in the context of parental divorce. Another key element of the project was the establishment of peer support groups, facilitated by parent activists, that were able to guide newly-diagnosed families through the process of accepting the diagnosis.

By the end of the project, antiretroviral coverage of children living with HIV had increased by 80 per cent compared to when the project began. The project proved the benefit of cooperation between Government and civil society in the fight against HIV, increased the number of children and parents committed to antiretroviral therapy, and ensured that families could receive psychological, social and legal support. The model of working with parents to promote their children's adherence to antiretroviral therapy may be recommended to the Ministry of Health and Social Protection (MoHSP) for further scale-up throughout the country, especially to remote areas.
Ever since the HIV/AIDS epidemic began in Tajikistan in 1991, the country has been taking active steps to combat the disease and prevent its spread. The epidemic began among injecting drug users and primarily affected the male population, taking the form of a concentrated epidemic. In recent years, the injecting route of transmission has been gradually declining in real terms and proportionately (Figure 1) while the prevalence of sexual transmission has increased, thereby leading to greater prevalence of HIV among women (Figure 2).

**Figure 1.** Number of new HIV cases registered among males, by transmission route (heterosexual and injecting): 2000-2012

- Male (injecting)
- Male (sexual)
In recent years, several steps have been taken to mitigate the impact of HIV on children in Tajikistan. To reduce cases of vertical HIV transmission, the Prevention of Mother to Child Transmission of HIV Programme (PMTCT Programme) was launched in the country in 2008. This has been very successful: of 488 children born to mothers living with HIV enrolled in PMTCT activities between 2008 and 2014 only five (1.2 per cent) were diagnosed with HIV. All of these children are registered with healthcare facilities and receiving antiretroviral therapy.

A second step was a Government Order issued in 2011 that set out the clinical symptoms that should lead to HIV testing (following WHO recommendations). This led to a sharp increase in the number of HIV cases registered. While in 2006-2011, the total number of children diagnosed with HIV was 140, between 2012 and 2015 a total of 496 children were found to be living with the virus. In 2015, a total of 140 new cases were registered among children (Figure 3). Of these children registered with HIV, 39.4 per cent were girls and 60.6 per cent boys. Further research would be required to identify the reason for this disparity.

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Figure 2. Number of new HIV cases registered among females, by transmission route (heterosexual and injecting): 2000-2012

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The cause of more than half (55.3 per cent) of all newly identified HIV cases is unknown (Fig. 4). Experts suggest that these cases may result from nosocomial HIV transmission.

**Figure 3.** New HIV cases among children identified, by time period (Source: Republican AIDS Centre)

**Figure 4.** Children living with HIV by route of transmission and by year (Source: Republican AIDS Centre)

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As children depend on the decisions and actions of their parents and/or caregivers, any measures to support children living with HIV need to engage with their caregivers. However, the parents may be reluctant to seek assistance from healthcare facilities and social support institutions, particularly if they believe that the infection was nosocomial. Meanwhile, other children do not receive medical care and social assistance because their parents / caregivers are not aware of the need to receive ART and the availability of services. Lack of awareness or mistrust of ART can prevent the early initiation of treatment and subsequent compliance with an antiretroviral therapy regimen, and hence lead to deterioration of the children's clinical conditions and shorter life expectancy. Delays to and irregularity of ARV drug usage can also lead to new resistant strains of the virus appearing, thus weakening the likelihood of the virus being controlled.² Given all these factors, according to a WHO assessment conducted in 2013 in Tajikistan, 114 HIV-infected children were still not receiving ART and required healthcare services. Therefore, a need was identified to improve ART coverage of children, as well as their access to other kinds of support, including psychological and material assistance. 

One important area of service provision to persons living with HIV and AIDS is timely diagnosis and treatment of other diseases that they are particularly susceptible and vulnerable to. Of these, the most widespread is tuberculosis. Therefore, under Tajikistan's clinical protocol all persons living with HIV should be tested for tuberculosis. In total, in Tajikistan 831 patients are co-infected with HIV and tuberculosis. This is 13.1 per cent of the total number of persons living with HIV. Figure 5 shows the number of children diagnosed with both HIV and tuberculosis. Children with HIV infection are particularly susceptible to tuberculosis and are more likely to develop multi-drug resistance. This is particularly problematic in rural areas, where access to tuberculosis specialists is limited.

² Psychological aid to peer support groups. Guidelines to psychological support and counseling for parents and caregivers of children living with HIV. Rossinskiy, Y.A. MoH RT, UNAIDS, UNICEF. Dushanbe, 2014, p.167.

Figure 5. Cases of tuberculosis detected among children living with HIV in Tajikistan, by year (Data provided by the National Tuberculosis Centre)
The project was intended to actively engage with parents and caregivers of children living with HIV and to ensure their commitment to ART initiation and adherence to it through:

a) Providing parents / caregivers with information about the antiretroviral programme in the country, the importance of early initiation of ART, prevention of opportunistic infections and the additional social assistance that is available to children and their families;

b) Establishing a network and peer support groups of parents and caregivers of children living with HIV to mitigate self-stigmatization and self-discrimination;

c) Facilitating better attendance of HIV positive children and their caregivers at healthcare facilities providing services friendly to children living with HIV.
The following flow diagram outlines the structure of the project:

**Outcomes:**
- Increased access to medical consultation
- Increased access to TB testing and treatment
- Empowered parents: positive living
- Increased parents' awareness on ART / HIV
- Established peer-to-peer support mechanism with parent activists
- Increased ART coverage and adherence
- Improved management of opportunistic infections (TB)
- Enhanced support: legal, social, economic, psychological, medical, and family

**Intermediate results:**
- Increased access to medical consultation
- Increased access to TB testing and treatment
- Empowered parents: positive living
- Increased parents' awareness on ART / HIV
- Established peer-to-peer support mechanism with parent activists

**Strategies:**
- Active community outreach (group sessions, individual counseling, consultations)
- Multi-disciplinary team to offer full package of services (social worker, psychologist, pediatrician, infectious disease specialist, TB specialist, lawyer)
- Support to networking of parents
- Partnership between MoHSP, Guli Surkh (CSO), and UNICEF

Outcomes:

Intermediate results:

Strategies:

Impact:

Improved quality of life of CLWH
Phase one of the intervention to improve the quality of life of children living with HIV in Tajikistan began in December 2013. The intervention was intended to provide support to children and their families through a multi-disciplinary team of healthcare and other specialists.

On 22 September 2014, a Memorandum of Understanding (MoU) was signed between UNICEF, the MoHSP and the NGO Guli Surkh to implement this project. The MoU was needed to formalize the tripartite cooperation and to emphasize government ownership of the project and, in order to institutionalize the service delivery model as well as to ensure sustainability. The MoU described the project objectives and specified the responsibilities of each of the parties, including assignment of specialists. The agreement also included the nomination of focal points and development of a monitoring mechanism by the Ministry. The agreement meant that the service delivery model developed for the project could be potentially integrated into the public health system in Tajikistan. This agreement is an example of good practice of cooperation between the Government and civil society to improve health outcomes.

A multidisciplinary team implemented project activities. It was comprised of the following professionals:

- A social worker (hired by Guli Surkh)
- A psychologist (hired by Guli Surkh)
- A paediatrician (who worked for the Republican AIDS Centre)
- A doctor specialising in infectious diseases (on the staff of the Dushanbe City Infectious Diseases Hospital, which has a department for treatment of patients living with HIV)
- A doctor specialising in tuberculosis (the HIV and AIDS specialist from the Republican Tuberculosis Centre – this team member was added when the MoU was signed with the Government)
- A lawyer (hired by Guli Surkh)
The paediatrician and infectious diseases specialist were given the tasks of assessing the health status of children living with HIV, identifying co-infections and developing individual ART schemes for every child. The tuberculosis specialist examined the children for symptoms of tuberculosis. If necessary, children were referred for additional testing. In addition to the medical examinations, the tuberculosis specialist also provided mentoring support for local medical professionals on HIV and tuberculosis.

The non-medical professionals also had key roles in the team. The psychologist was tasked with helping the parents to overcome their negative feelings and to encourage them to ensure their children received antiretroviral treatment. The social worker informed the families about the particular social support that is available in Tajikistan for families living with HIV. The lawyer supported mothers whose husbands had abandoned them, largely because of the discovery of HIV, to ensure they understood their rights to housing, alimony and other forms of support. The team travelled to the target districts and stayed for three days at each of the local AIDS Centres to examine children living with HIV and provide counselling to their parents.

The first meetings with the parents were very emotional. The team faced aggression, anger, pain and a sense of injustice towards the children, particularly among those parents who were not themselves living with HIV. A wall of mistrust and alienation had to be overcome between the parents and the specialists who came to help them.

In total 509 children were covered by the project. Of these, 257 were examined by and received counselling from the multidisciplinary team. It had initially been intended to cover 235 children, but by the time the team started its work many new cases of HIV among children had been registered. The other children received services following referrals by social workers in the pilot districts. Only a third of the children were in the first or second stage of HIV infection. The others were in stages three or four. This highlights the urgency of the need for treatment.

The doctors in the team took anthropometric measurements of the children, checked whether their weights and heights matched the standard, evaluated their development and overall condition taking into account the treatment they had received, analysed the prescribed treatment scheme and provided psychological support to parents and children that focused on accepting the HIV status and adherence to the therapy regimen.

At the medical check-ups it was discovered that several children had suffered side effects from antiretroviral treatment they had already received. Of these, 15 (35 per cent) had had allergic reactions, 17 (40 per cent) had gastro-intestinal side effects, 5 (11.9 per cent) had reactions in their nervous systems and 5 others (11.9 per cent) developed anaemia. Their treatment schemes were adjusted accordingly. All the test results and specialists' recommendations were recorded in the children's medical histories.
The project was particularly successful at identifying children living with HIV who had also contracted tuberculosis. As can be seen in Figure 5 (above, on page XX) in the first year of the project the number of registered cases of HIV / tuberculosis co-infection in children increased by almost 250 per cent compared to the previous year. In total, the tuberculosis specialist examined 257 children. More than half of the children did not have BCG scars, indicating that they had not been vaccinated against tuberculosis. Those suspected in the examination of having tuberculosis were referred for X-rays, sputum tests and tuberculin sensitivity tests. As a result of the additional testing, active tuberculosis was diagnosed in 47 children. To date, all the children have received treatment and are receiving follow-up care at the Tuberculosis Centre. Guli Surkh has reached an agreement with the National Tuberculosis Centre whereby the latter provides free services not only to children living with HIV, but also to adults.

### Table 1. Number of tuberculosis cases among children living with HIV identified under the project

<table>
<thead>
<tr>
<th>Covered areas</th>
<th>Total number of children living with HIV examined</th>
<th>Number of children with suspected tuberculosis</th>
<th>Number of confirmed tuberculosis cases among children living with HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dushanbe</td>
<td>65</td>
<td>27</td>
<td>21</td>
</tr>
<tr>
<td>Districts of Republican Subordination</td>
<td>90</td>
<td>35</td>
<td>14</td>
</tr>
<tr>
<td>Khatlon Oblast</td>
<td>49</td>
<td>20</td>
<td>9</td>
</tr>
<tr>
<td>Sughd Oblast</td>
<td>53</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>257</td>
<td>91</td>
<td>47</td>
</tr>
</tbody>
</table>

Psychological counselling had a vital role to play in the team's efforts. The fact that their child has contracted HIV is a source of major stress for parents and other family members. Shame and fear that others (even relatives) may find out about their child’s HIV status made them withdraw into themselves. Intensive psychological counselling was needed to bring the parents back from a state of self-stigmatization and self-isolation.

In order to provide the families with the support they need, Yuriy Rossinskiy, an international expert on psychotherapy and HIV, facilitated two workshops. One was a five-day technical workshop with 25 frontline healthcare professionals, which was focussed on how to provide counselling to parents and children. The other was a three-day training event for parents who wanted to facilitate peer support groups. The participating adults varied: some had contracted the virus,
while others had not but their children were living with HIV; still others were adults living with HIV who were not yet parents but wanted to be. Though training this mixed group was challenging at first, the positive thinking and energy of the participants who were living with HIV helped the other parents come to terms with their own family circumstances, and by the end of the training period all the participants had reached an understanding as one group. Several of the trainees went on to work as peer support volunteers with AIDS centres in their areas.

In our analysis of project implementation, we identified four particular components that led to the success of the project as a whole: co-operation between state and civil society; the multidisciplinary team; the psychological counselling, and the establishment of parental peer support groups. These components will be discussed in the next section of the report.

“...The workshop on psychological support changed my outlook on life and my attitude towards my child. Previously, I had been sick all the time, would often lose consciousness and felt utterly discouraged. I have now regained my faith and hope for the future!”

(From interview with parent activist)
The establishment of the multidisciplinary team was made possible by the agreement between the Ministry and the NGO to work together. This meant that the various specialists, who usually work in completely separate structures, were able to work together. The fact that a government body is involved means that the activities can continue after the project has ended. Government ownership means the Ministry and other stakeholders have taken the project results more seriously. The dissemination workshop involved the Deputy Minister responsible for HIV and AIDS. At the workshop lessons learned, future replication of good practice, and the need for continued partnership were discussed.

In addition to their specific roles as individual specialists, the six members of the team worked together to provide information about HIV; explaining what the virus is and how it affects a child's body, and drawing attention to the fact that people can live with HIV for many years while pursuing a productive and fulfilling life. The team also tried to make the parents aware of the importance of ensuring the wellbeing of their children, the role of adequate nutrition and proper care for children living with HIV, and the importance of early initiation of antiretroviral therapy and adherence to it.

Psychological counselling had a vital role to play in the team's efforts. The fact that their child has contracted HIV is a source of major stress for parents and other family members. Shame and fear that others (even relatives) may find out about their child's HIV status made them withdraw into themselves. Intensive psychological counselling was needed to bring the parents back from a state of self-stigmatization and self-isolation. This proved to be a complex task even for the multidisciplinary team. Parents would react in different ways: some would relent...
and agree to cooperate but others proved very hard to convince that refusing help could ultimately lead to their children's deaths. The team had to hold several meetings with each group to break down the wall of misconception and ensure they were heard. During the meetings it was revealed that, because of their poor awareness, lack of knowledge and fear of HIV and AIDS, many of the parents believed that an HIV diagnosis was tantamount to a death sentence for their children.

"... my son would often get sick. When I leaned about my son's HIV status at the hospital I asked the nurse about the disease. She said that once a person gets infected with HIV it develops into AIDS after a month and then the person dies. I was very scared for my child...”
(From interviews with parents)

Over the course of group and individual interviews, parents gradually opened up and started talking about their fears, the problems they faced with relatives and community members, disclosure of HIV status to their children, and cases of stigmatization and discrimination. They also asked how their children's health could be improved and how to explain to them why they have to take pills all the time. Parent activists proved a great help in situations like this. With their intrinsic understanding of the problem, they are well informed about HIV infection and ART therapy, and are open to dialogue. They can demonstrate the effectiveness of ART from their own experience, and explain how the child's condition will improve, what helps them keep to the drug regimen and how they deal with their children's questions about the need to take the drugs. Today, some of them help AIDS Centre staff work with parents of children living with HIV in communities. In some cases parent activists deliver drugs to women living in villages who agree to give the medicines to their children while concealing the fact from their relatives.

"For me taking pills and giving them to my children is a big problem since I don't have a house of my own and live with my step-brother. Every time I answer my relatives' questions I have to make up reasons why I'm giving pills to my children. This is why it is very hard to keep going”
(From interviews with parents of children living with HIV)
Another factor leading to project success, particularly in rural areas, was the establishment of peer support groups. Parents living in self-isolation had no idea that there were other people with similar problems around them. Coming to a meeting for the first time they were amazed to realize they were not alone and that there were people with whom they could discuss their problems and who could give them advice when needed. They also found out that they could receive medical advise without fear of disclosure.

Guli Surkh helped establish a warm and friendly common space where parents of children living with HIV feel at ease, talk to one another, share their achievements and build a sense of community.

"... after meeting the other parents I calmed down... I used to be very upset about my daughter's illness. When I came to the meeting I saw many other parents whose children were in an even worse state than my daughter. I thought: 'Thank God we are not alone and my child looks fine compared with the others': that put my mind at ease..."

(From interviews with parents of children living with HIV)

Initially, the parents were concerned about their children's fate: whether they would be able to marry and have children. On meeting the team, being provided with information about living with HIV and being informed that their children had a chance of having healthy children of their own, their fears were allayed and they started making plans for the future.
As discussed at the project dissemination workshop, the first step forward is to institutionalize and integrate the good practices documented to facilitate wider coverage as well as enhanced sustainability. The following gaps will have to be addressed in order to prepare the ground for full scale up.

One of the key challenges is to improve services for children living with HIV outside Dushanbe. The capital accounts for the plurality of children living with HIV covered by the project: 177 (34.7 per cent of the total). This is likely to be partly because the services available in the city are stronger. There are two Centres for Control and Prevention of HIV and AIDS in the city (the national and the city Centre). In recent years more progress has been made in Dushanbe than elsewhere at ensuring that healthcare professionals are accepting of persons living with HIV; and therefore their access to health services has improved. In addition non-governmental organizations are active in the city providing psychological and social support. In rural areas, by contrast, ensuring adherence to therapy is difficult because of low literacy and public awareness and the lack of specialists. UNICEF will work with partners to investigate how support within the healthcare system and through civil society and community level activities can be improved.

The limited number of practicing counselling psychologists in Tajikistan is a real problem, which makes meeting the great needs of project beneficiaries for psychological assistance very challenging. All members of the team provided psychological support, but at first it was not easy to overcome aggression and deep desperation, as demonstrated by the parents during workshops. Even after overcoming their own emotional turmoil, parents of children living with HIV need constant support from medical professionals and psychologists to start actively helping their own children to comply with ART and then to help other parents in the same situation. The project team successfully created a group of parent activists who actively took part in the multidisciplinary team's work and made a significant contribution to strengthening the commitment of the parents to their children's ART. Therefore, investing in human resources development to provide psychosocial care services as well as empowering parents and their network will continue to be a priority.
Some of the children living with HIV are adolescents who have already begun to ask about the pills and their health. This raises another problem that requires solutions today: the issue of divulging the child’s status. To make this as painless as possible for the children, a lot of work is needed from both healthcare professionals and civil society organizations.

The discovery that children have contracted the HIV virus disproportionately affects female members of the family, and particularly mothers. Because of prevailing gender norms, some women were even divorced by their husbands after their children's HIV status was revealed. The project sought to address this issue by providing access to services, including social, legal, and psychological assistance, and by establishing a peer support mechanism. However, the challenge of how to build more commitment from men to support their families at the most difficult times remains a challenge that requires changes in broader social norms around HIV and AIDS, and gender.
CONCLUSION

The approach used in this project gave tangible results. Cooperation between the Ministry of Health and Social Protection and civil society organizations once again shows its effectiveness to combat HIV. Psychosocial support for parents and caretakers was particularly instrumental in making them open to dialogue. Multidisciplinary approach facilitated the improved uptake of the comprehensive services by families living with HIV positive children. Peer-to-peer support mechanism helped parents and caretakers change their attitude positively toward improving quality of life of children.

The project increased the number of children and parents committed to ART, and all of them received psychological, social and legal support. Parents have realised that all is not lost for their children, and that they have a future.

The project only covered the pilot areas with the highest number of children living with HIV. Based on its example, the model can be recommended to the Ministry of Health and Social Protection for scaling up throughout the country.