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Children and Disability in the Context of Family Breakdown in Central and South Eastern Europe and the Former Soviet Union

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I. <u>INTRODUCTION</u>

This report is intended to develop understanding of the issues of children and disability in the context of family breakdown and thus contribute to informed programming. The report is not intended to be a full scientific study. By drawing on the real life experiences of children, parents and others, closely involved in the care of young people with disabilities in the central and eastern European and former Soviet Union region, it aims to forward a realistic analysis of current issues and options for the future.

In programme development, measures that have an impact on issues affecting children with disabilities are often perceived as 'add-on' rather than integral. That is, programmes are designed without being inclusive of the most marginalised and isolated groups and consequently don’t meet their needs. This document puts forward recommendations for programming based on an understanding of the rights and needs of children with disabilities. The information contained in this report is based on ongoing contact and discussions with children and families in the countries of central and eastern Europe and the former Soviet Union, in particular those countries in which EveryChild works, as well as on other data gathered by EveryChild staff working in the region.

In essence, the report concludes that all agencies interested in addressing the global development needs of the world's children, including EveryChild, should pay particular attention to addressing the specific needs of those children who have been marginalised by their societies as a result of their disability. The report recommends that EveryChild introduce a policy of *mainstreaming*, that is, systematically addressing, and incorporating measures that challenge discrimination and promote equality for children with disabilities into all programmatic, operational and organisational activities. To aid this process draft guidelines and checklists are proposed to help staff transform a *policy*, of defying prejudice and advancing equality for the region's disabled children, into a *reality*.

II. OVERVIEW

Children and adults with disabilities[1] are everywhere subject to constant discrimination in their daily lives. This is especially true in the emerging democracies of central and eastern Europe and the former Soviet Union, where services which support vulnerable and marginalised groups are in their infancy.

The communist legacy of political authorities deeming certain social groups ‘unacceptable’, for example people with disabilities, with alcohol or mental problems, had the effect of these populations being hidden or ignored. This has in turn resulted in a large institutional population of both children and adults with disabilities across the region. By maintaining children with disabilities in separate segregated facilities, society existed as if there were no people with disabilities. The perception that what was different was unacceptable, and was therefore hidden from view has never been widely challenged.

Today, children with disabilities continue to be variously perceived as ‘diseased’, in-human, lacking any capacity to grow and develop. Their rights as children and as humans are for the most part ignored. These perceptions result in widespread prejudice against children with disabilities, which are reflected in social exclusion, lack of dignity and respect, inadequate or non-existent educational opportunity and prejudicial medical treatment. There is little or no understanding of a child-centered developmental approach to care; support to families is negligible and, in spite of pockets of excellence, community services are almost non-existent. The use of large institutional facilities to care for children with disabilities remains commonplace.

Parents interviewed by the author in the region, who had abandoned their children to state care have variously offered these reasons:

- “The doctor in the hospital advised us to”
- “My mother-in law said I should forget about her and have another one”
- “My marriage was breaking down under the strain”
- “We couldn’t afford the medicines’
- “There was no one to help”
- “I was frightened of what people might say”
- “The staff in the hospital said I wouldn’t be able to manage”
- “My son needed 24 hour care, I had to go to work to support the other children, they were suffering because of him”
- “We were told it would be better for the child.”

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[1] This report refers to children with disabilities based on the UN definition of disability as ‘a great number of functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness.’ *Standard rules on the Equalization of Opportunities for Persons with Disabilities*, G.A. Res. 96, UN GAOR, 48th Sess. (1993).

Many of these reasons are not exclusive to parents of children with disabilities, however, the situation on abandonment appears to be exacerbated by the additional responsibility for parents of caring for a child with different and additional needs.

Figures indicate that whilst approximately 10% of the total population in each country has disabilities, (WHO 1978), 4% of children in residential institutions in central and eastern Europe and the former Soviet Union have a disability, (Tobis 2000). The Children's Health Care Collaborative Study Group (1994) however, reported that 19% of infants and young children in Romanian Baby Homes had a disability and in Bulgaria a recent analysis estimated that approximately 15% of all children in institutional care have a recognised disability, (UNDP 2000). Whilst it is difficult to determine precise data since methods of classification and methodology for collecting statistics changes from country to country, these figures would indicate that at least half a million children with disabilities are living in institutional care.

Nevertheless, despite the great pressures as parents of children with disabilities a significant number do care for their children successfully within the family. This report does not claim to have analysed and researched in depth the reasons why some parents abandon children and others do not. But rather, through the experiences of many families, it aims to make recommendations for future actions which can ensure children with disabilities are included, and do not continue to be isolated and marginalised within society. In the medium term, EveryChild believes the balance must shift away from institutional care for children with disabilities towards family and community-based support systems.

III. ISSUES

Professionals, parents and children across national borders are clear in voicing their priority issues.

i. Human Rights

The human rights of children with disabilities are not recognised in practice, particularly in the case of those with high levels of support needs. Their rights are often considered secondary to those of the rest of the population. Children with disabilities are considered to have little or no value. Equality of opportunity is a concept that constantly eludes children with disabilities.

> "We might have a disability but we are the same as everyone else inside."
> *Nadia, aged 15, Kyrgyzstan.*

ii. Social versus Medical Model

The picture or 'model' of disability that others carry in their minds governs behaviour towards children with disabilities. This model in turn affects the way in which society is organised. The medical model, prevalent in central and eastern Europe and the former Soviet Union, perceives disability as an illness and the person with disabilities as a patient who needs a cure so that they can fit into 'normal' society; since a cure is rarely considered possible the 'patient is banished from that society. The emphasis is on the condition rather than the person. The social model, on the other hand, recognises the person with a disability as an equal who is battling against the barriers to his or her development imposed by society. The emphasis is on social responsibility and changing the attitudes of others rather than on treating the person with a disability as if they were the problem.

The medical approach is very much evident in the language of disability, which in the former Soviet Union has traditionally placed an emphasis on the perceived medical 'defect'. The consequent scientific specialty of 'defectology identified disability with a diseased state. The role of the environment in supporting the person with a disability is ignored in favor of a diagnosis and treatment which often involved the separation of 'abnormal' individuals from 'normal' society.

> "My son doesn't need medicine to make him sleep. He needs to go to school."
> *Maria, mother of Volodya, aged 8, Ukraine*

iii. Support Services

Community-based support services are virtually non-existent. Where day care provision is available and deemed suitable, children are denied opportunities for education. Vocational education for children with hearing and visual impairment is often limiting and denies them the opportunity to proceed to third level education and therefore to succeed in the professions. Services continue to be provided on a segregated basis. Where available, social care benefits are inadequate. The medical fraternity continues to espouse ‘crank’ treatments and parents continue to seek ‘cures’ overseas. There are no early intervention services to support parents in providing care and stimulation for their infants in the most critically important first six months and in the early years.

> “The nurse in the hospital said there was nothing they could do and Mitko would have to go to the Mother and Baby Home. I was crying and then she said the only chance for him was to go to America to have an operation to cure his Down's Syndrome. I don't know how I'm going to raise the money.”
>
> *Mother of Mitko aged 7 months, Romania*

iv. Co-ordinated Support

There is little evidence of inter-agency working, and few examples of co-ordinated approaches to family support. Where a family is experiencing difficulty, the complexity of their needs is often mis-understood or ignored by professionals. Where the education, health and social welfare services have no linkages, obvious support solutions are often missed.

> “Radi, aged two, has cerebral palsy and spent the first years of her life in the hospital children’s ward. She was then moved to an institution for children with disabilities. The social-work team are working to help Radi stay with her grandmother in extended family foster care. The professionals' opinion is that Radi’s development has been delayed immensely in the hospital. The social work team regrets that they weren’t alerted to Radi’s situation earlier.”
>
> *Social Worker, Municipal Office for Social Support, Haskovo, Bulgaria*

v. Poverty

Children with disabilities often require special services and equipment, medicines and therapies which are not available from the state. Where a child is incontinent the laundry costs for the family may be inflated. Families on a low income may literally be unable to afford to care for their child. Additionally there is evidence to suggest that poverty can impact negatively on early child development (UNICEF 2000). Where a child has a disability this reduces even more their opportunities to grow and develop.

vi. Information

The availability of information, and the way in which it is given, is often crucial to the well being of parents, carers and children with disabilities. Parents have indicated that the most helpful sources of information and advice is often others with similar experiences. The language and terminology used by professionals is incomprehensible and off-putting. Negative attitudes prevail and, therefore, parents are often given misleading information and advice.

vii. Double Discrimination

Children from ethnic minority groups face even greater disadvantage than non-minority families in a similar situation. Poor housing and high unemployment levels amongst ethnic minority groups are already well documented, as is access to education and information. Families of children with disabilities are less likely to access available benefits and supports. Additionally many children from ethnic minority groups are mislabeled as 'developmentally delayed', often due to linguistic and cultural misconceptions. In the Czech Republic for example, Roma children are fifteen times more likely to be placed in a remedial special school than non-Roma, (European Roma Rights Center 1999).

viii. *Regulation*

There are numerous examples of parents actively lobbying for change on behalf of their children and succeeding in ensuring improved opportunities.

> An association for families of children with disabilities successfully lobbied the government for changes to legislation which assured the right to early years education for all children regardless of ability. However due to financial restrictions salaries were not available for the staff to teach these children. *Republican Centre for Persons with a Mental Handicap "MESSAGE", Macedonia*

However these incidents are relatively rare and it is unusual for action to be translated into policy and legislation. Where it is, the policy is often unregulated and ineffective in practice. It is only by understanding what particular circumstances create difficulties for children with disabilities and their families that the implications for change to policy and practice can be properly understood.

IV. EXPERIENCES FROM CENTRAL AND SOUTH-EASTERN EUROPE AND FORMER SOVIET UNION

Albania

After illegitimacy, disability is the next most frequent reason for institutional placement in Albania, (Rowlands 2000). The development centres in Tirana and Shkodra both report that poverty is a major factor in disabled children entering their institutions. Many children come to the institution because both parents need to go out to work. Whilst disability may not be the main cause of their *entering* institutional care, it is a significant reason for their *remaining* in care.

Financial assistance is available from the state for families with a disabled child. Payments are small and money alone is often insufficient to assist the family in managing to care for the child at home. Anecdotal evidence suggests that there is prejudice and lack of knowledge amongst some members of the medical profession regarding babies born with disabilities. Parents may not receive accurate information regarding their child’s disability, and it appears that some doctors actively encourage them to abandon the child. Training has been provided for staff and professionals working with children with disabilities; however, there is no data available about their programmes. Much of this training has been provided by international NGOs and has not been supported by effective legislative or policy reform. There are initiatives to improve the situation for children and adults with disabilities, but these remain segregated services, managed and financed by the international community.

Numbers of children with disabilities resident in social welfare institutions in Albania August 2000

Social welfare institutions for children aged:	Total number of children	Number (%) of children with disabilities
0-3*	139	21 (15%)
3-6	57	12 (21%)
Tirana 6-14	100	21 (21%)
Shkodra 6-14	99	25 (25%)
Saranda 6-14	58	0 (0%)
Total	453	79 (17%)

*Figures for Tirana 0-3 institution as at March 2000
(Rowlands 2000)

Bulgaria

There is little available reliable statistical information on the situation for children with disabilities in Bulgaria. However, it is estimated that approximately 15% of all children in institutional care have a recognised disability (UNDP 2000). This recent analysis of the reasons for abandonment of children with disabilities, concluded that the absence of psychological and social supports for parents at the point of diagnosis places children with disabilities at risk of being placed in an institution. The lack of reliable information and the heavy emphasis on a model, which invests power in the medical profession, results in families being severely stigmatised. The subsequent isolation is reinforced by the lack of supports and the "fears, prejudices and stereotypes are kept alive in the family itself" (UNDP 2000).

A model of day centre care has been established in the last ten years in approximately 17 Bulgarian municipalities; this is the only evidence of growth in community based services for children with disabilities. Parents action groups and international NGO's have stimulated much of this activity and the quality of services varies. The Center for Independent Living in Sofia, a Bulgarian disability rights NGO, recently issued a policy statement requesting recognition of the difference between human rights (dignity, respect, equal opportunity, self determination etc.) and entitlements (benefits, equipment, transport passes etc.). They illustrated instances where material protections or entitlements actually interfered with rights to employment and social independence. They also suggest that donors and the programmes of international NGOs often reinforce this confusion by giving material benefits without adding conditions that advance rights, and thus do not contribute to, or delay, legislative and policy change and, more importantly, the implementation of such legislation and policy.

> “As it is now implemented the disability law precludes integration into mainstream public schools and workplaces. Children…. are sent to remotely located special schools regardless of their ability to learn. Current policies further restrict access to work by forcing the disabled to withdraw from work in order to become eligible for pensions or mobility devices. Without the devices naturally, many that want to work cannot get there. Employers are asked to pay for special protections when they employ disabled workers; they naturally prefer less costly non-disabled workers.”
>
> *Equal Opportunities or Dependence, statement of the Center for Independent Living, Sofia, Bulgaria (2000).*

Georgia

A survey conducted by EveryChild in August 2000 revealed that an estimated 1,900 children with disabilities were in institutional care. The existing system, which once again is largely a Soviet legacy, is designed to identify and categorise children with the purpose of ‘correcting’ their defects. This involves segregating them from ‘normal’ children, which implies they are not considered a part of society. There is an excessive focus on ‘correction’ and ‘rehabilitation’ of the child’s impairments, which loses sight of many other rights of the child – to family, leisure, play and to be part of a community.

Many disabled children receive no education. Mainstream schools are unwilling to accept disabled children, so many of them are left isolated at home. Children with different impairments are often grouped together in special institutions and their education not differentiated according to needs. Some institutions whose function is to protect disabled children, in fact do the opposite. Reports of abuse and inhumane treatment of children in these institutions are not uncommon.

The criteria for accepting children into institutions lack consistency; children are increasingly being placed in residential care for socio-economic reasons rather than as a result of an adequate assessment of the child's needs. Children with significant impairments can be found among children with little physical or mental impairment. The condition of many institutions has badly deteriorated, and the level of care and treatment is low. Though the Georgian government is a signatory to the Child Rights Convention (CRC), non-discriminatory policies in the treatment of children with disabilities in society and in educational institutions have yet to become a reality.

As a result, there is a serious concern about their limited access to adequate health, education and other social services. However the Ministry of Education in its recent 'Policy and Strategic Plan Document' (Ministry of Education, Georgia, 2000) has acknowledged the need to address the issues facing children with disabilities by developing special programmes to consider the best interests of the child and to promote the full potential of children.

> "Families with disabled children continue to suffer from a negative attitude inherited from the past. Some parents of children with disabilities prefer to leave their child in special residential institutions, as there is little or no community or family-based care and support."
>
> *EveryChild Strategic Plan 2001-2004, for Georgia and the Caucusus*

Kosova

There is provision for children with hearing and visual impairment in specialised boarding schools. Both children and adults with disabilities are housed together in institutions, in appalling conditions. There are few integrated services and in the aftermath of the recent conflict, where there are so many pressing issues for the interim authorities, the rights and living conditions of children with disabilities have not been at the forefront of social reforms.

There are a number of international NGOs working with Kosovar civil society to put the issues firmly on the agenda and to raise public awareness of the necessity for debate. As the pressures mount to house the ever-increasing numbers of children without parental care, the institutional population is growing and the situation for children with disabilities becomes more precarious. Parents are reluctant to acknowledge the presence of a child with a disability in the family, and information is hard to come by. However the stigma attached to being 'different' has severely impacted upon the ability of children with disabilities to enjoy a visible place in society.

Kyrgyzstan

Many children in Kyrgyzstan are denied their rights as enshrined in the Child Rights Convention. Refugees, non-nationals, people without a residential permit (propiska), children with mental and physical disabilities have limited access to social welfare, health services and education. There is no effective governmental monitoring of potential discrimination regarding enjoyment of rights by these groups. Government statistics indicate that in 1997, the numbers of children registered at social support bodies exceeded 11,500.

Experience has demonstrated that the term 'children' is applied loosely when referring to people with disability, and often encompasses people over 18 years old. This is not only a regional phenomenon but an attitude that still prevails in parts of western Europe.

Children with disabilities have few opportunities to remain at home with their families. Placement in special boarding schools (where conditions are often appalling) is the main form of support, denying many children the right to growth and development. Children with disabilities have no access to the general education system and whilst in principle a system of 'home schooling' exists in which a teacher visits a child at home, in practice this does not continue. NGOs are attempting to start integrated education for disabled children in comprehensive schools and non-specialised kindergartens. Local authorities in some oblasts (Naryn) support these initiatives, but other authorities usually misunderstand them.

It is estimated that 62.3% of the population of Kyrgyzstan lives in poverty (NGOs in Kyrgyzstan 2000). Whilst these conditions endure, children with disabilities remain at the edge of society whilst families struggle to maintain a basic standard of living in the face of acute deprivation.

> “Standards of living necessary for development of children are not ensured for most children in The Kyrgyz Republic.”
>
> *NGO Commentaries To The Initial Report Of The Kyrgyz Republic On The UN Convention On The Rights Of The Child, 2000*

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Macedonia

Macedonia faces the political and economic transition process affecting all countries in the region. Additionally Macedonia is placed in an unstable political region, was severely affected by the recent crisis in Kosovo and is currently in the midst of its own violent ethnic conflict. There are high levels of unemployment and many families rely on state welfare. Against this background, vulnerable groups become even more marginalised and isolated, since service development in the social sector does not have priority status.

Children with disabilities comprise one of the most vulnerable groups in society with an estimated 18,000 children and adults with learning disabilities in Macedonia (Fountain 1997). Traditionally, care has been based in large institutions in rural areas and there is limited provision of services to enable children with disabilities to remain with their birth families. A concept of inclusion for people with disabilities is not widely accepted and there is limited public awareness of the issues facing children and families.

The government of Macedonia has supported initiatives to relieve the situation for disabled children and their families but has not provided resources or practical assistance.

It has fallen to the NGO sector to push forward reform and initiate activity aimed at improving the lives of the population of children with mental disabilities.

Between 1998 and 2000 EveryChild established a working partnership with a Macedonian NGO, Republic Centre for Helping Persons with a Mental Handicap - MESSAGE, to develop community-based services for children with disabilities in ten sites nationally. An agreement was signed with the Macedonian Government to establish units within state kindergartens for children with disabilities, representing Macedonia's first step on the path to an inclusive educational policy. The project's sustainability was assured as NGO members were trained as volunteer staff and local authorities met the running costs. In a complementary strand of work, EveryChild provided training and technical assistance to develop the capacity of the NGO to advocate and to develop joint-working relationships with local authorities. With EveryChild support, the NGO has engaged with the national government to bring about legislative changes and improvements in services for children with disabilities.

Moldova

Moldova displays the same regional pattern of inconsistent service provision, with responsibility for vulnerable groups being placed with a number of ministries. Conditions for children with disabilities in institutions range from adequate to appalling. Professional training is minimal and based on the medical model that does not promote the individual rights of children in a consistent manner.

High levels of poverty, economic depression and a collapsed social support system result in the most vulnerable becoming even more marginalised. There is anecdotal evidence to suggest that here, as with many other countries in the region, many disabilities result from poor nutrition, deficient pre and post-natal health-care, and environmental pollution. This is a subject worthy of wider investigation.

Since 1997 EveryChild has been engaged in a partnership with the local authorities in Chisinau and the national government which has demonstrated that by recognising the potential of every child for growth and development and providing the necessary supports to families of children with disabilities, including those with profound and multiple disabilities all children can be cared for within a family environment in their own communities.

13 profoundly disabled girls have been moved from institutional care in the most primitive and isolated conditions to care within their own families where support is offered by a trained and dedicated child protection social work team. The range of services also includes a small family type home to provide preparatory care and accommodation for an increasing number of children with disabilities and preparation for short-term foster care.

> “The situation of the children with disabilities is not changing considerably, because these issues are not of high priority on the Government agendas.”
>
> *EveryChild Country Director, Moldova*

Romania

Romania is unusual in that responsibility for children, including those with disabilities, now lies with one national body, The National Authority for the Protection of Children's Rights and Adoption. This move is intended to end the confusion surrounding responsibilities; legislative and policy change and implementation and so remove inconsistencies in approach. There are 35 residential institutions, Centres of Recuperation and Rehabilitation for Disabled Children (formerly known as Camin Spital) for children with disabilities, with an estimated total population of 3,000. However this figure does not include children with disabilities living in leagane for children aged 0-3 or the Casa de Copii for children aged 4-18. Conditions in the Camin Spital are often much worse than in other institutions. Evidence suggests that transfer procedures are not observed closely and that many children with disabilities aged 3+ remain in the leagane.

Alternative services are not provided uniformly across Romania and, whilst there are pockets of good practice, children with disabilities remain on the margins of society with little infrastructure support available for families. There is little training available for staff working in the Camin Spital, although many international organisations have provided opportunities for short courses and study visits abroad. The challenges of economic decline, poverty and a sense of national despair results in the rights of children with disabilities being relegated to bottom of the pile.

> “There are positive developments in fostering of children with disabilities in Romania. In Maramures one child with a physical disability has been placed, but such placements are the exception.”
>
> *EveryChild Technical Adviser, Maramures, Romania*

Russia

Reliable statistical information relating to the situation for children with disabilities is hard to come by. The Soviet system did not accept "differentness" and left children isolated in segregated facilities. However up to 40,000, (Korkunov et al 1998 & Altshuler et al 1998) of the estimated half a million children living in Russia's institutions have a disability. "The Russian system provides many pathways into the institutional setting and very few out." (Bauer et al 1999). Medical staff recommend institutional placement to parents at the point of diagnosis.

Some parents who bring their children home often abandon them later when the realities of caring for a child with special needs become overwhelming or unaffordable. Others are referred to a 'medico-pedagogical' commission when they reach school age. The commission meets and assigns the child a diagnosis (often without meeting him or her) based on medical reports. The resulting recommended 'treatment' often requires an institutional placement. Once in the system it is almost impossible to change direction.

> “Natalia, who has a congenital deformity of the fingers of her right hand, was sent to a new special kindergarten for disabled children, and thus was unable to enter regular school when she was seven. Her parents are divorced and her mother does not have the time or energy to fight the authorities for a new diagnosis. However she is worried about Natalia's future; being labeled as disabled and not having access to a decent education reduces her future opportunities.”
>
> *Psychologist, Moscow, Russia.*

There is a widespread belief and acceptance that the medical professionals know best and that state institutions are better for children with special needs. Parents are denied information, and power lies with the medical profession. The stigma attached to having a family member with a disability often encourages grandparents and extended family members to conspire with the professionals. Other families maintain children at home secretly, sometimes ashamed by the blow they feel they have been dealt. Other parents, aware of the appalling conditions in institutions, struggle to maintain their children in the family, but continue to neglect their need for stimulation, education and treatment.

Russia's economic difficulties are often cited as a reason for the poor levels of service provision for vulnerable children. However as a matter of international law, human rights must be protected. Where children are subject to inhuman or degrading treatment, or to arbitrary detention, Article 4 of the Convention on the Rights of the Child requires States Parties 'to undertake all appropriate legislative, administrative, and other measures for the implementation of rights recognised in the present Convention'. As a side note, Russia does not, as a matter of law or policy, currently commit itself to allocating available resources to work towards the goals of the CRC.

Ukraine

The Soviet legacy of hiding or ignoring certain social groups that were deemed unacceptable has resulted in shame and stigma becoming associated with disability. Additionally a lack of coherence in childcare policy governing work with children has resulted in a fragmented system which does not meet the needs of children with disabilities. Ukrainian parents are at the forefront of reforms in policy, legislation and alternative care provisions for children with disabilities. Promoting a rights based approach, parents have broken through the barriers which isolated them and formed strong groups and associations which implement services and lobby for change and reform. While pressure is often put on local, national and international groups to maintain the status quo and accept minor improvements as progress, these parents are demanding and achieving full rights for their children in terms of service support and education.

Model resources exist which aim to facilitate full integration of children with disabilities. Additionally, some state funding is provided to local and national associations for disability. However these organisations tend to portray children as sick and in need of material assistance. They do not demonstrate any lobbying activity and are less about rights and more about consolidating the place of people with disabilities in society as second class citizens.

“We started ten years ago with the parents association 'Nadiya' and soon discovered that there were more than 2,500 children with cerebral palsy, developmental delay or motor problems in Lviv.”

“Pressure was and is put on parents to place their disabled in institutions by telling them they will be better cared for in a specialised environment. The doctors say that parents won't be able to manage.”

“Of the many battles a parent with a disabled child has to fight, this one, to keep the child, is the first.”

“We want alternative services to be targeted to decrease the numbers of admissions to institutions. Family homes, L'Arche[2] communities, big families with retrained institution staff, these kinds of alternatives are needed instead. Access to mainstream education and centres where our children can learn to grow and develop and spend time in a positive atmosphere.”

“Our children need help from the earliest moment, but they can receive that help at home. They need to learn life-skills so that they can take their rightful place in society.”

Parents in conversation with the author at 'Dzherelo' Children's Rehabilitation Centre, Lviv, Ukraine

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[2] L'Arche is an international network of over 100 communities in 29 countries, where people with learning disabilities live and work together with assistants.

V. IMPLICATIONS FOR PRACTICE

Children and adults with disabilities, their parents, carers and guardians recognise clearly the issues which contribute to family breakdown. They are also clear in their understanding of what needs to be changed in order for them to achieve equality of opportunity. As organisations working with and on behalf of children, families and communities the onus is on us to break the cycle of perpetual charity and include in our strategies clear measures to promote maximum equality of opportunity.

We can do this by considering these eight principles.

1. Adopting a Rights Based Approach

In order to have an impact on the lives of children with disabilities and their families, national and international organisations need to respect and promote a rights based approach which should be central to all planning and policy decision making. Ensuring equality of opportunity for all children requires us to understand and commit to the international conventions which support child rights, human rights and the fights of people with disabilities.

Article 23(1) of the CRC requires that a child with a disability should "enjoy a full and decent life, in conditions which ensure dignity, promote self reliance and facilitate the child's active participation in the community". The 1971 UN Declaration on the Rights of Mentally Retarded Persons recognises that people with disabilities have " the same rights as other human beings".

In 1994 the UN introduced Standard Rules on the Equalization of Opportunities for Persons with Disabilities (StRE) in order to ensure that "girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others". The Preamble states clearly that "persons with disabilities, and their parents, guardians, advocates and organisations, must be active partners with States in the planning and implementation of all measures affecting their…rights." Rule 9 further states that " persons with disabilities should be enabled to live with their families." In addition Rule 14 urges State Parties and other organisations to ensure that "the needs and concerns of persons with disabilities should be incorporated into general development plans and not treated separately".

All programme planning should ensure that community integration is prioritised over any form of institutional care. As such "…services should be available in the local community where the person with a disability lives", StRE Rule 3.

Community based support systems should be adequate to permit children to remain with their own family and mechanisms to support substitute family care should exist. A broad range of cohesive services should be developed to ensure that children with disabilities are fully involved in the life of their communities.

In promoting growth and development, a primary right for children is the opportunity to education (CRC Article 28). Whilst this right is often thoroughly violated, in many countries new services are being developed which offer some educational programming. This may include education for life skills as well as the usual academic subjects. Day centres, as opposed to schools, predominate in the new service development, considered by some as progress and by others as yet another segregating initiative. The importance of ensuring what schooling is available to all children should not be lost in the debate around the most appropriate way of providing this.

Should we promote an integrated model as opposed to specialised provision? There is no doubt that attempts to make systems more inclusive are more likely to prove successful in promoting full integration and equality of opportunity however there remain voices arguing for an extension of separate specialised provision. This should not however, distract us from the primary task of building on existing provision rather than concentrating on 'deficiency' in what we find, in order to access institutional donor funding. "Moves towards more inclusive practice need to be realistic in taking into account the barriers they face…..negative attitudes…policies that lack flexibility to respond to pupil diversity…and the actions of those who…have a vested interest in maintaining the status quo." (UNICEF1998).

2. <u>Adopting a "Social Model" Approach to Children and Disability Issues.</u>

In order to ensure equal opportunities for children with disabilities we must accept that they are first and foremost children. The disability, which results in a functional limitation, is secondary to their innate humanity. As such we should provide the child with opportunities to maximise their growth and development, enabling them to participate fully in community life and work towards higher levels of independence.

Equating disability with illness is damaging and involves erecting barriers to independence. The balance of power shifts in favour of the medical personnel and the child is denied opportunities whilst parents and carers become more dependent, isolated and marginalised. Of course where the child with a disability has an associated illness or chronic medical condition they should receive the highest quality healthcare available. However, it is vital to make clear that this medical intervention is to treat the illness not the disability.

3. <u>Ensuring the Development of Community Based Support Services.</u>

The lives of children and parents can be transformed by providing access to local support services. Service plans should recognise and include support to families and communities to enable them to care adequately for a child with additional needs. Children can safely remain at home where a parent receives adequate support. Children can grow and develop where they are exposed to opportunities for learning.

The availability of a range of essential services ensures that children with disabilities have increased opportunities to achieve their potential. For example:

- early intervention including emotional and psychological support at time of diagnosis and activities for learning with the child from birth
- parent and family counselling
- play-schools/kindergartens
- schools/education services
- respite care
- siblings support groups
- after schools clubs
- transport and special equipment
- parent and community education programmes
- substitute family care programmes

This is not an exhaustive list. Children with disabilities, their parents and carers are the real experts and have often provided key leadership in the development of innovative programmes. They should therefore be actively involved in the development of new community programmes (UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1994).[3] The individual needs of individual children will vary and require individual responses. Additionally, services should reflect the possibility of need for extended care into adulthood and individual plans should take this into consideration. Once again, the responsibility lies with us to ensure that local and national governments engage with civil society and, in particular, users of services to develop plans for service implementation which fully meet local needs.

4. Ensuring Support and Service Development is Co-ordinated.

In order to allow children with disabilities the opportunity to enjoy equality of opportunity and participation in family life it will be necessary to adopt a multi-agency/multi-disciplinary approach to working. For example, where a child's right to education is being denied because the responsible state body for issues in relation to children and disability lies with the Ministry of Health, we must support joint working. By bringing these authorities together to understand their responsibilities and, by supporting them in working towards a joint policy and service planning approach, we can be assured of improvements in the lives of children and families. The establishment of strong links between responsible authorities and local civil society should underpin all programme planning and service development. Steering committees, working groups, planning teams should be facilitated to engage in joint working not just for the purposes of individual programme implementation but for the purposes of a longer term strategic planning approach for all children and family services.

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[3] "Persons with disabilities and their families should be able to participate in the design and organisation of rehabilitation services concerning themselves." UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Rule 3 (3)

5. Implementing appropriate and value for money programming.

Poverty is having a major negative impact on the support for social welfare services in all of the countries of central and eastern Europe and the former Soviet Union. All interventions should recognise the implications for service development and ensure that programmes comply with the national poverty reduction strategies. Where programming suggests service development that involves long-term and costly overheads the sustainability of the plan must be re-evaluated. If we are to ensure that ownership of initiatives lies locally, then we must ensure that they are able to continue into the future without external intervention. Investment in training for a voluntary parents support group which offers early intervention services is likely to be more effective, have a broader impact and be sustainable in the long term than building, equipping and funding running costs of a small group home for life for 15 children.

6. Providing appropriate and realistic information.

Children with disabilities and their families need to have access to appropriate and realistic information presented in a relevant and practical manner in order to allow them to make informed choices about their lives. Negative use of language, obscure terminology and misleading diagnosis and prognosis will confuse parents and disadvantage children in accessing opportunities.

Language, in particular, has become an emotive issue in the world of disability. Labels and terminology have in the past reflected negative, de-humanising and often criminal associations. Labels like, ‘imbecile’, ‘retard’, ‘idiot’ and ‘spastic’, continue to be used in many societies in a wholly derogatory way. In addition, the terms ‘disability’ and ‘handicap’ are often misused, and this leads to further confusion. *Disability* is a functional limitation or impairment which may be permanent or transitory. *Handicap* refers to the limitation of opportunity to take part in the life of the community on an equal level; it describes the environmental obstacles to full participation. The debate on language has, in western Europe, assumed the false mantle of political correctness and is often unfairly vilified. It is important that all development activity challenges prejudice and promotes equality within the context of local norms.

Understanding both the limitations and possibilities for their children's lives will enable parents to have the confidence to advocate on behalf of their children. Practitioners, professionals, policy planners and legislators need to be exposed to the realities of disability issues and to be educated in accepting responsibility for provision of appropriate responses. Promoting positive images of children and adults with disabilities within the public sphere will support new initiatives by harnessing local support and increasing understanding.

7. Ensuring equal access to all minority groups.

It is widely recognised that minority ethnic groups and non-nationals in central and south-east Europe and the former Soviet Union experience social and material disadvantage and have to surmount additional barriers to access equal services. Estimates suggest that Roma are over represented by 70% in the 'special school' for children with mental disabilities system in Bulgaria (Penn 1999). However, it is clear that these numbers are not a true reflection of the Roma community. What is known about ethnic minority families caring for a child with disabilities is limited, but it is feasible that where they are disadvantaged in accessing employment, housing and statutory services they are likely to have higher levels of unmet needs in relation to a child with disabilities. The families of disabled children should have appropriate information, and the importance of language and attention to cultural detail or tradition must not be underestimated. In particular they must be supported in the process of gaining access to benefits and be systematically involved in new initiatives. Only then will society be able to break this cycle of chronic deprivation and ensure that all children with disabilities and their families are able to participate.

The Kiev Centre for Social Work with Disabled Children was established with assistance from UNICEF in 1999. Services are provided on a multi-disciplinary basis and the joint management committee includes representatives of the parents association. The service is located in a building on a housing estate with other child and family, youth and disability oriented organisations.

"Sacha aged 10 didn't go to school before. Together we have been coming here, three times a week for individual sessions with the psychologist. Now Sacha is in mainstream school. The difference between then and now is like the difference between night and day. Sacha is more socially developed. There is a big difference in her relationships with other people, which is important for the whole family. It is easier to be more optimistic about Sachas future. What works at this centre is the partnership between parents and professionals. Before there was no information and no help. Now this centre provides both."

Mother of Sacha aged 10, Kiev, Ukraine

For a more detailed analysis of the situation of minority children and families in the region see Carter 2001 (forthcoming).

8. <u>Special Circumstances: War and Children with Disabilities</u>

War is a “survival” situation where rights are neglected, lost and forgotten. Wherever possible we must address the specific needs of disabled children who are doubly vulnerable in conflict situations. Where they live in institutions, the staff may have fled and there may be reduced access to food, water and sanitation. When families become refugees, the child's disability may limit movement and eventually restrict access to services and opportunities in a resettled environment. By maintaining a rights-based approach and including children, parents and guardians in planning and decision making, we can ensure that children with disabilities are not discriminated against further in conflict situations.

VI. CONCLUSION & ORGANISATIONAL IMPLICATIONS

In adopting a policy of inclusion of children with disabilities in overseas programming EveryChild is committed to promoting human rights and children's rights as outlined in the UN conventions.

In doing so we must be seen to be adopting an ethical approach to business practice. Where there is no legislative imperative to adopt policy in relation to employment of people with disabilities[4], the organisation should refer to its moral obligations in promoting equality in the workplace in relation to gender, race and disability and is encouraged to follow good practice guidelines. It is recommended that EveryChild implement the requirements of the Disability Discrimination Act 1995.

Further, the report recommends that NGO's such as EveryChild introduce a policy of *mainstreaming*, that is systematically addressing and incorporating measures that challenge discrimination and promote equality for children with disabilities into all programmatic, operational and organisational activities. EveryChild is to propose guidelines and checklists to help it's staff make a policy, of defying prejudice and advancing equality for the region's disabled children, into a reality (see Annex 1) and we hope that this will set a standard for other organisations.

In conclusion, we believe that all agencies interested in addressing the global development needs of the world's children must take systematic action to address the specific needs of those children marginalised by their societies on the basis of disability.

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[4] The Disability Discrimination Act 1995 exempts employers with less than 20 staff or where employees work wholly or largely outside Great Britain

VII. USEFUL CONTACTS

1. UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, (1994) http://www.un.org/esa/socdev/enable/dissre00.htm
2. Child Rights Information Network. www.crin.org
3. News, information and links to disability information www.youreable.com
4. Association for Supported Employment (links to publications/books) www.afse.org.uk
5. European Roma Rights Centre http://www.errc.org
6. Centre for Independent Living - Sofia, Bulgaria cil@aster.net
7. "Dzherelo Centre" for children with cerebral palsy, Lviv, Ukraine dzherelo@icmp.lviv.ua
8. Rebublic Centre for Helping Persons with Mental Handicap - MESSAGE , Madedonia violeta_mk@hotmail.com
9. "Nadiya" Association for Children with Cerebral Palsy, Lviv, Ukraine rehablv@link.lviv.ua
10. BMB rehabilitation devices, sports products and aids for disabled people, Sofia, Bulgaria bmb@bulnet.bg
11. "Viltis" Lithuanian Welfare Society for Persons with Mental Disabilities viltis@post.5ci.lt
12. EveryChild, London, UK www.everychild.org.uk
13. International Disability and Development Consortium www.iddc.org.uk
14. Disability Rights Commission http://www.drc-gb.org/drc/default.asp

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WHO (World Health Organization). 1978. *Classification of Disability*. Document Pro 29, Annex 1. Geneva.

IX. ANNEX I

DRAFT CHECK LIST

DISABILITY MAINSTREAMING AND PROGRAMME PLANNING DECISIONS

I. The Strategic Dimension

What are the needs and issues of concern to local children with disabilities?

Have children with disabilities, their parents and families participated in the assessment of these needs and concerns?

Who should we work with locally to identify the needs of children with disabilities?

Have the needs of disabled children been considered at a strategic level in your country strategy?

Do our local partners consider the rights and needs of children with disabilities on a systematic basis?

What are the weaknesses in governance and capacity that prevent us addressing the needs of disabled children?

What are the weaknesses in governance and capacity that prevent local partners addressing the needs of disabled children?

Are there legislative changes that need to be made to address the needs of children with disabilities?

Are we in regular contact with agencies or individuals who can advice us on incorporating the needs of disabled children into programming?

II. The Operational Dimension

Are the needs of disabled children met in existing projects?

If not, can disabled children be incorporated into existing projects without major restructuring?

Do new projects specifically address the needs of disabled groups?

Have the families of disabled children been involved in the development of projects?

Will the project exclude children with disabilities?

Is it possible to make the project inclusive?

Does the proposed project address the needs of the individual child?

Does the proposed project avoid the medical model of childcare?

Does the proposed project adopt a "social model" approach to children and disability issues?

Will the proposed project shift the balance away from institutional care for children with disabilities?

Have we ensured the development of community based support services?

Will the proposed project support the right of the child to live in their own home?

III. Programme Cycle Management Principles

Does the project advance the rights of disabled children as enshrined in the UNCRC?

Does the project ensure that support and service development for disabled children is co-ordinated?

Is the proposed project culturally appropriate?

Will the project be value for money and sustainable in the local environment?

Will there be an increase in knowledge about disability rights and needs issues?

Will the project increase awareness of disability rights and needs amongst practitioners, professionals, policy planners and legislators?

Will the project increase awareness of disability rights and needs amongst parents, families and children?

Will the project ensure ensured equal access to all children with disabilities irrespective of their national and ethnic origin?

Do you have systems in place to monitor and evaluate how successful inclusion of disabled children has been?

Have we ensured partnership and collaborative approach?

How will the project ensure that the needs of disabled children are considered on an ongoing and systematic basis during and after project implementation?