

**Report on the study visit to the UK**  
of the Kyrgyz in-country project manager

within the HealthProm project "Supporting young disabled children and their families in KR"

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Dates of visit: 1 – 5 February 2010

**Brief overview**

During one week study visit I visited 6 organizations that work on disability issues in the UK (5 of them in London).

The visit was very useful and fruitful in terms of understanding and seeing what multidisciplinary approach is and how it works, receiving first hand information how service providers work (incl. parental NGO, day-care centres, other NGOs), what other campaigns can be conducted to attract publicity and possibly politicians' attention. Two day-care centres I visited (Phoenix and Mosaic) are fully government-funded and all services are free of charge to parents but Mosaic is considering to introduce a small fee (in Kyrgyzstan many families cannot afford expensive services but they do not really value free services.) Lots of very useful information has been provided by the Phoenix centre which are ready instruments to be used by our ministries (the Social provision agency and the healthcare ministry). These materials will definitely be translated over this year (hopefully) and used by our partners and will also be presented to the relevant ministries and concerned organizations in the country. Visiting the Ups and Downs organization of parents of disabled children was important as they were willing to visit Kyrgyzstan and share their experience and skills with parents and similar organizations here. If it happens this might be one of the first international exchange visits between parental organizations in Kyrgyzstan.

If a minister's visit organized to the UK, above or similar organizations should be visited (and only one day-care centre such as Phoenix centre which has everything) and perhaps the minister should also have the opportunity to learn how the UK legislation is implemented.

Date	Activity	Follow-up
1 February 2010 (Monday)	Where: HealthProm office (104-108 Grafton Rd, London NW5 4BA) Who: Tanya Buynovskaya, the programmes and partnerships manager Staff meeting with Tanya Buynovskaya re: - latest project developments and news - programme for the week - job appraisal, agreement review, project activities for 2nd year, HP project plans for 3 year - training needs for project manager and partners, training for maternity hospital staff in June 2010 (by Jonathan and Mark), - public awareness (seminars for medical establishments – college and maternity staff) - look for opportunities of ARDI "coaching" of the Belovodskoe internat - evaluation of the project - plans for the conference (budget, venue, dates, partnerships, sponsors...)	SKYPE number  Training in KG (project management, evaluation, etc.)  Continue public awareness  Prepare volunteers among parents  Prepare for June training (establish contacts, find out more info, questionnaires)

	- publications	Prepare to the conference
2 February 2010	<p>Morning Where: RNID office (Royal National Institute of Deaf, 19-23 Featherstone Street, London EC1Y 8SL) Who: Robert Burley, public affairs manager, and Agnes Hctor, campaigns manager</p> <p>The RNID office is located in 4 (or 5) storey building where are there about 50 people on each floor. I was greeted and welcomed by Robert and Agnes who both mostly work in PR. I briefly introduced them to the HP project in KG and gave them some informational materials.</p> <p>Some brief notes of what RNID rep's said:</p> <ul style="list-style-type: none"> <li>- they establish contacts with potential key people in the government (agencies) which may become influential people in the future (one of their contacts in a ministry became on the key people in the government)</li> <li>- one of their successful approaches to working with their target group was replicated all over the country; at the moment they are working on making government (NHS) provide up-to-date hearing aids and services to people and children with hearing disabilities (which is happening)</li> </ul> <p>campaigns:</p> <ul style="list-style-type: none"> <li>- one of the ways - increasing public awareness through "where they are" approach (e.g. which means going to places like Discos, night clubs where they meet young people and share about dangers of loud music to their hearing ability),</li> <li>- supermarkets (usually 2 people: deaf person + volunteer wearing RNID T-shirts and tins for donations + handing out info), seeing businesses (our clients it's beneficial to your business),</li> <li>- visual peaceful campaigns (e.g. a group of people gathering in front of the parliament and signing songs before the New Year – the main aim is to attract media and publicity)</li> <li>- peaceful demonstrations (recent one was for high university fees) = meetings with local mass media = meetings with local administration</li> <li>- an annual reception for MPs (they have a contact in parliament who helps to invite other MPs): for 2 hours, prepare informational pack (very simple, accessible info), they take photos with MPs, invite local mass media</li> <li>- publish press-releases in local mass media (where MPs come from) and send them back to MPs with other info on their activities (making links between MPs and RNID activities so that they</li> </ul>	<p>They promised to send links to cost-effectiveness materials (in the US)</p> <p>Establish and work with a key people in the ministries</p> <p>Peaceful campaigns can be replicated (especial those visual ones)</p>

	<p>feel that they are a part of the activities)  - keep close contacts with their members</p> <p>funding:  - they run day-care centres and employment services which are funded by the government (this is still not seen as a priority for the government)  - RNID has a fundraising team  - RNID is a membership organization and has 38 000 members  - Average membership fee is about 25 GBP (which can vary depending on income of their member)  - in 2008 they received 35 mln GBP (8 mln GBP from businesses, 12 mln GBP from donations)  - they have established links and contacts with certain businesses which donate regularly (UK law supports that)  - evaluation, reporting and transparency are key to successful fundraising</p> <p>Disabled children:  - when a disabled child is born (s)he gets registered with local GP who then sends to professionals, local social services (who often visit the child at home – this is usually in London)  - a local authorities provides necessary funding for services (which are free)  - a disabled child is then seen by a group of professionals who provide a statement (что-то типа диагноза) which describes child's needs and refer to appropriate services in the area  - all necessary technical aid is provided free of charge and paid by the local authorities</p> <p>RNID where possible employs anticipative approach; it is also a member of the Disability Coalition Charities which is large force in the UK.</p>	
	<p>Afternoon  Where: the British Library  Meeting Jonathan Watkins, HP consultant  We discussed project training in June 2010 for medical staff in Bishkek and Bokonbaevo.</p>	<p>List of participants with their qualifications  Questionnaire  venues</p>
3 February	<p>Morning  Where: Mosaic centre, Kentish Town Health Centre (2 Bartholomew Road, Camden, London NW5 2A)  Who: Amanda Fernando, manager</p>	

I was accompanied by Candice Sly, HP project administrator.  
Brief introduction to HP project in Kyrgyzstan + some informational materials.

UK law says: any child regardless of his (her) disability must get education starting from 5 years. Parents can chose where their child could go. There are mainly 3 options: mainstream schools, schools with special classes (may vary), special schools (for those with severe disability).

Mosaic is an integrative centre with multidisciplinary approach located in the state-of-the art building (sort of policlinic in our country) where it occupies part of the building. It is not run by parents and a government funded centre.

It provides services right from the time when a disabled child is born (or even before when a mother knows that her child has a disability and she is referred to Mosaic) until this child is seen off to school. It employs 40 people most of whom (30) work on a part-time basis.

Disabled children:

- Mosaic has all professionals available to diagnose and work with any child
  - multidisciplinary approach – how it works: a child is referred to the centre (they can have 2-3 meetings each week), 3-4 professionals + parent(s) and a child gather in a special room to observe a child and talk to a parent for 2-3 hours. In some cases a diagnosis is already known (confirmed)
  - a Mosaic key worker is appointed who will be responsible for helping parents to receive what they are entitled to (like benefits, better housing, aids, breaks) and to meet child's needs (therapy, rehabilitation, day-care services and etc.)
  - parent(s) regularly visit the centre for observation, progress check and problems discussion;
- Mosaic will also open a day-care centre where children can attend every day

Funding

- Mosaic is fully funded by the local authorities; all services are free of charge
- Mosaic pays for carers so that a family can have a break (when they leave their child to a temporarily carer); it also pays for play-centres (or day-care centres)
- Mosaic works with 6 other organizations (NGOs) which provide other services Mosaic cannot do, like home visits, youth involvement, joint plays and outings, and etc.)
- government and local authorities are interested to work with them as keeping a child in a boarding institution will cost 150 000 GBP per year

	<p>- they are discussing to introduce small fees  Mosaic recently started a parent's forum to make parents more active.  Parents meet up 6 times a year (also funded by Mosaic but this will be cut down in 2010)  Parents and young disabled people were also involved in employment panel that interviewed potential staff. Mosaic also informs the parents of services budget for the coming year and consults how this money should be spent (in terms of services).  Mosaic plans to start a young people's forum.</p>	
	<p>Afternoon  Where: CountinYou, Ealing parent partnership service (63 Mattock Lane, London W13 9LA)  Who: Alex Webber, coordinator  Intro to HP project, info materials.</p> <p>ContinYou provides services to parents of disabled children.  Their work is based on the code of practice (procedures of providing services, professionals, parents, other organizations...) They have a Parents' forum (meetings, focus-groups, trainings); parents' views delivered to the local authorities. CountinYou represent parents interests before authorities, connect them with other useful organizations and services... They work in collaboration with others (they provide educational services, others – rehabilitation).  They organized a forum of local disability organizations to share news, ideas, projects (so as to avoid doing the same things in the area). They get funding from the local authorities and other projects.</p> <p>Among their activities are:</p> <ul style="list-style-type: none"> <li>- they conduct research (their clients) and send the official the results – which leads to changing policies</li> <li>- facilitate communication with authorities and local organizations and groups</li> <li>- it is critical to collect any data (on their activities), monitor the progress and report back to the authorities so that the officials feel that work is being done and there are results</li> <li>- advertise in the local mass media about their activities which attracts clients</li> <li>- publish service leaflets for new parents which explain what to do in certain situations</li> <li>- volunteers contact with businesses, government agencies and other organizations as well as work with their clients</li> <li>- support groups (for parents)</li> <li>- local authorities show their contacts in their directories or letters</li> </ul>	<p>Should some links to useful info</p> <p>ARDI - Organize a forum of local disability NGOs to share experience and news?</p> <p>Collect data, monitor and report to the authorities – is important</p>

	<p>- public awareness: visual presence in medical, social and educational establishments (posters)  - regular reporting to the local authorities.</p>	
	<p>16.30  Where: Bromley Early Support, Phoenix Children's Resource Centre (40 Masons Hill, Bromley, BR2 9JG)  Who: Sally Harrison</p> <p>The Resource Centre (RC) is a government-funded centre, located in a large 2-storey building with everything in it for providing multidisciplinary services to families of disabled children (from consulting and support to day-care services for children). They work from pregnancy (when a diagnosis of a child is known) to preschool children. All needed professionals are available at the RC who usually work there but some are invited from other places (for diagnosis and observation of the progress). All other visiting professionals are not extra paid as it is a part of their job (and they were explained that it is for development of children). RC has several classes, a sensory room, a pool, a playground, all necessary equipment and even an artificial horse (for hippotherapy) . All RC's doors are usually locked. A coordinator gathers a multidisciplinary team (medical and social professionals, psychologist and others) 2-3 times a week for an assessment of a disabled child with parents present: diagnose, assess needs, support to the family, fill in a family support plan (which is copied to all professional present at a meeting). This plan is then implemented and parents know what to do and where to go next.</p>	<p>Sally gave some informational materials (for parents and children support: like family planning file, brochures on various disabilities and etc.) which will be translated this year and possibly presented to the Agency on social provision and the Ministry of Healthcare.</p> <p>Equipment for children shouldn't be expensive as most of it can be done locally from local materials.</p>
4 February	<p>Morning  Where: EveryChild (4 Bath Place, Rivington Street, London EC2A 3DR)  Who: Nicola Piggot, coordinator of CA projects  Accompanied by Tanya Buynovskaya, PPM</p> <p>They currently closed the office in Kyrgyzstan but will review in 1 year. EveryChild has a similar project in Azerbaijan which is being implemented by partners in 3 areas: policy-gatekeeping, DC in 2 institutions (in capital and outside), parental committees.</p>	
	<p>Afternoon  HP office.  Discussed the following: evaluation, plans for 2010 and further, HP office in Kyrgyzstan,</p>	

	Tanya's visit to KG.	
	18.30 HealthProm steering committee meeting. I briefly introduced to the latest developments of the project in Kyrgyzstan.	
5 February	<p>Where: Ups and Downs, local NGO of parents of children with down syndrome (Taunton, outside of London) Who: Wendy (head of NGO), Alice, Carol (all parents of children with Down syndrome) Accompanied by Tanya Buynovskaya, PPM Brief intro to HP project in Kyrgyzstan.</p> <p>An established small NGO of parents of disabled children which serve parents in the South-West of UK. Their office is located at Bibic (British Institute for Brain Injured Children). They work with parents and professionals (who work with parents and children). Their office is full of various size photographs of parents and disabled children. They had also recently published A4 photoalbum of their parents and children. And they also:</p> <ul style="list-style-type: none"> <li>- gather information and share it with parents and authorities</li> <li>- protect and lobby their rights and interests</li> <li>- train medical staff (on how to work with parents)</li> <li>- have publications (have a parent - professional photographer)</li> <li>- provide outreach services to parents</li> <li>- provide learning resources for parents and children</li> <li>- provide early support.</li> </ul> <p>At the end we discussed possibilities of working together on joint training for parents and their organizations in Kyrgyzstan this year.</p>	<p>Photoalbum is a great instrument of attracting new parents and changing attitudes (of visitors, volunteers)</p> <p>Plans for a training this year (details to be confirmed)</p>

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16 February 2010