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The BEARR Trust: Supporting vulnerable people in Eastern Europe, Central Asia and the Caucasus



Young staff at the Training Café, Almaty, Kazakhstan (see page 13)

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The BEARR Trust Small Grants Scheme 2019

The BEARR Trust is pleased to announce its Small Grants Scheme for 2019 and invites applications from NGOs, voluntary associations and other non-profit organisations. Full details are given below. The deadline for applications is close of business on **1 February 2019**.

The field to be covered by the Scheme in 2019 is:

Projects dealing with violence against women and girls in Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine and Uzbekistan.

The Trust may wish to support a number of initiatives through the scheme, so proposals for grants of up to £3000 are invited. Awards will be made on a matching basis, and not exceed 50% of the overall cost of a project.

Applicants must present costings in pounds Sterling, but grants may be paid in Sterling, US Dollars or Euros as best suits the recipient (at the exchange rate prevailing on the date of transfer). Recipients will bear the cost of any conversion into local currency. Projects should normally be completed within six months of receipt of the funds. The BEARR Trust reserves the right to commission independent evaluation of any project funded.

Please download:

SGS Application Outline

SGS Guidelines and Tips

SGS Checklist

What are the aims of the Scheme?

The 2019 Small Grants Scheme is intended to support NGOs, voluntary associations and other non-profit organisations which aim to prevent or deter violence against women and girls, or which support victims of such violence.

In addition, the Scheme aims to encourage these organisations to:

- share experience and learning among NGOs with relevant aims
- disseminate good practice more widely
- facilitate cooperation with and/or coordination among NGOs and other organisations working with relevant groups
- improve awareness of, or engage public institutions in addressing, the relevant issues
- propose other, imaginative ways of achieving the Scheme's aims

Who can apply for the grants?

The scheme is open to applications from NGOs, voluntary associations and other non-profit organisations active in the areas covered by the Small Grants Scheme 2019 (Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine and Uzbekistan).

How to apply

Applicants must fill in the SGS Application Outline in English and send it by email to info@bearr.org by close of business on **1 February 2019**. You should put in the subject line: SGS 2019 – bid – NAME of NGO. If you are unsure about the quality of your English text, please feel free to submit a Russian version (but only as an addition to the original application in English).

The application should be no more than 2 pages. It should include information about your organisation and any partner organisation(s), and the nature and objectives of your project, as detailed in the SGS Application Outline.

Applications of more than 2 pages will not be considered. See SGS Guidelines and Tips to avoid other common mistakes which could make your application not eligible for funding.

Criteria for selecting successful applications

Initial selection of applications will be done according to whether or not the application contains all the information asked for, the extent to which it furthers the aims of The BEARR Trust, and the evidence that good use will be made of the resources available.

The BEARR Trust does not give grants for equipment.

To make sure your application fits all basic requirements please use the SGS Checklist.

What happens after an application is received?

The Trust will acknowledge applications as they are received. If you are submitting your application within the last week of the deadline, please be patient in awaiting this acknowledgement. It might take us up to a week.

A shortlist will be drawn up by a panel of experts for further detailed consideration. The Trust will contact applicants for any further information or clarification it needs. Trustees will review shortlisted proposals and make a final decision at their meeting in April. The Trust will inform applicants whether their proposals have been successful shortly after that, and make the outcome public once all grants have been accepted.

All applicants will therefore receive by email:

- an acknowledgment of receipt of their application;
- notification of whether or not they have been awarded a grant.

Due to the high number of bids we receive we regret that we are not able to give feedback on unsuccessful bids.

The BEARR Trust Small Grants Scheme 2019 is funded by donations from generous individuals, companies and foundations, to whom the Trust extends its thanks.

Questions

Please feel free to ask for clarifications before you submit your application. You can write to Anna Lukanina-Morgan at thebearrtrust@gmail.com in English, Russian or Ukrainian.

Down Syndrome in Tajikistan and Britain: a personal experience

Tahmina Hakimova-Rees

I am from Tajikistan but moved to the UK about 10 years ago with my husband. When I found myself pregnant I was over the moon as I had waited such a long time for this child. During the pregnancy I was asked if I wanted to have diagnostic tests, including for Down Syndrome (DS), to which I said yes of course, do whatever is available. When the results came through I was told I had a very high risk of having a child with Down Syndrome, and that I had the choice to do an amnio test which would give us a more certain diagnosis, but which also carries a 1% risk of miscarriage... We chose not to do the test, as we felt strongly that it wouldn't affect any of our decision-making regarding our child. Some specialists we encountered, like the head of the ultrasound department, were very nice, but I did feel a slight pressure from some medical personnel to have the amnio and then abort the child ... because that is what most women do in this country. But my whole being and values disagreed and protested!

So we progressed with the pregnancy without thinking too much about this issue, although it was always there in the back of my mind. Once our son was born the hospital staff were incredible - they very quickly picked up some of the attributes of Down Syndrome (such as a gap between his toes), which led to additional checks which identified a hole in his heart. Within hours he was in the neonatal ward being given specialist treatment. They explained to us that the chances of Down Syndrome were high, but a definitive test would take several days. So, we waited 7-8 days for the blood test results and for the diagnosis to be confirmed. The doctors who gave us the news spoke to us in a very supportive and professional manner, providing general information about DS and telling us where to go to get more information and help.

In Tajikistan, there are no tests available to confirm a DS diagnosis, as parents told me. Parents are mainly told when some physical feature like eye shape is picked up. The majority of parents with whom I have spoken told me that sad-faced doctors would announce the diagnosis in a very negative way, saying that the child is ill and will not be able to do much in this world – just give him/her away, abandon or leave your child and we will take care of him (meaning they will give him to an orphanage). The doctors say that a child with DS cannot walk, talk or do anything 'useful' in this world and will be a burden to the parents.

In many cases in Tajikistan, unfortunately, mothers-inlaw interfere or fathers themselves give the woman an ultimatum: choose either the 'sick' child or the husband and his family. The father often abandons the mother and child. Gender issues also come into play here, as Tajik women are always blamed for giving birth to a child with DS.

You do not usually see children with DS or any other disability on the streets of Tajikistan. There are many reasons for this, but the most common is sheer embarrassment, so the children are hidden away. For some parents it may be a way of protecting their child.

Another big difference between the two countries is that from the very beginning in the UK we as parents were guided on what to do in terms of our child's health, what diseases children with DS are prone to (heart, thyroid, ears, vision), so there are clear dates and guidance on the medical card when we see specialists on a regular basis to make sure our baby is safe and healthy. Everyone was and is very professional and always speaks positively. We were especially grateful to professionals for the sense of aspiration they had for our son from an early age – conversations focused on what he would be able to achieve, not what he couldn't.



In Tajikistan, there is no such guidance because doctors do not take a positive attitude to children with DS and they lack up-to-date information. Instead, I heard from parents (and my recent blog post) that neurologists prescribe for babies and children with DS unnecessary and harmful medication and stimulants for their brain blood circulation etc. This damages their development and can cause organ failure. And, since parents generally trust doctors, they buy this expensive medicine and give it to their children

In the UK the medical record of the baby with DS has an attachment which tracks the growth and development of the child in relation to what would be expected of a child with DS. In Tajikistan, children with DS are compared with ordinary children and as a result parents are reduced to tears by each comparison. The director of the Association of Parents of Children with DS (SiDA) in Tajikistan told me



after she heard about the medical record in the UK: 'I wish we had such an attachment. When my daughter was growing, every time we went to see the nurse or doctor to measure for example her head, the nurse would tell me how wrong her head measurement was, making me feel so depressed.'

There are many support groups in the UK. The first organisation we turned to was the Down Syndrome Association in London. They were just wonderful in supporting us and listening to our worries and giving us hope and optimism. And guiding us on how to support our child.

Later there were many charities we went to for physiotherapy, occupational therapy, speech and language therapy. All of these services are free under the NHS. I know that parents in the UK are sometimes not happy with the help they get but I always think how lucky my son is to be born and grow up in the UK. I don't take it for granted, since every time I visit my country and meet parents, I see how challenging it is for them to raise a child with DS in Tajikistan. The government does not provide any support or free services.

In Tajikistan a child with DS is not included in society, usually doesn't go to an ordinary nursery school, and as an adult doesn't work. Children are put into special boarding schools or institutions together with other children with

special needs or disabilities. And you can imagine the conditions and attitudes in those institutions.

Another great thing in the UK is the mums' online forum (Mumsnet) where initially I could talk and ask my questions and air my worries, and it was so empowering and encouraging to see that it was not just me going through this.

In Tajikistan DS is still beset by stigma and stereotyping. Or even maybe just lack of awareness. I grew up seeing only one child with DS, who was not necessarily playing with us but was around...and at some point, he just disappeared. Since I had never had any interaction with children with DS and didn't know what to expect, I was in a way

afraid of him. Doctors do not accept such children as equal members of society and don't see any worth in them. They just pity parents and children with DS or any other disability.

Now since my son is 6 and in Year 2 at school, I can share little bit of our experience of inclusion. His school is amazing, and we are very lucky to have Safroz there. They are very inclusive and do their best to support our son, and to make sure he is part of his class and the school. But we heard from other parents of children with special needs in other schools that the law says one thing but it is sometime challenging to get schools to follow the law. Some parents we know have gone through tribunals so that their child can get an Educational Health and Care Plan which adequately meets their child's needs. And to get schools to provide the necessary care and truly include the child in classroom activities and lessons.

In the last two years, I have become an activist on social media for parents of children with DS in Tajikistan. I carry and spread a positive perspective on DS. I became a blogger and established an online platform both on my website and Facebook for the parents of children with DS in Tajikistan. Interestingly enough, these platforms are also engaging parents from other former Soviet countries as well. Today, I am very excited to see that my initiative is growing and the number of parents I interact with is growing. The beauty of this is that parents are supporting each other now, sharing their experiences, and I always share my experiences, which they really appreciate. Not everyone has access to the internet in Tajikistan and via the parent group we are spreading the word to parents from rural areas and those without internet access.

Another charitable organisation has opened in Tajikistan called 'Open Hearts'. They work with children with DS and other special needs and I am one of the founders of this charity. I think they have a great potential to change the lives of people with DS in Tajikistan!

As I tell the parents of children with DS in Tajikistan – together we have power!

Photos: Tahmina Rees



BEARR Trust Annual Conference 2018 'Disability and Inclusion in Eastern Europe and Central Asia'

Report by Biljana Radonic Ker-Lindsay, BEARR Trustee

The BEARR Trust's Annual Conference on 16 November gathered together a diverse group of speakers from NGOs, journalism and academia sharing experiences on disability and inclusion from Armenia, Ukraine, Georgia, Moldova, Uzbekistan and Russia, as well as from the UK. With the active participation of about 50 disability specialists, civil society representatives, students and members of the public in the audience, the conference explored a variety of issues related to disability and inclusion, such as attitudes towards people with disabilities, including widespread stigma; inclusive education and training; leaving care, accommodation and supported living; broader accessibility issues; and employment and employers.

Following a welcome and introduction by The BEARR Trust's new Chairman, Nicola Ramsden, the first session provided a general overview of attitudes towards disability and inclusion from the perspective of parents, NGOs, governments and the general public in Russia and the UK. Anna Portugalova, Director of the NGO Downside Up in Moscow, which focuses on improving the lives of people with Down Syndrome, highlighted challenges caused by

the lack of data regarding the number of people with Down Syndrome in Russia. The issue of unreliable and non-comparable statistics on disabilities was echoed in other sessions as being prevalent in many countries around Europe and globally, which makes it difficult to arrive at evidence-based policies. Many governments, including the Russian, are increasingly relying on data collected and approaches piloted by disabilityfocused NGOs. Anna



raised another important issue – the lack of support for adults with disabilities regarding both care and education – which resonated strongly with speakers from other countries in Eastern Europe and Central Asia (EECA) and the audience from the UK.

In a emotional and deeply personal presentation, **Andrea Bennett**, journalist, former BEARR Trustee and Chair of Trustees at the NGO For Us Too, and mother of a disabled person, emphasised the importance of taking into account the needs of parents, from delivering diagnosis to the time when children transition to adulthood. Andrea talked about the positive changes

in perceptions towards disability since the 1970s in the UK. She also highlighted the many challenges that parents like herself currently face, including dealing with excessive bureaucracy when accessing social services. Significant cuts to welfare, school budgets and other public services over the past several years have decimated the services available to people with disabilities in many parts of the UK.

The second session focused on disabled people leaving

care and the challenges they face to find appropriate and accessible accommodation. **Maia Shishniashvili**, a

founder of the NGO Hand in Hand from Georgia, described her challenging but rewarding journey to develop an effective approach to supported living for disabled adults, so called 'community-based housing'. The advantages of a family-like environment, fostering independence of people with disabilities and their inclusion into local communities, are obvious – particularly in contrast to institutionalised accommodation. An inspiring



video showed how acquiring a profession and finding a job completely changed the life of Tamara, one of the residents with disabilities. However, Maia also pointed

out the financial difficulties her organisation faces in resourcing this approach with the government providing only half of the necessary funding.

Dilmurad Yusupov, a doctoral researcher at the Institute for Development Studies at Sussex University and co-founder of the Uzbek NGO Sharoit Plus, shared the findings of his research on the potential for applying the principles of community-based inclusive development (CBID),



a multi-sectoral, bottom-up approach to social inclusion of disabled people, in the traditional mahalla system in Uzbekistan. Dilmurad raised the issue of the Soviet legacy of institutionalisation built on the functional model of disability based on the person's 'usefulness to society' which is still prevalent in many post-Soviet countries. He also pointed out how the cultural and religious understanding of disability leads to stigma against people with disabilities in Uzbek society, particularly in rural areas.

The session on inclusive education and training featured

Tanya Buynovskaya,

Director of Operations at the UK based charity HealthProm, who talked about one of the charity's flagship projects, the Siberian Initiative for Inclusion. The project is supporting the inclusion of 1200 children with disabilities in the education system in 4 remote regions of Siberia through



partnerships with local civil society, parents and local government. Tanya highlighted positive developments in the regulatory environment in Russia, particularly the 2017 federal law prohibiting discrimination against people with disabilities, and the increase in the number of students with disabilities in inclusive education. However, Tanya

also talked about the many challenges in implementation leading to continued overreliance on institutionalisation and segregated education in the country.

Viorica Cojocaru,

a specialist at the Moldovan NGO CCF (Child, Community, Family) shared her experiences in running a programme for reintegrating a group of children with hearing impairments from a poorly-functioning



residential institution into their biological families, foster/guardian homes and a family type children's home. Viorica described the incredible progress the children achieved by being in a family environment and properly supported at inclusive mainstream and specialist schools equipped with functioning hearing aids, modern assistive technologies, musical instruments and educational materials for rehabilitation. Viorica also highlighted an issue that resonated in some other countries, namely the fact that hearing impediments are not identified early enough through screenings at birth and in early childhood, often due to a lack of specialists, particularly in remote regions.

The final session focused on the employment of persons with disabilities, the role of employers and the importance of digital access. Iryna Los, Director of the Centre for Legal Assistance of the Open Doors NGO in Ukraine, drew several lessons from a project supported by BEARR which her organisation implemented in Nikopol. Good coordination and cooperation among all relevant stakeholders is vital. State employment



and social services, employers, trade unions, educational institutions and also, crucially, disabled people themselves through their support organisations – all need to work closely together to overcome the numerous challenges facing disabled job seekers. Retraining to acquire professional skills that are in demand by employers, development of soft skills and mentoring are also very important as preparation for a successful transition from schooling to employment.

Vardine Grigoryan, a Board Member of the NGO Disability-Inclusive Development in Armenia, shared her own story of searching for and eventually finding a job as a person with a disability. She also revealed the sobering 2018 statistics that only 8% of people with disabilities of working age are employed in Armenia: 92% are jobless or economically inactive. Vardine also pointed to a number of promising state programmes that



could improve the situation, such as workplace adaptation for employees with disabilities, internships for young disabled people and financial support to entrepreneurs with disabilities. Closing on a positive note, Vardine also mentioned how the Armenian government is trying to incentivise employers by providing a range of assistive technologies free of charge and partial payment of the salaries of disabled employees.

In several sessions the participants discussed the implications of the ratification – or lack of it – of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) by different countries. While ratification in itself does not necessarily lead to incorporation into national legislation or effective implementation, the states' obligation to report on implementation focuses the minds and resources of the authorities. Also, the opportunity for

NGOs to provide 'shadow' reporting on implementation is a powerful took for activists to push for improvements.

In her closing remarks, Nicola Ramsden followed the positive note and constructive attitude of speakers in stating that, although many long-standing challenges remain and new challenges emerge in EECA, there are positive signs of progress in de-institutionalisation and growing collaboration between NGOs and other actors, including governments. Nicola also emphasised the need

for increased outreach and spreading of best practice to ensure that disability inclusion gains in prominence and leads to further improvements in the lives of people with disabilities and their families as well as benefits to society at large.

Speakers' presentations can be accessed here.

More photos here and on the back cover.

All photos by Anna Lukanina-Morgan

BEARR's key events in 2019

Moldova Conference, 11-12 April 2019

The BEARR Trust is planning a conference in Moldova in April 2019 in partnership with the Free University of Moldova (ULIM). It will take place in ULIM's building in the centre of Chisinau.

The theme of the conference is 'Migration and Social Change in Eastern Europe'. Its aim is to bring together experts and NGOs working in the field of health and welfare and provide an opportunity for networking, sharing experience and promoting best practice. The conference will focus on Moldova but look more widely, with participants also invited from surrounding countries, either in person or through live-streaming.

The sessions will cover positive aspects of migration, such as remittances, women's empowerment and the launch of small businesses by returning migrants, as well as more negative aspects, mostly flowing from the absence of the 'missing generation'. The event is intended to be very practical, with workshops on such topics as strategy, administration and fund-raising.



The BEARR Trust Annual Lecture, 6 June 2019: 'Russia's Place in the World'

BEARR is delighted to announce that Bridget Kendall will give the 2019 lecture, to be held on 6 June at EBRD.

Bridget Kendall specialised in Soviet and Russian studies after graduating in Modern Languages from Oxford, pursuing postgraduate studies at St Antony's College Oxford and Harvard. She joined the BBC in



1983, serving as Moscow correspondent from 1989 to 1995, Washington correspondent from 1994 and diplomatic correspondent from 1998.

In 2016 she was elected Master of Peterhouse, Cambridge. She continues to broadcast for the BBC as an external contributor. Bridget is also a Patron of BEARR.

The BEARR Trust Annual Conference, 15 November 2019

The conference theme in 2019 will follow that of our 2019 Small Grants Scheme in focusing on Violence against Women and Girls. In many societies this is often an unseen and socially tolerated crime.

We will be inviting speakers from the region and from the UK, and looking at how gender-based violence is viewed in society, how legislation and the authorities deal with it, and how far intervention by NGOs and voluntary groups is raising awareness and changing the situation for the better.

We will include in the topic domestic violence, trafficking, forced marriage, and other forms of abuse of women and girls.

Further details of the above events will be available on the BEARR website and in the monthly Bulletin nearer the time.

If you would like to be on the mailing-list for these events, please contact us at info@bearr.org.

The BEARR Annual Lecture: Shaun Walker 'Putin's Russia and the Ghosts of the Past'

Few visiting Russia for the first time in early May would guess that the now ubiquitous orange and black St George's ribbons at Victory Day only made their first appearance in 2005. For Shaun Walker, who gave this year's BEARR Trust Annual Lecture on 20 September 2018, hosted by the European Bank for Reconstruction and Development, this 'invented tradition' is just one manifestation of the way in which memories of the past are increasingly pressed into the service of the present state.



Shaun Walker first arrived in Moscow in January 2000, just as Vladimir Putin ascended to the presidency. For the past 18 years, he has been a sharp observer of Russian politics and society, first as a freelance journalist, then as a reporter for The Independent, and latterly as The Guardian's Moscow correspondent. His book, The Long Hangover: Putin's New Russia and the Ghosts of the Past draws on assignments across Russia and, most recently the conflict in the Donbas in an 'attempt to make sense' of the Putin years.

Part of this is understanding the state's quest for a unifying 'national idea'. Following the collapse of the Soviet Union, the newly-independent Baltic states could enthusiastically embrace their 'return to Europe'; in Central Asia, appeals to semi-historic national sentiment were more or less successful in cementing new regimes. Russia's challenge was greater given its previous dominance within the USSR and loss of status after the fall.

From before the start of his presidency, Putin saw the restoration of Russia's 'great power' status as a central policy objective, warning in a 1999 article of the risks of the state's 'relegation' to second or third tier status. This meant recovery from the catastrophic economic losses of the 1990s. But from Putin's perspective, it did not just mean that: it also meant the restoration of Russia as a 'hard' power and moral concept.

However, the idea of 'restoration' was not straightforward. There might have been nostalgia among

many for the Soviet Union, but an appeal to a socialist past was hardly likely to be welcomed by business, and a return to a pre-1991 system was neither viable nor desirable. Putin himself summed this up in his famous comment that 'only a person without a heart would not mourn the loss of the Soviet Union – but only a person without a head would want to recreate it'.

In this context, victory in the Great Patriotic War provided a unifying reference point: a source of pride around which the 'nation' could unite, and which the state sought to augment. This marked something of a break with the recent past: in the postwar years, recent experience of loss made remembrance of the War relatively sombre and muted; during and after perestroika, much of the pomp and ceremony that accompanied it disappeared. But since the early 2000s, official commemorations of victory have become larger and more powerful: heavy weaponry returned to the main Moscow parade in 2008, and commemorative symbolism has become more widespread.

But as those with direct experience of the conflict pass, what is the nation actually remembering? In Shaun Walker's analysis, the focus of official memory is increasingly on Russia's role as victor: 'through you,' Putin told veterans in 2002, 'we have become a nation of winners,' with the baton of victory handed down to their descendants. In other words, victory is the contribution of the memory of the War to the 'national idea', more than a broader sense of shared suffering or remembrance.

That memory of victory can be pressed into the service of the present. In the first place, victory in 1945 presents a clear contrast to the 'tragedy' of 1991, and modern-day victories (the 'restoration' of Crimea, for example) can be painted as a continuation of the spirit of '45. But at the same time, the War narrative can serve to obscure alternative narratives of Russia's painful twentieth century history. From the 1980s onwards, movements such as Memorial spearheaded new acknowledgement of historic oppression, but official support for this has been reduced in recent years: even in Magadan, a city built out of the Gulag, official memory of repression is marginal in comparison with the popularisation of wartime victory.

Perhaps this is because the War is seen as a conflict for national survival, in which Russia (or the Soviet Union) faced down an existential external threat. This external threat persisted after 1945 in the form of the United States and the West, and from the state's perspective, this threat remains today (and has intensified since NATO expansion). The specific nature of the enemy may have changed, but the concept of Russia as isolated, threatened and prepared to fight back remains. Every victory first needs an enemy, and there is continuity between the War memory, the postwar Soviet world view and the state's current stance.

'Memories' of the War, and concepts of the enemy finally bring us to the current conflict in Ukraine, particularly in the characterisation of Ukrainian nationalism as 'fascist' (a widely – and very broadly – applied term in communist propaganda). Certainly, some elements in Ukrainian politics deserve the term, but the wartime label was quickly adopted by the Russian media to denote a much larger 'enemy' category. In the Donbas after the declaration of the Donetsk People's Republic, Shaun met Alexander Khodakovsky, a thoughtful military advisor to the DPR junta and who described the imagery of the War as a driving force of Russian nationalist sentiment, as an effective means of identifying those who remained loyal to Kiev as the enemy (Khodakovsky's reflections on where this might all lead seems to have proved too much for the local regime, which later sidelined him).

There is no doubt that the popular memory of the War (the 'cult of the War' as Shaun called it) has been a unifying idea. But will it fade as 'real' memories of the Soviet Union recede? In the medium term, probably not: the scale of the conflict was epic (and of course far more devastating than for the Western Allies), and all families have a connection to it (albeit with a couple of generations of separation). And anyway, Russia is not the only country for which the War acts a central part of national identity: Britain is an obvious example of another victor country with its own war myth.

However, wartime victory does not provide the only narrative. Despite the shadows of Crimea, the Donbas, the Salisbury attempted murders and international sanctions, many in the wider world were perhaps surprised by the sunshine and welcome of Russia's 2018 World Cup. So far, the impact of sanctions in the wake of the Ukraine crisis has not damaged the Putin administration; in fact, Western pressure may have reinforced the perception that Russia stands alone, surrounded by enemies. But perhaps in the long run, winning doesn't have to be a zero-sum game.

The BEARR Trust is grateful as always to EBRD for hosting and supporting this lecture.

Report by Ross Gill, BEARR Trustee Photos by Anna Lukanina-Morgan.



For more photos click here

BEARR gets involved in marathons

Oxford

Nicola Ramsden celebrated taking over the Chairmanship of BEARR by taking part in the Oxford Halfmarathon in October. She trained hard in the French Alps and on the pathways of Harpenden for the 13-mile Oxford run, which went from Broad Street to the University Parks via many iconic

landmarks, including the Radcliffe Camera (location of one or two essay crises in her younger days).

The run raised £4,600, including a bonus from a generous supporter who rewarded Nicola for beating her predicted time! The funds have made a significant contribution towards the cost of BEARR's new website, which is now being designed and built.

This is Nicola's second sponsored event for BEARR, following her triathlon in 2008. What next, Nicola?

Chisanau

Jane Ebel, a BEARR Trustee, has spent the last 10 years working in Moldova with vulnerable children and children with disability, so it was only a matter of time before she combined her enjoyment of running with



her belief that sport and a healthy lifestyle should be accessible to everyone on a regular basis.

In September she ran in the first ever fully inclusive Marathon 4 All, held as an integral part of the annual **Chisinau Marathon** – no small feat in a country where very often, those with disability are kept out of sight.

Jane says, 'The Marathon 4 All was one of the most uplifting and moving tributes to the children and young people themselves and to those Moldovans who spend their lives helping them to realise their potential. Importantly it raised awareness of what inclusion can and should look like, as well as celebrating the fabulous work that so many NGOs and individuals in Moldova, do.'

London

Charlie Walker, also a BEARR Trustee, will be running the **London Marathon** on 28 April in support of BEARR.

This will be his second shot at the Marathon, and he hopes to improve considerably on the donations he raised last time – following a last-minute decision to take part. We hope BEARR's friends and supporters will be generous in sponsoring Charlie. He hopes that the proceeds will be enough to fund an additional project under BEARR's Small Grants Scheme.



Small Grants Scheme 2017 and 2018: project reports

Mental health in Gomel Region, Belarus

Grantee: Chernobyl Children's Project UK, with Supporting Children Together, Gomel, Belarus

Project: Rehabilitation for children and adults after treatment in psychiatric hospitals

We have worked with the children's department of the Psychiatric Hospital in Gomel on and off for almost twenty years. We have provided toys and equipment, delivered training and brought the Head of the Department on educational visits to the UK. But sadly very little seemed to change.

The Children's Department held around 50 children from 3 to 15 years old and was nearly always full. Most children stayed for three weeks and the vast majority of them should not have been in the hospital at all. There is a great stigma in Belarus attached to having spent time in the Psychiatric Hospital, which can live with someone throughout their life.

Then three years ago the arrival of a new Director at the Hospital prompted us to try again. We brought him on a visit to the UK with the Region's Director of Health to look chiefly at community care; brought the Chief Paediatric Psychiatrist on a visit too and began a programme of training in the educational sector for those working with children with autism, to try to keep such children out of the hospital.

The numbers of children staying in the hospital have now halved; a unit has been established for day patients and there is consensus that children with autism or ADHD should not generally be admitted to hospital.

In autumn 2017 we began a project funded by The BEARR Trust to work with children with mental health problems, aimed at keeping them out of the hospital. We employed the Regional Chief Paediatric Psychiatrist as a psychotherapist, and she worked with several psychologists, also employed half time through the grant,



to support children and their families. Most of the work took place in the Regional Early Intervention Centre.

They worked with 60 children, sometimes individually or with their parents and more often in groups. There were group sessions for parents to discuss the problems their children were experiencing. Parents found great support from each other as well as from the professionals.



There was an individual session of body psychotherapy for each child once a week, and art therapy sessions which children undertook with their parents.

Families were visited at home if they requested this, or if a child was in crisis, so the whole family could be involved in the discussions. Siblings were included in the work as much as possible, for their own benefit and also for the understanding and support they could bring to the child experiencing problems.

Training was given to the staff of the project and many others working in this field, by a Child Psychiatrist and a Clinical Nurse Specialist from the UK.

At the end of the grant period, Chernobyl Children's Project was able to continue the work on a slightly smaller scale for a further six months.

We know that the parents greatly appreciated the work carried out through this project and believe that it made a great difference to their children and to the relationships within their families.

In November I met four of the mothers who took part in the project and the three psychologists who have been working on it. The mothers could not have been more enthusiastic about the support they received.

One mum has an 8 year old called Sasha who was thought to be hyperactive, had no friends and school could not cope with him. He has calmed down considerably and is making friendships, and people are saying they hardly recognise him as the same child.

The second mother has a 12 year old who was wetting the bed and suffering from anxiety. The programme has solved his enuresis and massively improved his confidence.

The third mum is guardian to a boy of 12 who has been with her since he was six. They wanted to adopt him but he doesn't want to be adopted and wants to know about

his birth family. He suffers from lack of trust, anxiety and being slightly hyperactive. Being in this project has helped him so much he recently said 'Thank you mother for bringing me to meet people who could give me so much help'.

And the final mother has an 8 year old who is autistic. He is non verbal but bright and is now included in a mainstream school with a tutor. His ability to interact with the world has greatly improved during this last year.

At the beginning of this project a Child Psychiatrist and Clinical Nurse Specialist in ADHD went to Belarus to do some training. One of the psychologists said that she thought she knew a lot as she has worked in this field for many years but what she heard in their training was like a revolution in her brain.

We believe that the professionals involved, both directly and indirectly, in this work have realised how much support can be given in the community to children who would in the past have been referred straight to hospital, and that they will attempt to continue this support whenever possible.

Photos: Elena Kazachenko

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From thought to action; from action to heart

Grantee: Ukrainian Catholic University, Lviv

Project: Overcoming the Stigma of Mental Health Disorders in Ukraine

For the last few years, Ukraine has been ranked as the European country with the highest number of mental disorders among its citizens – almost 1.2 million people in Ukraine (more than 3% of the total population) suffer from various mental health issues. Unfortunately, this figure is growing each year. At the same time, Ukrainians who suffer from such problems usually do not seek assistance from professionals because of the high level of stigmatisation of mental health disorders typical of post-Soviet societies.

Among the factors that stimulate the stigmatisation of people with mental health issues is bias and negative coverage of these problems in the Ukrainian media. They propose 'models' for society's perception of mental disorders and assign features of mental disorders to certain emotional reactions and even to personality traits. As a consequence, people are not able to recognise symptoms of mental disorders and are afraid to ask for psychological help. That is why the UCU Institute of Mental Health initiated a project aimed at reducing the stigmatisation of mental disorders in the Ukrainian media by expanding the evidence-based knowledge of journalists (students and professionals) in the field of mental health.

A key part of the project was a 3-day training session for media professionals entitled 'Issues of mental health in the media.' The training session gave journalists and students an opportunity to receive reliable data on evidence-based mental health problems. The participants familiarised themselves with contemporary views on common mental health problems and discussed with invited specialists the social, ethical and legal aspects of coverage of suicide and aggravations of psychiatric disorders. Special attention

was given to learning non-discriminatory language. They had a special class dedicated to communicating with people suffering from mental health problems or



people under the influence of emotional distress while conducting a live interview or collecting material for an article.

Among the challenges that the trainers met during the session, one of the most common was that participants had many questions about mental health that were not directly connected to the subject of the project. For example, they were interested in practical recommendations on how to provide psychological assistance to people who have suffered because of military action in eastern Ukraine, or they asked the trainers' opinion on health care reform in the sphere of mental health, which was broadly described in the media at that time.

A pleasant supplement for the participants were classes on mindfulness-oriented cognitive behavioural therapy (MOCBT): an approach to addressing the psychological difficulties of people, connecting the concept of awareness with the ideas of cognitive-behavioural psychology. This programme is officially recognised as one of the most effective psychotherapeutic interventions and is recommended by the National Institute for Clinical and Health Excellence (NICE) in the UK. The main goal of MOCBT is to free people from the tendency to respond automatically to thoughts, emotions, and life events. Thus participants gained new skills in stress-management and mental well-being that could directly influence ways of thinking and public attitudes.

Another aim of the project was to expand society's awareness of mental health problems and the influence of the media on stigmatisation. Thus, UCU launched an information campaign. For example, 1,000 leaflets about overcoming stigmatisation of people with mental health problems in the media were published and distributed among the media and NGOs. These leaflets were based on questions asked by the journalists during the training sessions.

Thanks to the implementation of the project 'From Thinking to Action, from Action to Heart: Overcoming the Stigma of Mental Health Disorders,' 122 people developed effective skills of communication and interaction with people with mental health illnesses or mental disabilities. They expanded their awareness of mental health problems, and we believe that they understood their capacity to help Ukrainian society overcome the stigmatisation of mental health issues.

At the end of the project, the local media expanded their cooperation with the UCU Mental Health Institute. Together we initiated a public campaign on overcoming stigmatisation, and involved non-governmental organizations and public educational institutions in the discussions. We believe that the coming years will see a reduction in the stigmatisation of people with mental illnesses in Ukraine.



Photos: Irina Koroletc

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A challenge for caregivers and specialists in Armenia

Grantee: SOS Children's Villages, Yerevan

Project: Children with mental health issues: a challenge for caregivers and specialists

Caregivers and specialists from the Kotayk and Idjevan SOS Children's Villages participated in this 2017 project. The aim was to create a beneficial environment for children with mental and behavioural problems.

SOS Children's Villages is a hub, providing multidimensional assistance to vulnerable children and



their families. One of the organisation's main activities is providing comprehensive care for children without parental care. The Children's Villages are groups of homes in which orphans are raised in a family environment. Their upbringing is supervised by the mother of the family, who is the key person involved with outside professionals in any therapeutic treatment needed.

In this project the training was conducted by high-level professional specialists. The information, methods and materials presented during the training sessions met the initial goal of the project.

The first workshop, which was organised for specialists in the psycho-pedagogical team, was about diagnostic techniques which allow them to make a quick professional diagnosis, in order to reveal the child's level of mental development and behavioural problems.

The second workshop was dedicated to post-traumatic stress disorder and the special characteristics of work with children with such problems.

During the third workshop the participants gained an essential knowledge of psychiatry. The trainer presented materials about the most common psychological diseases, the symptoms, the characteristics and the working methods required for each child with the disorder, with an emphasis on those problems which were common among the children of the SOS Children's Villages.

The specialists noted that the diagnostic techniques gave the participants an opportunity to make a quick and accurate professional diagnosis. For example, in the past the level of mental development was decided by use of a questionnaire. After the training it became possible to analyse the level of a child's mental development through a picture, which is far more interesting for the child.

The SOS mothers of Idjevan and Kotayk SOS Children's Villages participated in a three-day training course on the principles of working with children with mental disorders. Video materials, card methods and games were conducted during the course, which also addressed theoretical questions.

After completing the training the caregivers had a more accurate understanding of what to expect from a child with psychological disorders, how to organise the child's upbringing to reach the best results, and in what direction to develop their skills to enable them to have a profession and employment in the future. The SOS mothers also learned simple exercises to support the child's adaptation in the initial period, that of 'breaking the ice', establishing warm and friendly relations with the child, as well as support for the child's cognitive processes, such as the development of memory, focus, imagination and logic.

One of the SOS mothers who had a child with behavioural problems under her care noted that before she acquired these techniques it was difficult for her to make connections between that child and the others. The other children avoided him and complained about his behaviour. But after the training the SOS mother organised a family game which allowed them to become closer, as well as changing the status of that child in the family, because being the game's host allowed him to acquire



aspects of leadership, which in due course led to a calmer moral and psychological atmosphere in the family. Now, even if a game is played in the family which is difficult for the child, he is involved in organising the 'technical' part of the game, for example dealing the cards, watching over the rules etc.

At the end of the training course the caregivers were given manuals describing these and other exercises.

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The Training Café model for employment

Grantee: Psychological Association NGO, Almaty, Kazakhstan

Project: Establishment of a School of Social Entrepreneurship and Psychosocial Rehabilitation, to train professionals for an expanding network of Training Cafés

The Psychoanalytic Association is an NGO established in 2005 to improve the quality of lives of people with psychosocial and intellectual disabilities; to educate and train mental health professionals to contribute to the welfare of those in their care and to enhance their professional skills; and to advocate for social inclusion of vulnerable population and improve social services.

The NGO opened its first Training Cafe in 2015. The cafe is a social venture for the supportive employment of people with mental disabilities. In Kazakhstan, people are greatly stigmatised and discriminated against because of their psychosocial and intellectual disabilities. Official

statistics state that there are more than 200,000 people with mental disabilities in Kazakhstan. About 18,000 are locked in psychiatric institutions; the rest are at home or hide their disabilities.

The Cafés also spread the idea of the social enterprises employing people with disabilities. In 2018 February a second Training Cafe opened – the Ale Pub, supported by the Trafigura Foundation.

The School has run a variety of programmes on supportive living and employment such as 'Give me back my Legal Capacity'. Several textbooks have been published and distributed: 'How to run a Clubhouse for Mentally Disabled Young People', 'The Social Venture Training Café as an Alternative to a Psychiatric Institution', 'Guidelines for Drug Prevention among Students'. We collaborate with local officials and NGOs to advocate for the rights of people with disabilities all over Kazakhstan and provide them with training courses for professionals and their patients, schoolteachers and their students. Our School also creates a platform to share the Training Cafe model of employment of young people with mental and intellectual disabilities in Central Asia.

According to the Ministry of Labour and Social Protection, only 50,000 of the 626,000 people in Kazakhstan with a disability, mental or physical, are employed. Thus, our society suffers socio-economic losses due to the lack of recognition of people with disabilities, and the high cost of government spending on their treatment and maintenance in institutions and special service centres.

In the BEARR-supported project, the School of SE&PR got together 100 specialists from Kazakhstan and Central Asia to show the participants methods and techniques for opening social enterprises providing supportive employment of people with disabilities. Participants came from 14 big cities in Kazakhstan, and one each from Tajikistan and the Kyrgyz Republic. Since the course we have provided Skype support for participants if they have any questions or ideas that need to be developed and implemented.

Results:

- 100 participants attended the School of Social Entrepreneurship and Psychosocial Rehabilitation.
- They learned to write grant proposals. 50% of the participants sent their first grant proposals to different foundations and stakeholders.
- 1 participant finalised research on 'Deprivation of legal capacity and mental health' and is getting ready to publish it.
- Participants from three cities are working on adapting and testing a new franchising system in public health for a Training Café.
- 60% of the participants conducted 2-day workshops using new methods learned at the School.
- A participant from Taraz is starting a pilot social café with employees who have psychosocial and intellectual disabilities.



 Our organisation's specialists took part in three round tables in Almaty and Astana on Psychosocial Rehabilitation and Employment of People with Disabilities.

We face two huge challenges:

- It is a challenge to motivate professionals to get away from the old model of looking at disability and move to a human rights perspective.
- It is a challenge to open a social enterprise in Kazakhstan due to the lack of a legal framework for social entrepreneurship. Thus, a social enterprise is taxed like a regular business, which creates additional barriers to opening and running socially-oriented businesses.

Photos (here and front cover): Ardak Toleubay

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Baking and sewing skills for young people with special needs

Grantee: Centre for Strategic Initiatives NGO, Khmelnytskyi, Ukraine

Project: 'Good Chances for Good Changes', to teach baking and packaging skills to young people with disabilities

The NGO embarked on this project together with the mini-bakery Husylda, whose Director, Alla Farvashcuk, had previously worked with disabled young people in the NGO Dva krila (Two Wings). The project goal was to help young people in Khmelnytskyi with special needs to find better opportunities for their future careers. In our

beautiful city of more than 260,000 people in western Ukraine, there are 3 special schools for such children: school #8 for children with physical disabilities, school # 32 for children with mental disabilities, and school # 33 for deaf children. In addition, according to Khmelnytskyi Department of Education, there are about 70 children with special needs who are being educated at home. We also wanted to



cooperate in our project activities with other local NGOs who work with young people with special needs.

So, we started classes at the bakery and found that young people loved this project. They liked to be involved in the kind of activity where they could bake tasty buns and cakes and have them for tea after the class.

From September, when the school year started, we also engaged senior schoolchildren (14-16) in the project. Three special schools visited the bakery and wanted to be a part of the project. At this time we also met the management of the Education and Labour School, which provides skills training for senior schoolchildren in various professions. They have classrooms equipped for cooking, sewing, and other professions, enabling disabled young people to work there comfortably. It was decided that we should organise bakery classes for senior schoolchildren with special needs based in this School. The contract was signed and cooperation started.

As the interaction between our NGO and the special schools grew, we began to implement other ideas together. We wanted to be united under the title 'WE ARE SPECIAL' and founded a Facebook group describing our joint activities https://www.facebook.com/groups/814094938988954/

For example, senior schoolchildren from school # 32 decided to decorate paper boxes for the cakes baked at the Education and Labour School. With the help of their teachers, children adorned boxes with little flowers and Christmas trees, for goods to be sold at the Christmas Fair opening in Khmelnytskyi on 1 December.



After the project 'Good Chances for Good Changes' came to an end, 'WE ARE SPECIAL' developed other activities. The Education and Labour School proposed that the senior schoolchildren with special needs be involved in a sewing class. Sewing is a skill that is very popular in our city, and at these classes young people learned to sew Ukrainian flags. This work is not very complicated for disabled young people, and the flags could also be sold at the Christmas Fair together with the baked and other craft goods. Special school # 32 also wanted to have a sewing class. Their idea was to sew simple shopping bags with nice prints, to replace plastic bags for the many Khmelnytskyi people who care about the environment. The Centre for Strategic Initiatives found a local company sponsor which allocated funds for the fabric and thread.

The Centre for Strategic Initiatives received the approval of the Khmelnytskyi Department of Trade to sell the

goods at the Christmas Fair in the city centre. Students from Khmelnytskyi National University (Department of Technology and Design) wanted to help with the goods, and the Young Journalists Press Club was also very helpful in making little plastic clay pigs with wings as Christmas tree decorations. These funny special pigs became the symbol of our project and attracted many Khmelnytskyi citizens and visitors. People donated money via the charity box, and bought baked goods in beautiful boxes, flags and pigs, and other items donated by our partner organisations.



That first winter weekend we collected enough money in our charity box to buy materials to allow us to continue the sewing and baking classes, showing that local people support 'WE ARE SPECIAL'. We have a team now of people from our NGO, the Education and Labour School, and Schools # 32 and 33 who want to develop this project further. We are in contact with other organisations that can support us financially in future.

We have brave dreams of running our own cafeteria and bakery, and our own sewing workshop. This could allow former schoolchildren with special needs and other young disabled people, after finishing their bakery and sewing classes at the Education and Labour School, to work and earn money to meet their needs. We plan to involve a professional psychologist in this project, who will work with families with disabled children. We dream of demonstrating that it is possible for them to have a successful career, even in Ukraine and in hard times. We are grateful to BEARR and all those who believe in us and our project, and of course we give special thanks to all our friends with special needs.

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About the BEARR Trust

Patrons: The Duchess of Abercorn, Vladimir Ashkenazy, Elena Bashkirova Barenboim, Robert Brinkley CMG, Lady Ellen Dahrendorf, Myra Green OBE, Bridget Kendall MBE, Sir Roderic Lyne KBE CMG, Sir Jonathan Miller CBE, Mike Simmonds, Rair Simonyan, Dr Robert van Voren, PhD, FRCPsych (Hon), Sir Andrew Wood GCMG

The BEARR Trust is a British registered charity. It was formed in 1991 to act as a bridge between the welfare and health sectors of Britain and the former Soviet republics. Its mission now is to help children and other vulnerable and disadvantaged groups in Eastern Europe, Central Asia and the Caucasus. We believe the best way to do this is to help small NGOs working in health and social welfare to build knowledge, know-how, skills and contacts including with those doing similar work in the UK. We pursue our aims by:

- supporting organisations committed to reform in the health and social sectors
- facilitating networking and exchange of information
- · encouraging sharing of experience and learning
- helping organisations working in the region to identify potential partners
- providing seed funding to assist selected organisations to launch or extend partnerships.

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The BEARR Trust endeavours to include

as wide a debate and as broad a range of

opinions as possible in the Newsletter to

capture the diversity of NGO activity in the

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Newsletter Editor: Ann Lewis; layout: Leila Carlyle

