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### **SECTION 1. PROJECT INFORMATION**

<i><u>Project Title</u></i>	Increasing access to basic services for children with intellectual disabilities in Kyrgyzstan through empowerment of parents and parents' groups
<i><u>Project location</u></i>	Bishkek city, Talas region and Bokonbaevo village, Issyk-Kul
<i><u>Reporting period</u></i>	1 January 2011 – 31 December 2012
<i><u>Implementing Partners</u></i>	<b>HealthProm</b> Kelechek HP ARDI Nurbala Shoola-Kol
<i><u>Project Funder</u></i>	ICCO
<i><u>UK Project Manager</u></i>	Tanya Buynovskaya
<i><u>KG Project Coordinator</u></i>	Azat Israilov

### **SECTION 2. SUMMARY REPORT**

#### **a) An analysis of the implementation of the action plan, including explanatory notes in the event of changes**

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The project progressed well during all stages of its lifetime and all outcomes were achieved. Together with our Kyrgyz partners we achieved even more than we had planned and succeeded in extending the benefits of the project to more children and parents than originally planned.

During Year 1 and Year 2 we successfully completed all project activities as per the action plan agreed, with some minor adjustments and modifications which didn't have any negative impact in the overall outcomes of the project. We discussed all proposed changes or expected delays with the ICCO office in advance, and always asked for their prior approval and confirmation before making any changes.

In Section 3 we have included a detailed description and analysis of all project activities in each of the three project results.

#### **b) Summary of main project achievements**

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The main achievement of the project is a significant increase in number of children with disabilities (including intellectual) and their parents in three project locations who have received access to improved community-based support services. In total, **2,088 children with disabilities (at least**

**60% of them with intellectual disabilities**) have directly benefited from the project, some of the most significant positive changes to the lives of these children and their families are:

- Children with intellectual and physical disabilities in three regions (Talas region, Bishkek City and Bokonbaevo village of Issyk-Kul district) have received access to improved community-based educational, health and social services. We achieved this by further adapting and developing our model of support for disabled children and their families with a focus on early childhood intervention and activation of local parents. 10 family support centres have been established and further strengthened as local centres of expertise and examples of good practice in providing family support and educational services. We are planning to expand this model in all seven regions of Kyrgyzstan and are currently expecting a response from UK's Big Lottery Fund about funding for this work.
- The project has built local networks and our partners' ability to mobilize local communities and relatives of disabled children to become active in three targeted regions. It is such a network of active parents and community members that will insure the sustainability of established family support centres and the on-going fight for the rights of disabled children and for the improvement of services for these children and their families.
- Children with disabilities and their families have become more visible in their communities and now regularly participate in various inclusive activities and events.

### **Result 1. To improve access to basic educational, health and social services for children with intellectual and other disabilities.**

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During the two years of the project we provided educational, health and social services to **2,088 children with disabilities** in three project locations. This number includes:

- **192** children (with 80% having intellectual disabilities) who regularly attended (or are visited at home) **10 family support/day centres (FSC)** – 8 in Talas region, and one each in Bishkek city and Bokonbaevo village;
- **260** children with severe and multiple intellectual disabilities living in state care in two internats/residential homes in Belovodsky and Pokrovka villages. They attended annual summer camps, received anti-epilepsy medication Depakin, attended a newly opened day centre in Pokrovsky internat and received massage from Uplift volunteers.
- **689** children with disabilities were medically assessed by teams of doctors from Bishkek and Switzerland (586 by NCMCP + 75 by dentists + 28 by Switzerland).
- **947<sup>1</sup>** children involved in regular social and inclusive events such as the campaign "Driving against indifference!"

The main focus of the project was on intellectual disabilities, with at least 60% of all children covered by the project having intellectual disabilities.

#### **Main achievements:**

- The established ten family and child support centres (FCS centres) not only provide access to education and day care facilities, but also serve as local hubs for families of children with disabilities, that empower parents, build up their skills and capacity, and increase their confidence in their children and in themselves. During the project these FCS centres provided consultations, information and advice to **317 local parents** on such issues as child disability, child development, local services for disabled children, social benefits entitlement, domestic violence and many other topics. The project also provided paid employment to 19 people, including 13 parents of disabled children.
- During the project we helped open **2 new family support/day centres** – "Aiar Bala" on the premises of Pokrovsky internat in 2011 and "Nur Bala" in Talas town in 2012. The project also contributed to empowering parents of children with autism in Bishkek who opened their own

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<sup>1</sup> We have clarified this figure and have included only those children that were included into activities along with many other children with no disabilities

day centre for children with autism in autumn 2012. With the help from Kelechek HP they established a new NGO Hand in Hand, which is now registered with 60 members and is the first of its kind in Kyrgyzstan.

- The project has successfully built the capacity of **ARDI day centre** in Bishkek– they received large premises (ground floor in a 2-storey building) from the Kyrgyzstan government through the Ministry of Social Development in October 2011. It is again the first such case in the country when the government provides free premises for an NGO to run a day centre for disabled children. This allowed them to expand their work from 8 children to 25 children.
- To improve access of disabled children to healthcare services in remote areas of the country we organized two planned visits of medical teams from Bishkek to Talas and Ton regions, which were postponed from 2011 to 2012 due to the presidential elections in November 2011 and severe winter conditions. These visits took place in April 2012 (Talas region) and June 2012 (Ton district), when 9 doctors from the National Centre for Mother and Child Protection (NCMCP) in Bishkek conducted a series of medical examinations and check-ups of **586** children with disabilities in 24 locations in these two regions. During both medical visits the parents received practical advice about required medical care in medical establishments and at home, needed treatment and medicines, many received referrals to local medical services or to Bishkek hospitals, either for hospitalization or for full medical examination. All parents stated that these visits were of a huge help to them as many could not afford to travel to the capital and if they could, then they often had to wait a long time to get an appointment at a hospital or NCMCP.

A relative of Jamal Syrgakova who has an intellectual disability, said: *"Jamal has hypertension and frequent seizures. She was treated as recommended for the last 10 years. Now she has received a new prescription from the doctors who treated very well my sister; the doctors also examined my daughter who was born with umbilical entwining and as a result suffers from adverse effects. We were referred to a specialist. We would like to see the doctors more often."*

A mother of Ulan Anarbekov (15) with epilepsy: *"We have been unable to get an appointment with Dr Babajanov before. I'm glad that this visit gave me an opportunity to this doctor and he recommended to have an EEG in 8 months and prescribed necessary medications with vitamins. We are very grateful for the doctors' visit."*

- In addition to the above outcome, we also organized two additional medical visits to Talas region – one by the Kairos private dental clinic in Bishkek in June 2012; and one by two physiotherapists from Switzerland in October 2012. Dental team examined and provided basic dental medical care to 75 children with disabilities and Swiss physiotherapists examined 28 children with cerebral palsy and provided practical advice for parents, staff and heads of FCSCs.
- Another significant achievement of the project is the fact that **41** children with disabilities (19 in 2011 and 22 in 2012) of those regularly attending FCSCs successfully started school during the time of the project – some went to special needs schools and the majority – to mainstream state schools!

## **Result 2. To create a network of parents' NGOs on a regional level to promote the rights of children with disabilities and their parents**

During two years of the project we significantly strengthened the already existing network of parent-led groups/day care centres in Talas region, which now comprises 10 centres that meet regularly for networking meetings, training sessions and regional forums. The members of this network are very supportive of each other, always ready to help other members and find regular meetings and communications (in person, by telephone and e-mail) very useful and encouraging. This network is facilitated by Nur Bala, which also functions as a regional resource and support

centre for the network members in the region. This network successfully organized two Talas regional forums– one on child disability issues in January 2011 and the other - on the project outcomes in November 2012. These forums were attended by more than **200 participants each** representing parent-led and other local NGOs, regional state administration, local authorities, social, medical and educational government agencies, child protection department, businesses, regional Muslim administration. These forums increased the visibility of issues, parents, and their NGOs in the region and as a result 2 of the FCSCs – Aktilek and Tan Nuru – received support and funding from the local authorities starting from 2013.

Main achievements:

- In March 2011 partners organized a successful **first international conference on children with intellectual disabilities**, with more than 150 participants from 14 countries. This conference was jointly funded by ICCO and the Big Lottery Fund with a focus on intellectual disabilities, which was influenced by the ICCO-funded project. A national network of day centres formed at this international conference resulted in ICCO funding a **network platform for NGOs** working on child disability issues. Later this platform transformed into a national network Zhanyryk, with local project partners being the active members of this network. Establishment of the **Central Asian Network on Autism (CAAN)** was also announced at this conference, which unites various autism NGOs from all Central Asian countries.
- Through regular training and workshops the project raised skills and knowledge of **414** parents, staff of local parents-led NGOs, and day centres, social workers and health care professionals in Bishkek, Talas region and Bokonbaevo village. We organized 18 trainings and seminars, 4 week-long organizational consultations for all Talas Family Support centres and 5 study visits to Bishkek, Bokonbaevo, Jety-Oguz and Macedonia.
- During the project we recruited at least **99 volunteers**, both parents and young people (mostly students), who helped with various activities to all 10 project partners.
- We strengthened fundraising capacity of all implementing partners through training, fundraising strategy, consultations and direct support to centre's staff. These fundraising efforts resulted in partners submitting **20 new project** proposals with seven of them being successfully funded with total amount of 68,888 euro directly and indirectly affecting the ICCO-funded project.
- The project built the training **capacity** of the Association of Parents of Disabled Children and Nur Bala. ARDI staffs, who are parents themselves, can now provide high quality training on such topics as child development, running a day centre, project development and self-help groups. Nur Bala can provide a wide range of consultations to parent-led NGOs and day centres, including on such topics as child development, capacity building and fundraising.
- During the time of the project, implementing partners organized and participated in at least **3 advocacy nationwide campaigns**. One of the campaigns was on autism. All of them were organized on a national level where partners from at least 4 regions of Kyrgyzstan got involved in organizing the same actions in their respective regions.

**Result 3. Increase the level of inclusion of children with intellectual disabilities into wider society through changing attitude to positive amongst key stakeholders.**

The project successfully increased the visibility of children with intellectual disabilities and their family and ensured that there were more opportunities for social inclusion of these children in Kyrgyzstan. More children, who would have previously been isolated in their houses, now actively participate in various public events and activities and are slowly accepted as members of their local community. At least **947** children were involved in regular social and inclusive events such as the Driving Against Indifference Campaign, concerts, celebrations and joint activities.

Main achievements:

- The project received extensive coverage in local and national newspapers, online, on radio and TV. There were at least **87 appearances in mass media** (mostly internet – 59

cases) related to the activities within ICCO-funded project. 8 newsletters on the project were sent out to over 130 subscribers.

- Publication and distribution of **2400 booklets, 300 posters, 1000 directories on disability** (with database of Talas organizations) and **120 Talas research copies** helped our Talas project NGOs increase awareness, gain trust and strengthen their relationship with local agencies and government officials.
- During 2011-2012 we also administered the only and largest disability informational network **ARDI Tarmak** with nearly 130 subscribers sending our and/or forwarding other information about grant opportunities, competitions/contests, study visits and scholarships and disability.
- Implementing partners organized and participated in **21 meetings** with national, regional and local officials - 9 round tables, over 10 important regional and local government meetings and 2 regional forums in Talas.
- At least **753 participants** participated in national and local **advocacy campaigns** organized during the time of the project. The project also funded a first **inclusive event for children with autism** at the day care centre of the Hand in Hand NGO of parents of children with autism.
- ARDI day centre received large premises from the Kyrgyzstan government through the Ministry of Social Development. Within the first year of receiving these premises they showed such positive outcomes that the Ministry of Social Development showed their interest in rolling out this approach to other day centres in other regions.
- **2 day centres** Aktilek-Akdoobo and Tan-Nuru have been promised funding from their local authorities for 2013 and onwards (meaning NGOs will be fully funded by the government).
- The Pokrovskij internat's director was temporarily suspended from his post as a result of pressure by Kelechek HP and colleagues from Uplift and My Family & Society because of systematic violations of children's rights to descent services (unfortunately, at least 5 young children with disabilities had died during 2011-2012). This was despite the fact that the project attracted financial and material support and even involved the director to the study trip to Macedonia to learn from their experience on internats.
- The ICCO-funded project has played an important role to help open **the first day centre Aiar Bala within the state residential institution** (orphanage) for children with disabilities in the Pokrovka village in June 2011. It is now successfully working and even has become one of the more advanced centres among other Talas FCSCs, who were established some time ago. This centre was among only three FCSCs which received certificates from ARDI on successfully completing their child development training.

All the above achievements and activities helped us raise awareness and understanding of issues faced by children with intellectual disability and their rights, recruit new volunteers and supporters, and promote the project and the work of its partners. All the PR activities and advocacy campaigns also aimed to bring positive changes in the attitude to children with disabilities among the general public and make these children more visible in the Kyrgyz society. After each event we informally spoke to some participating children and their parents to find out their views and feelings, and all agreed that they really enjoyed these events, made new friends and felt a part of their community.

As part of the project our volunteer made a short film about the project, which you can find in the report annexes.

### **c. New opportunities and threats in the external environment**

During the project we identified the following new opportunities for all partners:

- All partners have jointly developed a new partnership project to expand the model of community-based rehabilitation and support services for children with disabilities and their families to the rest of the country. The Second Stage Proposal for a new three-year project

was submitted to the UK's Big Lottery Fund in January 2012 and we are currently waiting for their decision. If successful, HealthProm will work in partnership with Kelechek HP, ICCO, Uplift, ARDI and Nur Bala as well with other NGOs in new four regions on the development of national network of Family Support centres providing direct help and support to young children with disabilities in all seven regions of the country.

- the Ministry of Social Development is now very supportive of HealthProm's work and is interested in further supporting local centres as well as in possible collaboration with HealthProm and Kelechek HP in developing and piloting new models of community-based support for children with disabilities in local communities and in state residential homes for disabled children, starting from the Pokrovsky and Belovodsky internats.
- Kelechek HP, ARDI and Nur Bala have successfully built their capacity and have become NGOs that are now well known and respected throughout the country. They were successful in raising funds from local government, other local and international donors and from the local community. This allows them to work independently from HealthProm and successfully develop and run their activities and new projects without involvement from HealthProm.
- There is a need for developing early years' services in the country, together with ARDI centre. If successful, these services could then be rolled out throughout the country with the help of the Ministry of Social Development

and threats:

- Quick turnover of key staff in the government, particularly in the Ministry of Social Development, which makes it difficult in getting and sustaining a long-term support to our projects from the government.
- High turnover among staff in local day centres due to low pay.
- Instability in funding such work for all partners.
- Partners relying solely on external funding which may be difficult to access to or decrease.

#### **d. New developments in the organization**

The project has had a significant impact on all project partners and activities:

*HealthProm UK* has submitted a new project proposal to expand the work on child disability throughout the country to the UK's Big Lottery Fund and is now waiting for its decision. In 2011 we developed HealthProm's Central Asian Strategy and are currently in the process of developing a separate country strategy for Kyrgyzstan, which should be ready by May 2013. HealthProm has also developed a new project targeting migrant women from Kyrgyzstan who now live in Moscow in order to prevent institutionalization of young children born to these women and who are at risk of abandonment by their mothers.

*Kelechek HP* became one of the first NGOs in the country to focus on children with intellectual disabilities thanks to ICCO-funded project. Kelechek HP has developed new partnership project with Uplift NGO to prevent institutionalization and support children with disabilities who live in state residential homes (internats)

The project helped *ARDI* develop their capacity as child development trainers and both HealthProm and Kelechek regularly involved ARDI staff as local trainers and experts in many training activities both years. Now they feel confident enough to train other parent-led NGOs and child disability NGOs in child development, parent empowerment, day centre development and fundraising. They have also received government's funding for their work at the centre.

In 2011 *Nur Bala* opened a resource centre that now provides extended support to all Talas seven day centres. They also opened their own family and child support centre in Talas town to meet the needs of families with children with intellectual disabilities in town.

#### **e. Gender specific components**

All project activities were directed equally at women and men, however due to the fact that in a family it is usually a mother or grandmother who looks after their disabled child, the majority of our beneficiaries are women. We estimate that at least 75% of all parents that received support from the project are female.

Out of ten family and child support centres, eight are led by women and two – by men. Only 4 project staff members out of 19 are male.

Out of 748 parents interviewed during the study in Talas region, 55.6% were the parents of boys and 44.1%- of girls. The vast majority which is 571 or 76.2% of respondents were mothers.

#### **f. Lessons learnt and recommendations for the future**

During the project we used every opportunity to assess the progress of the project and to evaluate and discuss any lessons learnt after each activity. All local partners submitted regular financial and narrative reports to the Kelechek HP and the joint report was then forwarded to the UK Project Manager at HealthProm. These reports were discussed and evaluated at the HP Project Group and Steering group meetings.

As part of the process of preparing final project report we have discussed key learning points from this project and the recommendations for the future:

#### **Key learning points:**

##### **1. It is important to invest in building capacity of local partners and stakeholders from the very beginning**

From the very start of the project we invested time and resources in building capacity of each local partner, with a particular focus on fundraising and networking. We also invested both time and money into building individual capacity of project staff and parents, and it proved to be extremely successful and beneficial for the projects' outcomes – e.g. most partners could successfully raise funds for the continuation of their work, they are well respected in the community and their staff are now invited by other groups and rehabilitation centres to share their knowledge and expertise.

##### **2. It is important to listen to parents and address their needs while planning and implementing project activities.**

We should have some flexibility in our work so we can modify our activities according to the needs of beneficiaries. We regularly talked to parents and project partners to learn their views and modified our activities and plans if needed.

##### **3. The sustainability of local work and local project depends greatly on strong parent involvement and effective parent- leaders.**

Some negative experience of the Bokonbaevo day centre's showed that parents are one of the main factors for sustainability. Good day centres exist around strong and active parents and we should consider this when working on new community based projects.

##### **4. The importance of replicating good models and examples of good work in other regions.**

E.g. Nur Bala has become a role-model of effective working with various organizations (not just project partners) and we should learn from this and use their experience when rolling out such resource centres to other regions of the country.

##### **5. Importance of involving volunteers.**

It is not difficult to recruit volunteers in any location (even in rural areas), providing that there is right recruitment, training and understanding provided for potential volunteers, especially for young people.

#### **Other learning points:**

- value of partnerships with government and with local NGOs;
- value of nurturing contacts with the press;
- value of nurturing existing partnership between partner organizations;
- if a group has a strong and active leader, it doesn't mean that they also have active parents /members locally.

**Key recommendations:**

- NGO leaders should be able to see the benefits of parents' involvement and empowerment and be able to understand and see that active parents are not threat to their leadership;
- Involvement of parents should be included and specified almost in every activity related to day centres;
- Any training should also include local parents as participants and/or at least one training should be conducted directly for parents;
- It would be more beneficial for the project if instead of study visits to other regions/countries we would in future invite relevant professionals to Kyrgyzstan (such as from Kishty, Tajikistan, or from Kazakhstan);
- Capacity-building trainings in rural areas should focus more on practical training on parent empowerment and child development as well as include transparency and accountability elements in some of the training;
- If possible we should consider local Kyrgyz trainers for involving in running any training and workshops, as there are now necessary and relevant existing resources and capacities available in Kyrgyzstan;
- Home visits and outreach work should be explored more as the way to empower parents and develop children that cannot attend a centre for various reasons;
- Income-generation activities should be included in the project and necessary funds allocated (not necessarily large);
- Reporting format and timing should be changed, perhaps produced together with partners to make it an easy and enjoyable task from which they can clearly see their progress (and compare against others).