

## EXPERIENTIAL ARTICLES

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# Community-based Rehabilitation in a post-Soviet Environment in Azerbaijan – Where Society meets Ideology

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### ABSTRACT

*This paper explores UAFA's experience, since 2002, in working with Azerbaijani stakeholders to move from the medical approach to disability, propagated by the Soviet model of planning and implementation, to a social, community-based approach. The paper highlights the common misconceptions and how these can be overcome, including the policy gaps that challenge effective implementation. The importance of creating and maintaining a core team is discussed, alongside the process that UAFA has developed for building up teams of CBR workers. Finally, the paper raises the issue of introducing outcomes-based evaluation in a society that has no such prior experience, followed by an account of the continual challenge faced by most programmes—namely, how to achieve sustainable funding.*

**Key words:** Azerbaijan, CBR, programme, development, outcomes.

### INTRODUCTION

When United Aid For Azerbaijan (UAFA) first started to practise the CBR approach in 2002, we were not aware that our work had an internationally recognised definition, let alone such a comprehensive strategy underpinning it, practised by thousands around the world and approved even by the WHO, UNESCO and ILO.

Today, 13 years after we started experimenting with community-based approaches to support children with disabilities and their families, we are constantly promoting the full meaning and wide scope of the CBR approach in order to raise awareness. It does not fit neatly into the sphere of reference for most people, especially for people in a post-Soviet community where labelling and compartmentalisation is an ingrained part of the culture, and services for persons with disability are medically-oriented.

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The Soviet Union was characterised by a top-down approach : Five-year plans created in Moscow, State monopoly on control, absence of independent NGOs and civil society organisations, a very structured medical approach to disability, and only isolation or institutionalisation for those with disabilities who could not contribute to the Soviet machine. What a challenge to shift from this cultural legacy to one where the child or person with a disability is central to all actions, where the community works together to create inclusive conditions!

## **CBR JOURNEY**

Our CBR journey started by responding to the needs of a 4-year-old boy and his family, who lived hundreds of miles from the capital, Baku, far from any services that might help this child with cerebral palsy. The family was at breaking point; the family members could not cope with the impact of the disability and had decided to leave the child in a residential institution. We met them on that fateful day when the child was brought to a Baku-based institution for children below 7 years of age. We had been running a skills training programme at this facility for several years, to build up the child development and rehabilitation skills of the care staff. The main goal was to eradicate the harrowing sights and sounds of children rocking in their beds, banging their heads against the wall, in complete silence or with arms outstretched to be comforted when an adult walked past.

Even though we could not persuade the family to take their child back home with them that day, they did listen when we told them about the negative effects of institutionalisation, and they took our contact details. We promised that if they took their son home, we would visit and teach them how to develop his skills at home, as a family.

A week later the family called us. On visiting their son at the institution, they were horrified to find that he had lost whatever skills he possessed and had been crying non-stop ever since the separation. They immediately decided to take him home. This was the start of our monthly, 5-hour long drive to reach the family and teach them how to develop the boy's independent living skills. In time, the family grew emotionally stronger, the father found employment, and the boy soon started going to mainstream kindergarten with his brother. Word spread in the community and more families started asking us to visit them too. Over a period of time we built up a group of children and their families. Someone donated toys and equipment. One family gave us space in their house. We found a volunteer and trained her. Our first CBR Centre was established.

Today, having established CBR Centres in 6 regions, we advocate this programmatic approach as a solution to the necessary transition from purely medical rehabilitation towards a combined medical/social rehabilitation model. There have been many achievements and challenges during the past 10 years, which are summarized here using the principles of CBR as a framework.

During our experience of advocating CBR in Azerbaijan, the following 5 key points were the ones that had to be explained and illustrated frequently, with the recommendation that they be given the most emphasis in a post-Soviet environment:

1. CBR is a programme approach, not a method of rehabilitation – an incredibly hard message to convey in an environment where rehabilitation is something that is ‘done’ to a child or person with a disability. Typically, most rehabilitation is provided at large, city-based facilities comprising many individual rooms and medical equipment. The focus is on ‘curing’ the disability, reducing the ‘defect’ in accordance with the State-approved practice of ‘defectology’. Disability is treated as a sector-specific issue, rather than a multi-dimensional issue. Therefore, the responsibility for diagnosis and treatment up to the age of 3 years rests with the Ministry of Health, with recourse to some sanatoriums which provide residential treatment. After the age of 3, provision of benefits and rehabilitation services are the responsibility of the Ministry of Labour and Social Protection, with two institutions for those from 4-18 years old who ‘cannot be educated’, and several for adults with disabilities. The Ministry of Education is responsible for most other institutions and for home education which provides some kind of education for children with learning disabilities. The policy gap is that there is no coordinating mechanism between the three Ministries at local or national levels. Without a joint approach to policy and planning, each State body views CBR within their own framework of responsibility, rather than as a holistic approach to meeting the many interconnected needs of the child, the adult and the family.
2. CBR programmes must include training in basic skills for community-based workers and other stakeholders so that the programme is sustainable and can grow over time. One of our greatest challenges logistically, but the most rewarding, has been to develop a cadre of community-based workers who can combine a wide range of skills to provide services, mobilise communities and empower children and families. This process helps to combat the huge

capacity gap in services for people living in the distant regions, because qualified or experienced people tend to leave their community and move to the capital, Baku, or go abroad to find work. It is rare to find anyone outside of Baku who has the qualifications and/or experience to work with children and adults with disabilities, thereby forcing families to travel to the capital for treatment. A secondary challenge for us has been the absence of qualifications beyond the medical degrees obtained at the Medical University. Paraprofessional status is not officially recognised, while modern therapy and alternative methods are not yet offered in higher education in Azerbaijan. In order to build up our training expertise, we have had to reach out to the neighbouring countries which offer qualification courses.

3. CBR programmes can include centre-based rehabilitation, home-based rehabilitation, raising public awareness, empowerment of children and families, early intervention services, inclusive education services, social inclusion through leisure and sports activities and so on. It has also been challenging to convey the message that comprehensive CBR programmes offer a variety of services, based on the wide-ranging needs that present themselves in every community; that it is not a narrow choice of day-care centres versus home visiting, or centre-based services versus institutions. A system that truly meets the needs of children with disabilities must have a variety of services that utilise evidence-based planning. Some families have been very stigmatised by the disabilities among their members and prefer to isolate themselves; even their neighbours may not know that they have a child or adult with a disability at home. Other families are extremely active and are ready to help others in the same situation. Services should have the flexibility to accommodate all people. An effective and efficient system needs to combine a variety of providers – State, NGOs, communities and private sector.
4. CBR involves the whole community to improve opportunities for children and adults with disabilities. This has been challenging because of the stigma, limited accessibility and lack of community approach to problem-solving; another legacy of the Soviet Union in which community was replaced by the State, and communities were not able to independently initiate this kind of civil society activity. When we organised the first parents' and family meeting in an open park cafe in 2004, there were still some fears amongst us and the group about what the repercussions might be. Interestingly, there were

no negative consequences and time has shown us that when a community is focussed on the needs of its children, mobilisation and empowerment activities are very effective.

5. It is **essential** to involve the parents and family members in the rehabilitation and inclusion activities. Medical treatment is typified by the doctor/client relationship in which the parents of a child are bystanders in the process of rehabilitation, accepting everything the doctor says, even if it is questionable. Including parents in the rehabilitation process ensures that they learn more about their child's condition and how to manage it at home, since for most of the time the child is at home and not with the doctor. As parents are the most powerful advocates for the inclusion of their child in society, it should be an essential part of our approach to include the parents and create opportunities for them to learn, share and be heard publicly.

## OVERCOMING CHALLENGES - IT'S ALL ABOUT THE 'TEAM'

After our initial practical experience with children and families starting in early 2001, first in institutions and then in communities, we realised that we needed a more academic approach to CBR. So in 2004, we invited an international CBR consultant to come to Azerbaijan and hold a two-week workshop. Those two weeks gave us the opportunity to not only produce a very detailed strategy, but also the time to debate as a team and achieve cohesion in our understanding. We think that this is the key to a team's success - strength which comes from a united mission and is understood within the same perceptual framework. Some members of the original team who participated in these workshops still continue to work as the UAFA core team. Others have gone on to propagate their experience through employment with State agencies, other NGOs and privately.

In 2005 there was a second workshop with the same consultant, and by 2006 we had the theoretical and practical experience to implement a strong strategic approach to fulfil the following objectives:

1. To increase coverage of early intervention services for children with disabilities.
2. To build capacity of families to mobilise themselves and to support each other.
3. To raise awareness about disability issues in the community and enlist community participation in the programme.

We implemented these initially in three regions of Azerbaijan – Yasamal district of Baku, Khachmaz (rural town in north) and Ganja (a major city near the border with Georgia, where CBR first started for UAFA).

### **Developing CBR workers in Azerbaijan**

1. Recruitment of CBR workers needs to be approached strategically, bearing in mind the lack of skills/experience base. One of the essential criteria is to find people who have an open mind regarding disability, who do not fear disability and who can easily adjust to understanding that disability is not a sickness to be cured. We recruit in two ways – first, through volunteering, and second, through training and selection. Volunteering has proved to be one of the best recruitment methods for us because it allows us to observe potential CBR workers in practice, to understand their capacity for working with children and their families, and their ability to work within a team. It also demonstrates that their motivation for work is not just financial.
2. After recruitment, the CBR workers undergo a long period of theoretical and practical training alongside more experienced colleagues. The aim of the training is to give them all-round knowledge of the frameworks within which the CBR model sits, as well as the skills development for working directly with children and their families. Our core team has received regular skills training from foreign specialists in child development, occupational therapy, physiotherapy, alternative communication, play therapy, portage, special education and social work. As none of these disciplines were available in Azerbaijan when we started out more than 10 years ago (and by 2015, only social work is a graduate course), we decided that it would be very useful to give the team a ‘toolbox’ of skills, so that they would have something for every occasion. If we were visiting a distant village and did not have something to offer, then this could be demoralising for a family who might be seeking help for the first time.
3. The costs and logistics involved in training region-based CBR workers cannot be underestimated. People leave, have children, find other jobs....and so, training needs to be ongoing, but funds are often not available to repeatedly train new CBR workers. One of the strategies we are now completing is the filming of training videos that show all the best practices in working with various disabilities and special needs. This will provide a basis of knowledge,

at low cost, and our core trainers can provide regular supervision through visits and Skype.

## **ENSURING QUALITY OUTCOMES**

Judging outcomes is a subjective issue, and tends not to emerge in the short-term. Again, this is a difficult area to develop in a post-Soviet context, where services are judged not on outcomes but on inputs and outputs, and quality is judged by the standard of infrastructure conditions. All our Centres are based in spaces donated by local authorities – schools, kindergartens, municipality buildings. We spend a small amount on functional renovation, and as much as possible on good equipment, learning toys and materials for the daily activities. If funds permit, we spend money on transport to enable home visiting, particularly in villages where there appear to be clusters of persons with disability but no services and little public transport.

As part of the original CBR strategy developed in 2004, we created a set of outcome indicators which we continue to use to this day. We also make sure that every child we work with is regularly assessed so that the progress can be evaluated. We believe that the best indicator of whether CBR workers are effective is if the children are developing, building up their independent living skills, being included in mainstream education and generally becoming involved in the local community. However, these outcomes do take time to reveal themselves and are rarely understood by those who are not trained or experienced in working with children with special needs. This is a drawback when trying to work with State bodies and engage them in funding.

## **FUNDING – THE CRUCIAL ISSUE**

Despite the best intentions of volunteers and local supporters, sound financial backing is vital in order to make a strong CBR programme. The budget needs to fit within the realistic capacity of the community resources so as not to create income disparities. For sustainability, we have always tried to cover as many costs with in-kind support as possible. Examples of this include space given by local kindergartens and schools, including utility expenses; toys and equipment donated by individuals and companies; transport costs covered by municipalities. The principle we follow is – ‘wherever possible, ask’.

One major success we had in 2012 was in convincing the Ministry of Finance to pilot State Contracting of NGOs as service providers. The policy pilot contained

all our learning from the past 10 years' experience, and included mechanisms for service specifications, performance evaluation and licensing/accreditation processes. Three of UAFA's services and three other NGOs were included in the pilot which was such a success that it was adopted and even led to the allocation of extra State budget for 2013. New services such as day-care and mobile rehabilitation services were included in the next round of tenders and by 2014 the service sector for children with disabilities was starting to blossom. Unfortunately, a change of administration at the beginning of 2014 was a setback to the progress, as the new Ministry representatives were not familiar with the concepts of State Contracting and CBR.

Every dip is followed by ascending to a new peak. It is important to diversify one's sources of funding, consider income-generating options and build up good awareness of the programme so that support of local donors is attracted. One local business has continuously supported our activities for 5 years, and now the outcomes for these children and young adults are receiving national attention.

It is these positive outcomes that keep us moving forwards. In June 2015, Azerbaijan hosted the first European Games and the issue of disability gained recognition. When the Flame came to his home town, one young man who has been part of UAFA's sports programme for many years, was invited to carry the Flame aloft in his wheelchair. Another sportsman with visual impairments, who has been so successful in the previous Paralympic Games, was chosen to bring the Flame into the stadium for the Opening Ceremony, in front of 60,000 people and an international audience of millions. A true step forwards for inclusion and appreciation of all abilities in Azerbaijan!

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