

Meeting the Challenges of Out-of-Home Care Provision

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INTRODUCTION:

Though it is difficult to separate the two themes of the conference, this paper concentrates on the challenges that face Azerbaijan in providing care for children who, for many different reasons, live in institutions outside of the care of their families. They are commonly referred to as 'institutionalised children'. However, this common reference will be examined within this paper to assess whether the use of this term presents additional challenges to the government.

The paper will primarily focus on issues related to children with disabilities because UAFA's research has demonstrated that, in the majority of cases, it is a wide-ranging spectrum of disabilities, combined with other social problems, which lead to long-term institutionalization or isolation from society. However, the strategies outlined in this paper should be applicable to other groups of children who become institutionalized or isolated as a result of social problems only.

All the strategies have been developed based on practical implementation by UAFA in 6 institutions which house children with disabilities. It will be many years before a full system of community-based services provides an alternative to institutionalization. In the meantime, many children in institutions are suffering; their rights are being systematically abused.

SECTION I

TERMINOLOGY, FACTS & FIGURES: who, how many, where – out of parental care

The following figures are compiled from data collected by UAFA surveys¹ in 2000 and 2004, with additional support from State Statistics Committee Annual Statistics and Ministry of Finance annual budgetary figures.

These figures should only be read as approximations which indicate the level of a particular need or problem. **Official figures provided by the government result from confusing data collection mechanisms** and the only way to truly verify the level of need or problem is by physically visiting the institutions. **As far as UAFA is aware, we are the only organization in Azerbaijan which has personally visited 95% of institutions across the country.**

i.	Number of institutions	69
ii.	Number of children in institutions	14,397 (average of 208 per institution)
iii.	Number of institutions providing year-round care to some/all children	32
iv.	Number of institutions providing for children with special needs	19
v.	Number of children in special needs institutions	3871 (average of 203 per institution)
vi.	Number of institutions in Apsheron Peninsula	36
vii.	Number of institutions in regions	33
viii.	% of children returning home every summer	64%

- i. This number consists of six official classifications of institutions plus one extra category–
- **Residential institutions** for orphans and children deprived of parental care
 - **Boarding schools** for orphans and children deprived of parental care
 - **General boarding schools**
 - **Specialized institutions** for children with special needs
 - **Specialized boarding schools** for children with special needs
 - **Baby houses**

¹ <http://www.uafa.org.uk/research&reports.html>

UAFA also includes the number of **sanatoriums** because, even though they are not officially recognized by inter-ministerial groups as institutions, they do indeed perform this function and house many children, particularly those with special needs, over long periods of time.

- ii. This figure was arrived at by visiting institutions, doing some headcounts, and performing telephone surveys – these figures are additionally corroborated by on-going project work in 12 institutions implemented by UAFA and other NGOs. The average figure is provided to enable further statistical approximations be made. The numbers of registered children per institution ranges from 2 – 830.
- iii. This figure represents approximately 46% of the total number of children in institutions. Therefore, a maximum number of **6500** children could be described as **institutionalized** because the remaining **8000** children remain in the **care of their family** and just visit the institution on a daily/weekly basis.
- v. This figure represents 27% of the total number of children in institutions and, thus, the major proportion of children who can be described as institutionalized.
- vi. The majority of institutions are situated in the Apsheron Peninsula to where parents send their children from across the whole country. This is a major factor in families becoming estranged as people can not afford the cost of transport between home and institution. It must also be noted that most of the institutions providing year-round care (iii) are situated in the Peninsula.
- vii. The institutions in the regions generally perform the same function as local schools whilst providing food and after-school care for parents who work. The majority of children return home every day or at weekends (because of distance).
- viii. This figure was arrived at during UAFA's 'Situation Analysis of Children's Institutions in Azerbaijan 2000', (see website link before) and strongly indicates the need of parents to use institutions for food/education.

CONCLUSION: SECTION 1 – TERMINOLOGY, FACTS & FIGURES

A definition of 'institutionalised child' is the most important detail to be agreed upon by the government and NGOs because, without it, many children are included in the official figures but actually live in the care of their parents – this distortion can become a major challenge to government as they try to outline and implement deinstitutionalization strategies. UAFA's tabulated information shows how much the figure for institutionalized children can be reduced if a realistic definition is authorized by the government.

UAFA recommends that the *institutionalized child* should be defined as:

'a child, living within a group of children, whose year-round parental care has been permanently substituted by the role of the institution'

The child becomes one of a group whose every action and behaviour is governed by regime. The strategy needed to help this group of children should be very different to the strategy needed to help parents cope with poverty – the main reason for utilizing institutions.

Each institution has its own identity, either at a community or national level, and this identity is a result of the role that parents ask the institution to play and the function that the staff consequently provide. This function does not necessarily correspond with its official name or role according to the list of six institution types. UAFA recommends that the role and function of each individual institution is recognized and the national deinstitutionalisation strategy launches from the parent's reasons for institutionalizing their child. Re-profiling of institutions would be a very simple start to this process.

Sanatoriums must be recognized as institutions which may include 'institutionalised children'. Sanatoriums currently provide services such as day-care (when parents must work during the day or night) particularly for children under the age of 7 years; long-term respite care for children with disabilities (for many children who need specialist attention and rarely return home) and summer care for children from boarding schools who never return home and are moved between school and sanatorium. Without recognition of their role, sanatoriums are unable to provide the support that these children need. Their role as day-care/respite care providers could be supported very easily and cheaply and play a large part in the development of alternative community-based services.

Many children in institutions, whether they are strictly defined as institutionalised or not, still come from very difficult home situations. As the UAFA survey 'Reasons for Institutionalisation 2002' indicated (see website link above), family break-up is a very common reason for a parent to send a child to an institution and, during this survey, responses from directors underlined that many of the children come from single-parent families. It is important that institutions meet this challenge – for example, we have not found one single institution with a child psychologist on their team, yet the need for this type of support is overwhelming.

Deinstitutionalisation is rarely understood as a strategy because the realities of institutions are highly complex and there is no 'one size fits all' solution. Strategy development must start from one point that provides a success for key stakeholders including government and the public so that the confidence needed to tackle more complex reforms is built up.

UAFA sees the **most urgency** in tackling the **deinstitutionalization of services for children with disabilities**. One strong advantage in this strategy's favour is that parents of disabled children are more likely to want to care for their children but have seen no other option to support their desire to remain a family unit.

SECTION II

DEINSTITUTIONALISATION IN AZERBAIJAN – Challenges at a Policy-Making Level

Azerbaijan continues to be governed by those who were educated during Soviet rule; having no prior experience it has been difficult for Ministers to initiate civil society and democratic changes and improvements that are taken for granted in the West. Often a catalyst has been needed to create awareness: UAFA's work with disabled children has acted as just such a catalyst. Many of the disabled children now resident in institutional care have been abandoned as a direct result of their disability: disability continues to be seen as an illness without cure; the responsibility is therefore placed on the state. During interviews with parents of disabled children, we asked them who was responsible for their child's care – the majority viewed that it was the responsibility of the government, some even saw UAFA as responsible. Abandonment/institutionalisation can also be an indirect result of disability as it invariably results in stress and economic hardship for already poor families (50% of the Azeri population live below the national poverty line²) a situation which is exacerbated as such families have no access to social services or community support and understanding. In such a scenario, a disabled child can infrequently be the trigger to marital breakdown and penury for the remaining parent. UAFA acknowledges that the most effective means to achieve a level basis for disabled children is **at home**; however, when no other options are available, we advocate that **residential care** should be of the **highest quality** whilst **alternative care options** and community-based support services are **developed**. What will make this possible are: 1. Legal and community recognition of the disabled, especially amongst government and society 'decision-makers', i.e. reduction in stigma and segregation. 2. Development of diversified system of care, i.e. de-institutionalisation. 3. Training of current and future care/medical/social staff, i.e. the transfer of skills and training of trainers. 4. Support for (poor) families in the community. 5. Educational, vocational and life skills training for the children/young adults.

In UAFA's experience of institutions in Azerbaijan, closure of institutions is not the answer. They provide the only resource available to parents and, as such, would increase their value if the **institutions were transitioned through training and development**, so that they simultaneously meet the needs of the families and surrounding communities as responsibility for childcare is handed back to the parents. UAFA's approach takes the best of the medical model of care and combines it with the social model in order to provide a model that meets the needs of all stakeholders **now**.

The means, method and impact of de-institutionalisation is a contentious issue. In UAFA's opinion after 7 years of experience of working in institutions at a grass-roots level, the focus should be to **transition** the institutions from the set of basic services they currently offer to new services that meet the holistic needs of the children and their families, e.g. teaching the child independent living skills such as feeding, dressing and toileting through the utilization of occupational therapy, physiotherapy and play therapy. Many parents send their children to institutions because they become too dependent on their parents for

² Page 5, Table 1, DFID Regional Assistance Plan for Central Asia, South Caucasus and Moldova. National poverty set at under \$2.15 per day.

every need and simply become too difficult to care for as they get older and heavier. However, institutions have the potential to become more than a rehabilitation centre – with creative and flexible management, they can meet the many needs for social support that each surrounding community has, as well as meeting the needs of disabled children and their parents from further afield.

For example, the same institution could provide a day-care service and vocational training to the community as well as providing respite care or long-term rehabilitation to families further away. The emphasis would be put on the parents to be the decision-makers in their choice of service, with a strict responsibility to take their children home at the end of an agreed period of treatment. It has to be stressed here that the majority of parents do not choose to abandon their children and so it is not unrealistic to expect an institution to perform and be successful in this type of social service.

Any strategy must also address the government fear of deinstitutionalization. This is basically a fear of change, of the unknown, but it is also a fear of funding streams being cancelled. ***The Government of Azerbaijan currently spends approximately \$900 a year³ per child in an institution. By comparison the Government spends \$20 a year per child in a normal school.*** One of the major obstacles that is consistently quoted by all organisations who are promoting deinstitutionalisation across the former SU and EE countries is that it is not in the interests of the institutions and government to reduce the number of children, as funding is linked to the number of children, i.e. the more children who are registered the more funding is given. This has led to corruption as numbers are often inflated and children are moved around from one institution to another to maintain long lists, all without primary benefit to the children themselves. The difficulties and pitfalls experienced by other former Soviet Bloc are not to be ignored, but UAFA hopes to learn from them simultaneously recognising that governments, including Azerbaijan, do not understand **how** to make the necessary changes as a legacy of 'central planning', i.e. those who must implement deinstitutionalisation have no experience of financial planning. For this reason, UAFA will advocate strongly (in partnership with the institutions and responsible Ministries) that funding be linked to the new services that the institutions will provide as a result of UAFA's training and development and that budgetary control is handed over to the institution. Under this scenario, it is in the institutions' interests to reduce the number of children in order that services provided are well-funded and not stretched to the limit

A change in the style of funding will also complement and enable an effective gate-keeping policy to be implemented. This policy will offer parents alternative options rather than permanent residence e.g. day-care, short and long-term respite, and psycho-social support for the parents. Gate-keeping should be the responsibility of a trained social worker and child development specialist, rather than the institutional directors who currently perform the task and employ an open door policy.

CONCLUSION: SECTION II - CHALLENGES AT POLICY-MAKING LEVEL

The strategy outlined above is taken from a proposal which UAFA will implement in partnership with the Ministry of Labour & Social Protection. The following list states some of the challenges that we will face in achieving change:

- Government is boosted by the oil sector and is not as interested in complete systematic reform as is the case in other post-soviet countries – it seems that grant-making bodies stimulate a government's interest in development
- Traditional decision-making means a top-down approach which can hold back creative reform
- Lack of genuine appreciation/understanding on the part of government of real social situation faced by poorest families due to bureaucratic distance from field
- Too much concentration on changing social policy laws rather than financial policy
- Post-communist mentality – government takes responsibility for everything and are reluctant to decentralize
- Lack of trust/confidence between government and NGO community
- Social services for children has seen slow progress before 2004 because Azerbaijan lacked a President's wife, a role which traditionally supports these issues

³ According to UNICEF Situation Analysis of Children's Institutions, 2000

SECTION III

DEINSTITUTIONALISATION – Challenges for Implementation of Policy

Staff are as much affected by the confines of the institution as are the children, **leading to very low levels of care and attention**. Staff have not been trained to *work with disabled children*, consequently, when the medical model is followed, children are regularly left in bed all day long or rocking on the floor – because staff must only see them as ‘sick’ and in need of medical attention.

UAFA’s work to date has centred on the expressed needs of the local context and has therefore led to improved capacity of staff and institutional change **from the inside**. Various methodologies have proved successful in different countries to achieve deinstitutionalisation of welfare services. However, it is important not only to look towards other countries in order to learn new systems but also to look within, using examples of which strategies work abroad and find those elements that do not fight in opposition to the challenges present in each individual country.

UAFA has been working in Ganjlik Psycho–Neurological Babyhouse for children aged 0-7 years since May 2000; during that time UAFA has trained and mentored more than 40 government care staff. Initially, the staff were arguably as disorientated as the children. The first training session had a massive impact because someone was making an effort to show interest in the care staff. The on-going training and mentoring has led to regime change – for example, none of the children are permanently confined to bed any more unless they are actually sick i.e. they have moved from the medical model towards the social model of care. As a result fewer children are becoming severely physically disabled – commonly most children developed severe and irreversible contractures as a result of being bed-ridden. We now see more children being taken home by their parents because the children are actually developing the independent living skills that the parents never believed was possible. Many others are being adopted by alternative families because the effects of institutionalization have decreased so much that most of the children are at a developmental level of any typical child the same age.

Nearly everyone agrees that the best place for a child is within a family but nobody can agree on the best approach to achieving this goal. It is naïve to suggest closing all institutions as children might be returned to families who do not have their best interests at heart. **Social services need to be in place to make sure that families can cope**; the institutional system can then act as a final safety net mechanism. **For UAFA, institutionalisation is always and ever a last resort**. For parents in Azerbaijan, an institution is often regarded as the place where their children will receive treatment for their condition. Why not **re-brand institutions**? This would entail a country-wide publicity campaign to change public perception of the role of institutions, showing that instead of places of abandonment for worst case scenarios, instead the institutions have become social centres which offer real education and therapy for disability, with the emphasis being on parental responsibility. This strategy means no job loss, just job gain, and many more families having access to support services with children’s best interests at the core. Everyone is happy.

There are currently five registered day-care centres for children with disabilities in the whole of Azerbaijan, which have been set up not by the government but by independent family associations. These centres support a maximum of 300 children who live at home. According to recently released government statistics, **43,342 children are currently registered as disabled in Azerbaijan**. There is an enormous need for more government-run day-care. Institutions can provide the solution through training, transition and re-branding – they are an existing resource which can be utilized effectively to the benefit, rather than the detriment, of children and parents.

In each institution, the following activities must be developed in order to achieve this goal.

- **Advocacy and development of child protection policy.**

Currently no policy exists to protect children in the institutions. Even if a policy is authorized, it would be difficult to implement correctly as the justice system is corrupt and difficult for poorer people to access. Thus, to meet these challenges, UAFA plans to develop a policy within 3 individual institutions, created with the participation of community members, institutional care staff, children and parents to give them equal ownership of the policy. Justice should be locally applied by an independently selected group and be a transparent process so that power is not concentrated in any individual’s hands.

- *Creation/extension of child development activities* offered for disabled children at three institutions (to act as referral centres/examples for the other 60+ institutions in Azerbaijan)– to include:
 - *Daily play therapy sessions*: which focus on helping children to develop independent living skills through group and individual sessions
 - *Occupational & Physio- Therapy*: focusing on the development of each child's independent living skills
 - *Special Needs Education*: child-centred approaches to education, for all children who are able to follow the national curriculum at a level appropriate to them
 - *Vocational training*: aimed at giving children/youths the skills necessary to gain paid employment or work experience
 - *Day-care*: an option for parents who need to work but want to remain a family unit
 - *Respite*: short- and long-term care for children whose parents need a break from the responsibilities that come with having a severely disabled child
 - *On-going assessment* and evaluation of child's development
- *Family reunification*: a thorough background search will be undertaken with all traceable families to discover which families will be willing to take their children home on the condition that they benefit from new community services.
- *Social Work Training and Practice for institutional staff*: to provide effective emotional support for children and families, disability awareness, social policies and conditions regarding current laws and benefits available; this activity complements Family Reunification.
- *Screening system/counseling* run by child psychologists in institutions so that children who have been abused and neglected can access professional help. None of the institutions in Azerbaijan has a child psychologist as a member of staff unlike typical schools. Information processed by this service would also help to understand clearly how widespread the problem of abuse is because no research has been performed in this area to date.

CONCLUSION: SECTION III - Why Does This Strategy Have A Good Chance Of Success

This strategy combines both the top-down and bottom-up approach. This combination offers the greatest probability of success rather than taking one or other approach. Additionally, skills transfer, if followed up strongly by mentoring, will always produce a positive effect on the staff and the children, at least, if the top-down approach does not work or is slow in progress.

This simple idea also avoids the creation of new bureaucracies or new layers of a complex system which is already designed to remove responsibility and pass it around. Use the current system and re-model and then there is more chance of government buy-in. At the same time, children and parents start to see the benefit immediately, rather than waiting for many years for new systems to be agreed, designed and implemented.

Finally, this strategy includes all stakeholders at every level of decision-making, from children to top levels of government. Children can make their own decision about what therapy or skill they want to concentrate on; parents can make their own choice about what service to use; staff can make their own decision about what activities to follow; directors can make their own decision about how to apportion their budget; ministries can make the decision to move from a medical model of care to an approach which meets the needs and rights of children, conventions that the government has already signed up to but has had difficulty in implementing.

The strategy presented by UAFA is the first stage of ensuring that the current support system moves towards an inclusive, community-based social service system which aims to keep the child with their own family. It is a step-by-step process and the goal can not be reached in a short time. It can only be reached when the public understands its common need and the decision-makers are able to meet this need. In the meantime, there has never been a more important time for the work of reputable development organizations to advocate on behalf of children and their families.