



32- 36 Loman Street

Southwark

London SE1 0EE

tel: +44 (0) 20 7922 7849

fax: +44 (0) 20 7922 7706

email: [info@bearr.org](mailto:info@bearr.org)

[www.bearr.org](http://www.bearr.org)

**The BEARR Trust Annual Conference, 18 November 2011**

## **So much, so little: progress and prospects in health, welfare and the role of NGOs**

The topic of this year's conference was chosen to reflect the 20<sup>th</sup> anniversary of the founding of the BEARR Trust, and that of the collapse of the Soviet Union and the centrally planned economic and social welfare system. The idea was to try to assess broadly what had happened over those years in health and social welfare policies in the countries which emerged from the USSR and in the development of the non-governmental and voluntary sectors, both of which were entirely absent in Soviet times. In order to attempt such an assessment BEARR invited speakers from Russia, Ukraine, Georgia and Central Asia – thus covering all the different regions in which BEARR is active – and the three sessions after the opening presentations dealt with three very important fields: families, people with disabilities and the elderly. Our speakers brought personal experience and research findings based on twenty years of data. They spoke eloquently and movingly of how NGOs are able to affect the lives of some of the most vulnerable groups in society, many of whom suffered disproportionately as a result of the long downturn after 1991 in the economies of all these countries, which have only in the last few years regained or exceeded the levels of GDP of 1990.

The conference was opened by BEARR's Chairman, Tony Longrigg. He warmly thanked the three sponsors who helped with some of the costs involved: the Great Britain Russia Society, Age UK, and Ukraine International Airlines; and the organisers and volunteers who made the conference possible.

In the first session, dealing with policy and practice in health and welfare over the past twenty years, [Alastair McAuley](#), University of Essex, talked about the economic challenges which have faced policymakers in the successor states of the USSR. By 2006 the long recession they experienced was over in most of the countries concerned, but the recession of 2008 has affected them as well. Using World Bank criteria for poverty levels (\$5 per person per day for developed states, \$2 for medium developed states, and \$1 for least developed states), he assessed that in 2002 47% of Ukraine's population lived in poverty, whereas in 2007 only 12% lived at this level. The number has since risen again, however. A participant commented that these figures were misleading, since about 90% of the Ukrainian population are excluded from the "big wealth"; he wondered if the gap was still growing or under control. Mr McAuley said it had stopped growing, and a middle class is developing. However, it

**Patrons:** The Duchess of Abercorn, Vladimir Ashkenazy, Elena Bashkistrova Barenboim, Myra Green OBE, Professor Geoffrey Hosking, Sir Roderic Lyne KBE CMG, Sir Jonathan Miller, Anthony Oppenheimer, Rair Simonyan, Sir Andrew Wood GCMG

**Trustees:** Tony Longrigg CMG MA MSC (Chairman), Megan Bick BA (Russian) MA, Robert Brinkley CMG MA, Janet Gunn CMG BA, Daryl Ann Hardman BA (Russian) MA, Her Honour Judge Marcia Levy, Ann Lewis CMG BA, Jo Lucas, Jenny Norton, Nicola Ramsden MA MBA, Robert Scallan MA.

was pointed out that the new middle class is not what is meant by “middle class” in western countries, where it is involved in civic activity, for example.

After 2000, reform of social welfare began. Pension and other privileges in the Soviet system became cash payments (which was not always popular with the recipients). In Central Asia, Uzbekistan and Kazakhstan have begun to reform their pension system, as has Armenia more recently, following World Bank recommendations. In Central Asia general practitioner services are being introduced. However, perceptions are also important: despite increased per capita incomes and a decline in poverty, many people still perceive themselves as worse off than in 1990. This is due to social exclusion, which persists given that the new systems are based on neo-liberal economic ideas rather than cradle to grave welfare. Healthcare reforms have not resulted in more efficient use of resources, and public dissatisfaction is widespread. About 50% of the countries of the region have introduced social insurance systems (payroll tax) while the rest retain the old system. Insurance contributions are supplemented by state budget payments and personal (informal) payments.

There is inequality between regions and between urban and rural areas. A sharp decline in male life expectancy has not yet been reversed by improvements in healthcare, largely because it is due to lifestyle factors (smoking, traffic accidents, and alcohol abuse). In addition, inflation and unemployment have affected outcomes for many people. All the states of the region signed up to the Millennium Development Goals, but few of them will reach their targets by 2015. As for the prospects, much will depend on the economic situation and institutional reforms. In Russia and Ukraine, social policies are not deemed a high priority, while in Kazakhstan, lip service is paid to reform but little is done, and Tadjikistan and Kyrgyzstan are very poor countries.

The second speaker was [Elena Topoleva](#) of the Agency for Social Initiatives (ASI), Moscow. In her overview of the development in the non-governmental sector in Russia she said that of 342,000 NGOs that have been established, only about 17,000 are really active. ASI has been functioning for 17 years. Most NGOs were set up in 1991-2005, with a subsequent slowdown, mainly due to the fall in foreign funding over the past 5-6 years. Some topics have fallen off the agenda. For example, when foreign funding was available, gender issues were prominent, but no Russian funds have filled the gap in that field. Similar trends are apparent in environmental issues.

36% of NGOs are run exclusively by volunteers, but in Russia only 3% of the public volunteer, and 23% of NGOs use no volunteers at all. Only 16% of funding comes from government sources. However, while NGOs identify lack of funding as the main challenge, in reality the largest problem is public indifference and lack of trust in the sector. Research shows that NGO influence and infrastructure are both lower than 15 years ago – again because of the drop in foreign funding. The picture is very varied according to region and sector of activity. Ms Topoleva described different forms of social involvement: at governmental level, there is the Public Chamber, which is controlled by the state but does some good and provides opportunities for issues to be raised with the government. Also at the official level there is the Presidential Council headed by Fedotov. It developed an economic reform strategy for up to 2020, and has set up a working group on public initiatives. The legal framework has also been developed, as has taxation of NGOs.

At another level there is civic activism, which has been growing but is not institutionalised. Two thirds of people surveyed said they take part in informal

activities, but these, such as help during the bush fires in 2010, take place in a parallel universe, and are not coordinated by organisations. 50% say they make donations; however, most donations are to individual needy people rather than to NGOs. Only 1-2% of the public donate to NGOs, but many would like to know more about them and are well-disposed towards them. But they lack knowledge of how to become involved.

Asked about the role of the Public Chamber, Ms Topoleva said that it serves as a bridge between the public and the government. It is also used by the state to raise issues such as environmental issues, for example when the state wanted companies to modernise in this area; and to publicise issues, thus providing a platform for official statements. On the subject of government organised NGOs (GONGOs), she said these can become successful and end up striving for greater independence as a result, and thus beyond state control.

The Russian government has begun to fund the work of socially-oriented NGOs – for example, in 2011 \$30 million will be disbursed. Some of this was spent on updating legislation and the regulative framework, some on professional training and some was given to the regions by competitive tender, in which 53 regions submitted proposals, and 30 received grants. A participant commented that in view of the decline in funding of the NGO sector, maybe social enterprises would be the way forward. Russia has a foundation for social enterprises and provides some grants. NGOs are becoming interested in selling their services. As for charitable giving, there is now legislation to provide for this but NGOs need to explain to people how to donate and claim tax back.

The next session looked at issues affecting families. **Maryna Gutgarts** from Ukraine talked about families with HIV. Ukraine has signed the UN Declaration on HIV/AIDS, but its implementation is patchy. Almost half of those infected with HIV are women, with 6000 new cases among women in 2010, but the state does not do much for the sexual and reproductive health of those concerned. Twelve countries, including Ukraine, are implementing a project to monitor the health of women with HIV. In Ukraine it was found that there was a clear lack of specific action to prevent infection among women. There is also a lack of advice on prevention of infection among women and children, and in schools; and little effort to prevent mother to child infection. There is a need for advice for couples in which one person is infected about pregnancy and childbirth, and some is given by NGOs but this is confined mainly to the cities. Training of medical staff in the care of people with HIV – some doctors and nurses refuse to treat these women – is much needed, and while the international declaration guarantees the right of people with HIV to bear children, in Ukraine health workers often insist on a termination if an HIV positive women becomes pregnant. It is assessed that 70% of HIV positive people encounter discrimination and denial of their right to healthcare. Many also have to pay more for healthcare.

There is a project “Children Plus” designed to help HIV positive children to lead a normal life. It trains teachers working with them and also advises them on disclosure and sexual activity. Many HIV positive children are sent to children’s homes, and society has little interest in them – until celebrity is involved, such as in a visit by Elton John which hit the news channels.

**Charles Buxton** from INTRAC spoke about women in extended families in Central Asia. There, the traditional family structure is under pressure because of the new capitalism, economic pressures and migration, but at the same time there are efforts to resist commercialisation, reassert patriarchy and tradition and revive religion. The Central Asian extended family is really a large joint enterprise. It is crowded, involves

complex money and non-money transactions (loans, living with relatives in the cities etc.), and important but costly ceremonies and rituals. There is a clear hierarchy in the family, and with a nomadic and oral tradition, particularly in Kyrgyzstan, male family members are expected to be able to identify their antecedents going back seven generations.

Many men are working far from home and send money back only sporadically or not at all (e.g. when they have established a new family). Women are also migrating for work reasons. Even when people do send remittances, it does not always reach the wife. So women have set up self-help groups, some of them involving micro-credit or dealing with domestic violence. Gender equality in the western sense is not easy to promote in Central Asia, and even when women are active in quite senior positions it is not accepted that they should, for example, go out to meetings in the evening. Some trends are regressive: there has been a recent doubling of the rate of religious marriages, not registered with civil authorities. When this kind of marriage breaks down there is no protection for the woman, who has to leave her husband's patriarchal home with nothing. Bride kidnapping is re-emerging. The use of contraceptive devices halved between 2000 and 2009. On the other hand, Kyrgyzstan has a 25% quota for women in its parliament – doubtless due to having until October a female Acting President. (Central Asian states have signed up to the Beijing +5 agenda on women's rights, but are unlikely to achieve its goals.)

In the session on disability, [Sergei Liubownikow](#) of Nottingham Trent University analysed three types of NGO in the disability field in Russia. They all engage in advocacy, in the sense of influencing the state elites, as well as advocacy with public opinion, and more or less coincide with the categories described by Elena Topoleva. He called the first group “marionette” organisations, comprising the regional public chambers, for example, and the All-Russian Organisations of the Disabled, Blind, and Deaf. These are government sponsored, and able to call up officials to deal with individual issues as they are collocated with the relevant social services departments. They take part in consultations on new legislation, which allows the state to say that it has consulted civil society. They provide a cushion for public anger and act as a buffer. Another participant thought the term “marionette” unjust, since the organisations concerned have a role in delivering services and monitoring government services. Their style is to solve problems piecemeal.

The second category are professional health and social welfare NGOs which learned from and used to be funded by western partners. They now have strong links with countries like Poland. They engage in activities that the state refuses to provide, such as needle exchange. The advocacy they undertake is informing their constituency of their rights. For these NGOs lack of funds rather than government obstruction is the main challenge. They try to access regional funding rather than federal sources.

The third group comprises grass roots NGOs. These are small with limited reach. They address administrative roadblocks and seek to establish relations with state authorities. The 2006 law on NGOs has helped them somewhat but they still find it difficult to secure foreign funding. They are under some pressure not to engage in advocacy. In response to a question the speaker confirmed that they lack capacity for evidence gathering in their field of activity. Both the second and third groups of NGOs employ mainly people with disabilities, which is not the case in the marionette organisations. A downside is that good people in NGOs tend to be enticed into government jobs.

**Ana Chakhava** from Apra Georgia in Tbilisi, talked about art therapy work with people with mental disabilities. Delightful examples of the [art work](#) and textile handwork produced by people her NGO works with were displayed around the conference room, and a number were bought by participants. The NGO started up in 2005 and has shown work at more than 30 exhibitions. She described the value of art therapy. Apra also comprised a parents' club with 60 members. They join in discussion of mental health reform and treatment, and exchange experience, all of which also helped reduce their sense of isolation. With BEARR's help, they are now working in other regions, and art therapy is to be introduced in all mental health facilities in Georgia.

The final session of the conference focused on the elderly. First, **[Elizaveta Dzhirikova-Ustinova](#)** from Sostradanie (Compassion) in Moscow described the organisation and its long partnership with BEARR. Sostradanie is one of the oldest NGOs in Russia, and works closely with Memorial, the organisation which researches the repression (Stalinist purges). When the two organisations were first working twenty years ago, there were still many survivors of the Gulag still alive. They suffered from ill health, poverty and post-traumatic disorder, and needed help and support. At that time Sostradanie had about 5,000 clients in Moscow and worked with 50 doctors, 50 nurses, and 200 carers. They had psychiatric professionals as well. In the early 90s welfare services were non-existent, and there was no legislation obliging anyone to help people until 1995. The state began by just buying food for elderly people, then started day care centres, and later diabetes and asthma management advice centres. But funding depends on how wealthy the region is, so Moscow can provide a range of services, while poor regions like Smolensk can not. Social services are still thought by many to be a state responsibility and they resent NGOs being active and especially having services contracted out to them.

In 1996 Ms Dzhirikova met a representative of BEARR, who helped set up an exhibition of art work by victims of the Gulag. The following year, she attended a BEARR conference – her first ever visit abroad. In 1999 BEARR sent chiropodists to Moscow to teach local people how to care for elderly people's feet. Then they obtained funding for a project to bring together NGOs and state services, and met with a group of British specialists to learn from their experience. Some of the lessons from UK experience had to be adapted – for example, she saw how ethnic clubs were organised in Britain, but the risk of nationalism in Russia meant that they established "Shared Memory" clubs for former prisoners of war for example, and professionals' clubs for former teachers. These clubs plan activities a year in advance – a very positive experience for elderly people. They also founded Rooms for Care – a scheme in which a student or a woman migrant from Central Asia lives in an elderly person's home in exchange for a certain amount of care. Ms Dzhirikova cited a range of other British experience which had been useful and could be adapted for Russian circumstances. New possibilities include setting up networks such as Age UK in Russia. It is not yet clear what it would focus but one challenge looming is the move in 2012 to a new healthcare system in which some supplementary or optional services will have to be paid for.

**[Galina Poliakova](#)** of Turbota pro Litnikh (Age Concern) in Ukraine described how the World Health Organisation visited Ukraine and informed the authorities that an organisation for the elderly should be set up. They asked Age Concern UK to help. The Ministry for Social Policy was not interested but the Rada (Parliament) was. Age Concern Ukraine was set up in 1999, and now has ten branches. There are no branches in eastern Ukraine, however, as people are reluctant there to become volunteers. Funding came from the UK, Germany, the EC and UN. Funds from the Ukrainian government would have been subject to conditions regarding veterans'



associations which the organisation would find difficult to fulfil, so were not provided, but the Ministry for Social Policy is a partner, for example on developing policy towards vulnerable groups. The organisation has 2,000 volunteers, most of them women. This took time to build up as there was no tradition of volunteering and most people, especially the elderly, assumed that it was the job of the state to provide any services of this kind. Most volunteers are over 55 years of age.

Among the difficulties faced by the elderly in Ukraine are the political changes of the 90s, changes in the economy and society, inability to adapt to a new context, feminisation of older age, inadequate income, and political instability. The main problem for elderly people is financial hardship – 46% receive pensions of 85 Euro a month or less. They survive by virtue of their stoicism from long years of hardship and from their kitchen gardens. Male life expectancy is 57 years and female – 76 years. Depression is very common among older women. Ms Poliakova's presentation showed the results of a number of surveys concerning discrimination against the elderly, and abuse of various kinds experienced by them. A new EU instrument on care homes for the elderly will be studied but will be difficult for Ukraine to comply with, as state-run care homes are huge Soviet edifices. Even so, there are waiting lists for places in them. Summing up, she said the challenges the organisation faces are all connected with the Soviet heritage, mainly the lack of experience of volunteering, lack of experience of NGO activity, and lack of a tradition of charity.

Bringing the conference to a close, BEARR trustee **Nicola Ramsden** drew out some themes of the conference:

- researchers now have not just anecdotal evidence but 20 years of data collected since the fall of the Soviet system to direct their field work;
  - the new middle class is not a pillar of civil society;
  - advocacy (lobbying the state) is not a major role of NGOs in the region
- there has been institutional change in Russia, with the establishment of the Public Chamber with its somewhat nuanced role.

The conference covered a wider range of topics than usually, because of the anniversary theme. This provided for a rich variety of presentations, both in content and style. The picture which emerged was both positive and less so, with evidence that NGO activity in health and social welfare in the region blossomed in the first 15 years after communism, but slowed considerably after western funding became more scarce; however, the NGO sector in its various forms has continued to develop and much has been learned. Now, NGOs work more than before with local authorities, but public awareness and willingness to volunteer are still areas with much scope for expansion.

**The BEARR Trust is grateful to the Great Britain – Russia Society and Age UK for their support for this conference.**

**The conference is also supported by Ukraine International Airlines, leading airline to Ukraine and beyond, including daily connections to Tbilisi, Georgia.**

