



Silenced Lives: Empowering the Disabled in Post-Soviet Karabakh

By Lucy Clements



In 1980 a Western journalist covering the Olympic Games in Moscow dared to inquire of a Soviet Union representative whether the USSR would be participating in the first Paralympic Games in Great Britain later that year. For the outside world, the Soviet representative's automatic retort "There are no invalids in the USSR!" came to reflect the carefully woven blanket of silence and exclusion covering the lives of disabled individuals in the Soviet Union.

Disability rights are a crucial, yet particularly painful issue in the former Soviet bloc, where for generations, individuals with physical and mental ailments were widely stigmatized, separated from the public eye and made virtually invisible through policies of social distancing and exclusion. With no real concept of rehabilitation in the USSR, the disabled were left with little choice or hope. During the collapse of the Soviet Union, many oppressive walls fell but the walls created by oppressive mentalities proved far more difficult to collapse. For the disabled in the post-Soviet bloc, the wall was a wall of silence, built on years of isolation and institutionalisation.

HART was created with the mission of giving a voice to all those trapped behind the walls of oppression. HART's ongoing work with individuals with disabilities at the Lady Cox Rehabilitation Centre in Stepanakert, capital of Nagorno-Karabakh, is a strong voice speaking out for the disabled, crushing the wall of silence.

Alongside the chorus of voices of its supporters, local HART partners at the state-of-the-art Rehabilitation Centre created from an bombed-out, forge new paths towards a more just society built on inclusion, dignity, and respect for the disabled.

Nargono-Karabakh, located in the south-eastern Caucasus, is still recovering after a devastating war with Azerbaijan in the early 1990's. The post-war humanitarian state was particularly serious due to the fact that after the Armenians emerged victors from the conflict and declared Karabakh independent, most major aid organizations including the UN and other large operations refused to provide much-needed humanitarian assistance to the region on the grounds that its independence was not recognised. This left the ordinary Karabakh people in a state of dire need, cut off from any large-scale funding. The most vulnerable groups—children, elderly, and disabled—found themselves at great risk.

The war also left many soldiers and civilians wounded or disabled and lacking even the most basic pain medications. Amputations were being performed without anesthetics. In spite of their efforts to fight for the independence of Karabakh, injured and disfigured soldiers returned home with almost no formal infrastructure to support their recovery and a prevailing Soviet cultural mentality already stacked against the disabled. This discrimination was exacerbated by unfortunate inheritances from the Soviet era: a total absence of a concept of rehabilitation, a traditional lack of government support for disability rights initiatives, and a generally poor level of education among the public and health officials alike about individuals with disabilities.

Over the past twenty years change has come in Karabakh and elsewhere in CIS countries, yet disability rights must be viewed as a fairly recent concept in the post-Soviet vernacular. Rehabilitation and physiotherapy were essentially alien concepts during the Soviet Union. Yet, in fact, very little is actually known about the treatment of individuals with disabilities during the USSR. It can be generally be said, however, that during communism, disabled individuals largely faced a social environment which treated disability as a source of “shame and denial, and a public environment in which the state took on the role of caretaker.” (Phillips, 2009)

Moreover, in line with the Communist mentality, citizens of the USSR were often defined as valuable or invaluable by virtue of their ability to work and actively contribute to the growth of the nation. In fact, as early on as 1918, the Bolsheviks began categorizing so-called “invalids” into two groups: “those who could work or who possessed the potential to work” and those “total invalids” believed to be completely incapable of work (Phillips, 2009). Due to the emphasis on labour capacity as a measure of human worth, the disabled were dealt with through practices of exclusion and isolation from broader society. For decades, the average Soviet citizen had little contact or realization of their society's disabled, who were systematically warehoused in secluded and ill-funded institutions. It is in such places that they were often left to live and die in dismal conditions—their lives unrecorded, their hopes, dreams, and talents lost in the vacuum of an isolated and forgotten existence.

The history of the disabled of course did not begin with the collapse of the Soviet Union, however, these atrocities only gained significant exposure with the opening of borders and the rise of NGO and grassroots activism. Yet, stereotypical perceptions persist surrounding the limits of many disabled individuals in the former Soviet bloc, resulting in lack of participation in employment and educational opportunities. In Armenia especially, this is only confounded by minimal access to transportation and wheel chair accessible buildings in the capital city of Yerevan and almost total lack of access in the regions.

While the exact number of individuals with disabilities living in Karabakh is unknown, in 2009 around 10,000 individuals out of a population of 140,000, were receiving disability payments. This significant proportion of the population is in great need of better rehabilitation and treatment options.

There is, however, a will for change in the Caucasus region. Armenia signed the Convention on the Rights of Person with Disabilities and its Optional Protocol in March 2007 thereby pledging to make education accessible to all, including the disabled. However, according to a 2010 report by the United Nations

Development Group, despite legal provisions granting special protections to the disabled, severe difficulties in enforcing those laws have resulted in the disabled remaining one of the most vulnerable social groups in Armenia. The disabled are at an enormous risk of poverty and illness due to lack of access to education, health, and protection and severe discrimination in the work place. In 2010, 92% of disabled people were unemployed in Armenia.

Moreover, according to Article Seven of the Convention on the Rights of Persons with Disabilities, states are also required to “take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.” However, in Armenia and across other CIS countries, widespread failure to provide suitable treatment for disabled children often exacerbates many treatable afflictions.

HART partner Vardan Tadevosyan now Director of the Lady Cox Rehabilitation Centre in Stepanakert, moved to Karabakh in 1999. Vardan originally became interested in improving the treatment of spinal cord injuries while working with the Red Cross. After the 1988 earthquake in Armenia in which 30,000 people lost their lives, the Red Cross arrived to find that no rehabilitation centre existed at all in Armenia and subsequently opened the first near Yerevan in 1992.

When Vardan transferred to Karabakh in the late 1990's he discovered that, as in Yerevan, there simply was no concept of rehabilitation. Vardan's vision to create a state-of-the-art treatment centre for the physically and mentally disabled became realized when the Lady Cox Rehabilitation Centre opened in 1999, the first of its kind in the region. Prior to the establishment of the centre, war victims and other patients were dying from treatable afflictions such as infections and pressure sores. Although the project originally began as a treatment facility for those wounded in the war, the patients rapidly began to include more children and adults born with physical disabilities whose needs were also generally excluded from the public eye.

Yet Vardan was branching out on his own. The community and government initially offered little support for the endeavor of establishing a centre in Stepanakert and many locals expressed confusion over Vardan's efforts to rehabilitate war veterans and other disabled people, a few suggesting that if he simply gave donated money to the disabled people of Karabakh they would be happy and secure.

For Vardan, the post-Soviet mentality and the lack of a concept of rehabilitation presents the main focus for the advocacy undertaken by the Rehabilitation Centre. Medical and government officials in the region still have little idea of what Vardan's team is trying to accomplish at the centre. Individuals with disabilities were hidden for so long that it is difficult to know how to help them now. Although Armenia has a constitution as well as several legal mechanisms to provide rights to the disabled, monitoring and implementation mechanisms have again been difficult to enforce.

For instance, Vardan describes how a child with a disability is often seen as a shame or a burden on the family. A disabled child, in spite of having one or two parents alive, is often given into care. After the child turns eighteen the future is even more precarious as no formal infrastructure at all exists to help adults with disabilities. The Rehabilitation Centre in Stepanakert is taking active steps to build a new culture of inclusion amongst the youngest generations in Karabakh. The first step is greater integration of children with disabilities with children who are not disabled. At the new Day Care Centre opened in 2008 at the Rehabilitation Centre, children with and without disabilities play side by side, helping to break down the stigma for the next generation.

The Rehabilitation Centre offers an oasis for many disabled who literally have nowhere else to go. Many venture from far and wide to be welcomed at its doors. Every day one patient, twenty-five year old Erik Manucharyan, walks eight miles to come to the Centre. Eric is deaf and dumb and has been visiting the Centre for painting classes for ten years. He now holds the honour of having the largest number of paintings in the

Centre's vast collection. Without the Centre, Erik would face the stark reality of isolation and nonexistent rehabilitation services.

When asked to comment on the future of disability rights in Armenia and Karabakh, Director Vardan remains optimistic yet realistic. He concedes, "Only 5% of what needs to be done for disability rights has been accomplished to date including accessibility of buildings, transportation services, and opportunities for the disabled to participate in the regular life of the community. The general public also needs to become more sensitive and inclusive of the disabled."

This will be a long journey, paved by the work of numerous post-Soviet NGO's as well as the hearts and minds of private individuals. In the meantime, Vardan continues his work with the disabled, encouraging their own empowerment, helping them strive for greater independence, and organizing classes in art, painting, wood carving, pottery, ceramics, computer skills, internet, and sports to create opportunities for creativity, learning, and recreation.

There is great hope coming from Karabakh. In a proper turn from the Soviet representative's 1980 famous denial of the very existence of the disabled in the USSR, Vardan proudly took many of the patients of the Rehabilitation Centre to compete in the 2010 regional Paralympic games in Yerevan. There his patients competed in boccia, table tennis, swimming and alpine skiing. No longer hidden behind closed doors, participants in the games were met with smiling faces and cheering crowds. Vardan plans to embark on initiatives to make sports for the disabled more popular in Karabakh and Armenia and dreams of organizing a championship.

The Lady Cox Rehabilitation Centre meanwhile continues to be internationally recognized as a "Centre of Excellence" and regularly hosts health care personal from the region including from Georgia, Chechnya, Ossetia, and Abkhazia who wish to take Vardan's therapeutic repertoire back into their clinics, offering hope and healing to those who previously had no hope. The efforts of Vardan, his team, and all his supporters are an amazing feat in the quest for offering lives of dignity and choice for all of Karabakh's disabled. Their voices break the wall of silence.

Bibliography

Phillips, Sarah D. (2009) "There are No Invalids in the USSR: A Missing Soviet Chapter in the New Disability History." *Disability Studies Quarterly*. Vol. 29, Issue 7.

