Disabled Children and Their Families in Ukraine: Health and Mental Health Issues for Families Caring for Their Disabled Child at Home

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SUMMARY. In the Eastern European countries included in the communist system of the USSR, parents of disabled children were encouraged to commit their disabled child to institutional care. There were strict legal regulations excluding them from schools. Medical assessments were used for care decisions. Nevertheless many parents decided to care for their disabled child at home within the family.

Ukraine became an independent country in 1991, when communism was replaced by liberal democracy within a free market system. Western solutions have been sought for many social problems existing, but ‘hidden,’ under the old regime. For more of the parents of disabled children, this has meant embracing ideas of caring for their disabled children in the community, and providing for their social, educational, and medical
needs, which have previously been denied. The issue of disability is a serious one for Ukraine where the nuclear disaster at Chernobyl in 1986 caused extensive radiation poisoning. This almost certainly led to an increase in the number of disabled children being born and an increase in the incidence of various forms of cancer.

This paper is based on a series of observation visits to some of the many self-help groups established by parents, usually mothers, for their disabled children. It draws attention to the emotional stress experienced both by parents and their disabled children in the process of attempting to come to terms with the disabling conditions, and the denial of the normal rights of childhood resulting from prejudice, poor resources, ignorance, and restrictive legislation. Attempts have been made to identify the possible role and tasks of professional social workers within this context. International comparisons show that many parents and their children do not benefit from the medical model of disability, and that serious consequences include the development of depressive illness among those who find that little help is available from public services. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. Email address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2004 by The Haworth Press, Inc. All rights reserved.]

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INTRODUCTION

On the 20th of October 1999 in the UK, Melody Turnbull murdered her two disabled sons for whom she had cared for 23 years. The story made newspaper headlines, leaving the general public shocked and disbeliefing. However, it was probably soon forgotten and replaced by other sensational news events. On the other hand, parents of disabled children and those professionals involved in their treatment and care were probably less shocked, for they were aware of many circumstances where the same thing might have happened. The emotional impact of caring for severely disabled, dependent children is probably too painful for prolonged attention by society.

Throughout the world most disabled children are cared for by their families (Thorburn 1985; Werner 1987; Alur 1987; Bridge 1999). Their
quality of life and that of their parents, families, and carers depends on cultural and religious attitudes, medical, educational and social welfare provisions, and on the legal framework that underpins national social policies. Stark contrasts may be found in qualities of care between developing countries, including those in transition from communism, and the Western world. However, the emotional consequences for families are probably very similar. Many parents feel driven by the need to seek treatments and cures for their children, and to find or develop educational opportunities to enable their child to be included in society.

This discussion paper has as its focus community care provided by families for disabled children in Ukraine, one of the largest of the fifteen states to become independent from the Soviet Union in 1991 and to change from communism to a market economy. As the result of these political changes, Ukrainians have turned to Western Europe for aid in developing a liberal democratic welfare system. This has included beginning to identify the role and tasks of professional social workers, and being more open to Western approaches to caring for disabled children.

In addition, Ukraine is of interest in that the number of disabled and sick children has increased considerably since the Chernobyl nuclear disaster in 1986, resulting in the birth of many congenitally disabled children and the diagnosis of many cases of thyroid cancer. The Soviet government deliberately downplayed the gravity of the situation, partly to avoid panic, but largely because the disaster demonstrated to the world the failing of the communist system.

Western aid has been provided to set up hospitals and health care clinics. An example is the US group FOCCUS (friends of Chernobyl), whose group members have been involved in going to Ukraine to provide training and in taking children and staff of centres in Ukraine to the US. The true extent of the disaster and its long-term effects will never be known as the cover-up has been so extensive (Dalton 1999 pp. 25-30).

Through massive publicity in the media, the world has been shocked by the ‘subhuman’ conditions discovered in Eastern European institutions for disabled children after the transition, particularly those in Romania (UNICEF 1997; Human Rights Watch 1998). However, much less attention has been paid to the many self-help groups, NGOs, and local authority departments of social protection concerned with providing care for disabled children within their families. In common with other Eastern European countries in transition, many social problems in Ukraine, including the plight of disabled children, emerged after having been largely denied and ‘hidden’ under communism, so that very little
definite information exists about the real extent of the problem (Kourkutchian 1998).

The material for this paper has been collected during a series of weeklong visits to Ukraine as a consultant to the newly established School of Social Work at the National University, Kiev Mohyla Academy (KMA), funded by Tempus from 1995 (Ramon 2000). Additionally, a similar visit to the Moscow School of Social Sciences provided an opportunity to observe the treatment provisions at the Moscow Centre for Children with Cerebral Palsy in 1998. In order to develop practice placements for the professional social work students from KMA, a series of consultations took place with social welfare agencies, many concerned with providing for disabled children in the community (Bridge 1999). Some interesting themes emerged from these discussions, providing the framework for this article.

Undoubtedly collecting material in this way has many limitations. First and foremost is the problem of not being able to speak Ukrainian or Russian and therefore being dependent on an interpreter. Also, cultural perspectives are very different and require some understanding. For example, Western visitors are always seen as a source of grant aid, so that information is selectively provided with that in mind. Many others involved in developmental projects in Eastern Europe have commented on these difficulties (Monk and Singleton 1995; Solomon 1994). Nevertheless, an emergent theme is about health and mental health issues for families and their disabled children, an aspect of care with global resonance.

**DISABILITY IN THE SOVIET UNION DURING COMMUNISM**

In order to understand the current situation in Ukraine, it is necessary to consider the historical context for social welfare provision and, in particular, attitudes towards disabled people. Despite obtaining political autonomy, the legacies of communism remain strong; for example, the social security and social welfare systems are based on Soviet legislation, although some responsibility has shifted to the local authorities rather than being primarily work-based. It is crucial, therefore, to examine Soviet attitudes towards the disabled, and the provision of welfare under communism.

Soviet society officially appeared to provide well for the welfare needs of citizens. Full employment was guaranteed and a universal social security system was administered through places of work. Health
care, education, and leisure activities were provided free of charge, and vast amounts of affordable public housing were available in purpose-built apartment blocks.

In his paper to the First International Conference of Social Work in Paris in 1928, Semachko stated that relief of the needy was the responsibility of the State. ‘Any worker in need has the right to be assisted by the State in all cases: sickness, infirmity, old age, unemployment, or distress due to any cause whatsoever’ (p. 533). While vigorously opposing ‘parasitism and begging,’ the principle duty of the State was to provide rehabilitation for all those who have found themselves, by chance, ‘eliminated from a life of normal work.’ For those identified as entitled to assistance, this should be provided in the forms of pensions, institutional care, and ‘special, vocational re-education’ to resume work. So strong was the dual commitment to work and rehabilitation that overnight clinics were set up for workers diagnosed with tuberculosis. After completing the days’ work, those diagnosed with tuberculosis would be expected to go to a sanatorium; replace working clothes with hygienic garments, bathe, eat a healthy meal and sleep with windows open to benefit from fresh air. In the morning they would return to work (Semachko 1929).

Thus, this philosophy appears to have provided for those disabled in war and industrial accidents, so long as they were able to resume productivity. Working people or ‘toilers’ were actively engaged in ‘the heroic construction of the new society’ (White 1999 p. 26). If they did not respond to rehabilitation and retraining programmes, their status was reduced, and political propaganda sought to deny and hide this evidence of a failing political ideology. Social barriers to inclusion in society existed in the form of poor access to buildings and public transport. Inadequate provision of wheelchairs and prostheses ensured that disabled people were largely hidden. Abroad the USSR took no part in the International Year of the Disabled 1981 (White 1999 p. 27).

Those born with disabilities appear to have been even less fortunate. The options were institutional care or being allowed a small pension. Children, assessed as handicapped through stringent medical tests, would usually be admitted to institutions, since legal classification as disabled prevented them from entering mainstream nurseries and schools. Thus, the birth of a disabled child meant that both the mother and child could not be considered as active, valued citizens. While parents or relatives of children less than eight years were considered incapable of gaining a livelihood by outside work, the expectation was that women as well as men would participate in the labour market. ‘Ideally, a woman is expected to
have children, be an outstanding worker, take responsibility for the home, and, despite everything, still be beautiful’ (Manovona in Slater 1995 p. 77). During the Stalin period, until his death in 1953, collectivist values were promoted. State children’s homes were considered to be even better places for the upbringing of healthy children than within families. This policy was discontinued under Khrushchev and Brezhnev (White 1999 p. 31).

Because of this closed system prior to 1991, it is impossible to know how far this political philosophy was implemented over the vast areas of the USSR. There were certainly considerable differences between provisions for urban and rural dwellers, and in different regions. The peasants of Ukraine rural areas were certainly considered to be recalcitrant. The Great famine of 1933 and the severe repressions under Stalin, in order to implement collective farming, had serious effects on the ‘rural base of traditional ethnic philanthropy’ in Ukraine (Kuts 2002 p. 81). In consequence, it is likely that rural peasants lived in poor conditions with little financial, medical, and educational support for their disabled children. In contrast a large well-equipped rehabilitation centre for children with cerebral palsy existed for wealthy party members in Moscow, staffed by teams of highly trained doctors and physiotherapists.

Accurate figures about the proportions of disabled children within Ukrainian society, and about those cared for in institutions and those in the care of their families, are not available until after 1991 (UNICEF 1997 p. 47). However, according to White (1999), ‘despite the totalising aspirations of many party officials and leaders before 1985, Soviet citizens were increasingly forming informal groups and even organisations in an attempt to address some of the unresolved social issues neglected by the official state welfare service’ (p. 17). Many of these voluntary organisations were self-help groups set up by the parents of disabled children as repression of social initiatives subsided under Gorbachev. It is probable that in many areas informal groups existed for many years before 1985 and were tolerated as not being obviously dissident. Kuts (2002 p. 81) writes that the Ukrainian population continued to practice traditional philanthropy at local levels, despite the fact that they were perceived to be acting in their own interests, contradicting a régime designed to eliminate individual and community interests.

It would seem, therefore, that the closed communist system in the USSR before 1991 was probably a mass of contradictions. Propaganda promoted a clear philosophy, but in practice social problems, including the care of disabled children, were provided for in many ways, both formal and informal. Without doubt there were wide variations in provi-
sion. State control co-existed with ‘a non-regulated, informal, crude and pseudo-market system’ as well as a burgeoning voluntary sector (Kourkchian 1998 p. 69, White 1999). How this uncertain system changed and developed during transition in Ukraine is the focus of the next section.

DISABLED CHILDREN IN UKRAINE DURING THE PERIOD OF TRANSITION FROM COMMUNISM

The Transition

The radical change from state control of welfare to a market economy happened suddenly and in an unplanned way. Life in the cities appears prosperous. However, in the country as a whole, poverty has increased as factories and the many associated work-based facilities, including crèches and holiday camps, have closed down. The derelict holiday camps, situated by the lakes in the Ukraine countryside, are evidence of the former glories of the communist welfare provision for citizens. Those still officially employed often do not receive wages for months, but continue to go to work to protect their social security entitlements, and because they are able to obtains materials from the factories that can be sold. Professionals also report waiting for months for their wages, so that subsistence and black market economies are essential for survival.

Commentators on the transition in Eastern Europe have noted that ‘the young, the dynamic, the mobile, the connected’ have benefited most from democratisation and the free market, ‘leaving behind the vulnerable’ (Binyon 1999; Manning 1995). Increases in homelessness, delinquency, child abandonment and alcoholism underline the inadequacies of social welfare strategies (Harwin 1996 p. 172, Manning 1995). While disabled children had always been marginalised under Soviet collectivism, reduction in the value of pensions, and the acute and escalating poverty experienced by families during the transition, could only make their situation worse.

Care in the Community: NGOs and Self-Help Groups

The focus of concern for disabled children in Ukraine has centred largely on those in institutions, and on those disabled and sick as the result of the Chernobyl explosion. So far, less attention has been paid to
the burgeoning voluntary sector provision, and in particular to self-help
groups.

The voluntary sector defies firm definitions, remaining, in Kendall
and Knapp’s words (1995 p. 66) as a ‘loose and baggy monster.’ Vol-
untary organizations range in size from small self-help groups to large
multi-national organizations like the Red Cross. They have in com-
mon a ‘not for profit’ approach, and involvement of volunteers. They
usually provide for special aspects of social welfare focusing on social
problems. Staffed by service users, volunteers, and professionals, they
may advocate and act as pressure groups for social policy change.
Thus, they combine ‘the more passive role of providing a service’ to
individuals, families and groups with identified needs, with ‘an inher-
ently political role’ of providing a ‘critical voice’ about public policy
(Reading 1994 p. 13).

The voluntary sector in Ukraine is as diverse as in the rest of the world.
Kuts (2002 p. 80) explains that ‘Ukrainian philanthropy in its collective
manifestation is rooted in antiquity.’ Informal support from family and
neighbours has always been vital, especially in rural communities. Al-
though repressions during Soviet times and the Great Famine of 1933
damaged this traditional philanthropy, communal philanthropy recovered
during the last years of socialism, and the tradition was urbanized with the
rural migration into the cities in the 1960s. Kuts (2002 p. 81) reports that
‘Ukrainian people still consider the community as the basic provider of
social support.’

After ten years of transition, some distinct themes may be identified
by Western observers about the development of informal and formal so-
cial welfare voluntary groups. The most striking features are how nu-
merous they are, how quickly new projects spring up, and the range of
problems for which they are designed. Many are set up as self-help
groups, whose interests were denied under communism. Coordination
between groups with the same interests in different areas seems to be
lacking, and usually discouraged as there is competition for outside
sponsorship.

Visitors gain an impression that a top priority for these organisations
is to obtain Western sponsorship so that, instead of collaborating with
each other and seeking alliances, the mood seems to be one of competi-
tion to entice visitors to their projects. While there is a real need for
sponsorship, this persistent agenda stands in the way both of useful col-
laboration between groups with similar interests, and of the genuine ex-
change of ideas.
An example of this dilemma was a visit to a self-help group, with the intention of advising the leader on ways to improve the centre. She was enrolled as a part-time student on a social work course at the KMA, so the aim was to help her to apply her learning to practice. However, the opportunity for seeking sponsorship from Western visitors proved too good to miss. Thirty mothers were present at the meeting, each accompanied by their disabled child, and each child's history was told in great detail. The most heart-rending aspect to this was the knowledge that many of these children’s lives could have been improved considerably with access to Western educational and medical services. The young adults would have been able to find employment in supermarkets, for example.

The priority given to fund-raising also caused some unease as the strength of corruption and duplicity is well known in Eastern Europe. Lloyd (1998) describes Russian society as ‘permeated by crime from top to bottom’ because in Soviet society so many normal activities were against the law. In relation to developing social welfare, Ramon (1995 p. 51) explains that ‘the boundary between legitimate perks and small scale corruption is not simple to determine for Western participants, when there are cultural subtleties to which they are not party . . . and there is the argument that everyone is behaving in this way.’

Donor concerns about dishonesty were also linked to frustrations caused by the endless bureaucracy associated with any provision of aid. An example of this was the gift of a bus to provide transport for disabled children from their homes to a voluntary project. The donors discovered that, for several months, the bus could not be used because it had not been licensed, and equipment for disabled children was locked away in order to prevent it from being stolen.

There were several opportunities to examine this burgeoning voluntary sector at first hand on visits as a consultant to work-based social work students from the KMA. It became apparent that these projects were initiated by mothers in response to two main factors: Firstly they wanted to save their disabled children from institutionalisation, and secondly they wanted their children included in mainstream activities, especially education. An example of the stringency of the legal regulations, requiring the segregation of disabled children in the community, was the rule that disabled children were not allowed to swim with able children.

This caused problems for a mainstream kindergarten used outside school hours by groups of disabled children. The Department for Education was not happy with proposal for disabled children to use the pool on the premises, and was looking for Western sponsors to refurbish an
unused crèche building nearby. The local school inspector explained that, apart from the regulations, she believed that the disabled children would be happier in a separate place of their own. This also seemed to be the views of parent initiators of the self-help groups.

The categories of children provided for in these specialist projects were usually identified by the disabling condition of child of the parent founder, although, in practice, many children tend to be multiply disabled. The parents had usually found accommodation in a building, previously used as a crèche in Soviet times, but shut down once the factories closed, and unemployment meant mothers could not afford day care and therefore did not need the facilities. The initiators tended to be articulate middle class women with professional training who were unwilling to accept their child’s hopeless prospects in society, and set about providing alternative forms of education, treatment, and day care.

Education

Most of the projects had an education focus, being alternative schools with parents as teachers. Some of these groups had been in existence for many years, and the parents/staff were anxious about the absence of work prospects or continued training for their young disabled adults. One project was seeking funding to set up a special centre for those too old for school where they might continue to learn skills for daily living, including cooking and laundry. Underlying this proposal were the fears of parents internationally about the care of these young adults, when their parents became too old to care for them or died. Having avoided institutional care throughout childhood, there seemed no escape in the long-term.

Teaching methods in these alternative schools tended to be pedagogic as is the custom in Eastern European education. Instruction and small formal group tasks were the usual practice. For example, a teacher of art painted her version of a butterfly and pinned up her painting for a group of six children with cerebral palsy to copy. They sat round a table each with some paints and a piece of paper. The teacher then proceeded to go round to each child in turn guiding their hands so that, by the end of the lesson, each of them had reproduced a copy of the butterfly to take home.

Medical Treatment

In many centres this educational focus was combined with medical treatments. These were based on the espousal of the medical model of
disability challenged fiercely by writers about the disability movement in the West, Finkelstein (1980), Oliver (1990), and Barnes (1991) for example. The underlying aim might be described as attempting to ‘cure’ a child, or to achieve as much ‘normality’ as possible, so that a child might recover sufficiently to be allowed access to mainstream services.

The treatments offered depended on the knowledge and skills of the staff. It was apparent that a range of extraordinary treatment approaches was available. Many of them appeared to have doubtful value from a Western perspective; they were difficult to understand, and seemed painful, even punitive. We were shown ‘the cabinet of electric sleep’ where children lay on beds in a dormitory wired up to electrodes. This treatment was supposed to produce a calming effect, as was using an electric comb. There were herbal treatments for undernourished children, and a version of speech therapy appeared to involve pulling out the child’s tongue and twisting it. Entering what was called a treatment room, we discovered a group of asthmatic children sitting round covered in white sheets looking like little ghosts as they inhaled special minerals infused into the air. The worst example of both doubtful medical value, and questionable ethical practice, was the regulation that children with cerebral palsy were required, by law, to have brain surgery to insert foetal material to restore damaged brain tissue. The requirement seemed to be related to establishing eligibility for disability pensions. This raises the ethical question about the sources of this foetal material in view of the fact that abortion is the dominant form of birth control in Eastern European countries (Hyde 1999).

The continued use of outdated treatment methods in Ukraine appears to be another example of the very variable standards of treatment and care available to citizens throughout the USSR. Health, medical care and training were prioritised under the Soviet system. Semachko (1929) gave a detailed description of medical facilities including Institutes for Physiotherapy and Orthopaedics in Leningrad and Moscow, although these were intended for those wounded in industrial accidents or in wars rather than for disabled children. However, in the 1970s Moscow parents of children with cerebral palsy initiated a project to build a rehabilitation centre, which opened in 1990 (White 1999 p. 62). Currently this centre provides Western treatments including hydrotherapy and Vojta physiotherapy, treatments rarely available in rural areas of Eastern European countries. The exceptions are Western sponsored projects, including the German sponsored rehabilitation centre in Chernobyl. It seemed that, despite being charitably funded, this centre charged patients for treatment so that access was restricted to those able to pay.
All the self-help projects lacked essential disability aids like wheelchairs and physiotherapy equipment so that conditions, with potential for improvement, were left untreated. These obvious privations were distressing to observe for those aware of possible, effective Western treatment approaches. The same could be said about educational materials including computers, paper, writing equipment, and toys. The ingenuity used by the staff to produce handicrafts out of household packaging and odds and ends was impressive. Very few children produced handicrafts for sale, although their art works and handicrafts brightened up the rather drab premises.

**DAY CARE**

Despite the educational and treatment aims of the staff, these centres also provided day care for the children of working parents and for those unable to cope. Some were open from 8 am until 6 pm, and cooked meals were provided. Non-participatory mothers were criticised by the staff, whose lives seemed to be devoted to their child’s world and the associated problems of disability. From a more sympathetic perspective, these mothers were often single parents trying to care for their disabled child at the same time as going to work.

This raises the question of how many children cared for by their parents were actually able to attend one of these centres. In Kyiv the Education Department provided peripatetic teachers for disabled children confined to their homes. This service was not available in rural areas and appeared to be less effective than it might have been since parents reported that the teachers were unreliable. It is probable that many disabled children are confined in small city tower block apartments and in rural dwellings for a number of reasons including inadequate transport, inclement weather, attitudes of shame, and poverty.

This situation echoes that in many parts of the world, the UK being a prime example, where middle class parents fight for and provide resources for their disabled children (Bridge 1999). The increase in rural poverty with associated ignorance and superstition means that it is likely that there are still many ‘hidden’ disabled children. A case study presented by a student, during a consultation, involved a young adult with Down’s Syndrome being kept tied up in the farmhouse while his parents worked. Initially they refused offers of institutional care by the Department of Social Protection because they had hoped he would be able to work on the farm. His violent behaviour, resulting from this cap-
tivity, meant they could no longer manage, and they agreed to accept the offer.

Therefore, despite the media attention to the plight of disabled, abandoned and orphaned children in institutions in Eastern Europe, access to Western views about the need to close them down and to develop a social model of disability towards caring for children in the community, appears to have had only minimal effect. Many authors have described projects to develop fostering and to begin the process of reducing the number of children in institutional care. However, these projects can only provide local and relatively small-scale improvements (for example, Tresiliotis 1994; Kukauskas 1999). Indeed, evidence from many sources indicates that numerous initiatives, buoyed by international assistance in Russia and other countries of the former Soviet Union, have not succeeded in alleviating the pressure on orphanages or in developing a coherent system of community support able to reduce the need for public care’ (Harwin 1995 p. vii). It is possible that the trend reported by Bertmar (1998) for really poor families in Armenia to obtain places in institutions, by trying to have their children registered as handicapped, may also be prevalent in rural areas of Ukraine.

**RELATIONSHIPS BETWEEN NGOS AND THE STATUTORY SECTOR**

How projects for disabled children relate to the statutory authorities is interesting. They are working in partnership and receiving considerable assistance. The Education Department may provide premises and pays the costs of utilities. Additionally, the Department pays the teachers’ salaries. It appears that voluntary organizations have to bargain with their local authority, agreeing to seek sponsorships in return for some assistance. Therefore, much depends on the interest of local authority officials, and on the bargaining power of the proposers. Concern was expressed about future mergers of local districts that might disrupt these alliances. Also, there are problems about the overlapping but extensive responsibilities of Education, Social Protection, and Health Departments.

Kuts (2002, p. 80) expresses strongly the view that the state is unable to satisfy basic social needs through ‘ineffectiveness of public management.’ However, it does appear that, in some areas, the statutory sector has begun to accept some responsibility for contributing to meeting needs of formerly disadvantaged groups. This could be the result of the many training oppor-
tunities offered to staff. For example DFID (Department for International Development, UK) has encouraged KMA to give priority for places on their modular courses to staff seconded from Departments of Social Protection. That local authorities are either unable or unwilling to fund projects fully has the effect of making their futures uncertain. The frustrating fund-raising activity of such organizations is a constant dimension to their work. As funding is usually time-limited, these organizations will always be precarious. While the success of the organization described here is to be admired, it may be that obvious success may discourage future sponsors on the grounds that their help is no longer necessary. In this case the local authorities will either have to accept full responsibility, or witness the closure of a valued resource.

**SOCIAL WORK EDUCATION**

Attempting to define the role and tasks of social workers within the context of these self-help groups is not easy. Above all, it is essential to avoid taking a Western blueprint for how professional social workers might be employed. In their Definition of Social Work (2001), the International Federation of Social Workers (IFSW) states that ‘the holistic focus of social work is universal, but the priorities of social work practice will vary from country to country and from time to time depending on cultural, historical, and socio-economic conditions.’ The challenge for those developing social work in Eastern Europe has been to stimulate social work activity appropriate to time and place in societies experiencing radical change (Bridge 1999; Slater 1995; Jack 1996; Horwath and Shardlow 2001).

From the discussion in this article, there appear to be four main areas for social work intervention. The first is on a therapeutic level with parents and with disabled children themselves. This should lead into the second, which is about promoting a social model of disability at both local and national levels. The third is about developing better understanding of multidisciplinary work, and the fourth is improving management of organizations, including fund raising. This is an ambitious list, but covers the areas discussed previously.

Experience of training social work students over this period of six years has shown that perhaps the most crucial area of learning is about management of organizations. This encompasses staff supervision and training in professional roles and their boundaries. Since the founders of these voluntary groups are usually involved as users and carers, they be-
lieve in promoting social justice; they have knowledge of the social problem they intend to address, but they welcome training in staff management issues and in the training and management of volunteers. Staff conflicts are likely to be heightened when staff members are personally affected by the service.

Social work activity must be divided between campaigning for social and legal change, and meeting the needs of service users. Zaviršek (1999) comments about developing social work in Slovenia, that political activity is necessary to counteract seventy years of repression. For social work education to have relevance to the burgeoning voluntary sector in Ukraine, the syllabus must include both political and therapeutic dimensions.

CONCLUSION

In many ways the collapse of the Soviet Union and the end of communism has been celebrated as the end of a repressive era, and an opportunity for the people of Eastern Europe to benefit from a free market economy and access to Western ideas and achievements. In practice, those monitoring the transition over the past decade have commented unfavourably on the social inequalities that have ensued and the emergence of serious social problems, previously denied or catered for through state welfare.

Since 1991 it has become possible for Westerners to obtain a better understanding of the extent and nature of the problems concerning disabled children in Ukraine. For parents and professionals in Ukraine it has become easier to access information about alternative treatments, equipment for the disabled, and educational approaches. The leaders of the self-help groups are active searchers on the Internet as a source of both possible sponsors and of information to improve the quality of their children’s lives. The courage and tenacity of the parent leaders in the voluntary sector is admirable.

However, the emotional pressures they are under have actually increased as the result of access to Western solutions. Their involvement in voluntary activity, with its associated process of seeking sponsorship through the private sector, is clearly totally inadequate to meet the needs of the large numbers of disabled children living with their parents in the community.

In addition this paper has drawn specific attention to the limited educational and rehabilitation facilities available to disabled children. In
particular concern has been expressed about certain treatment methods that appeared to be ‘medieval,’ punitive, and of doubtful therapeutic value. It appears that the developmental, social and emotional needs of many of these children are being sacrificed in the search for improvements and cures. This is little different from the desperate searches for effective treatments by parents of disabled children throughout the world who tend to put their faith in inadequately researched treatments (see Bridge 1999 chapter 10).

Caring for disabled children in Ukraine has become a public issue as the result of increased access to Western ideas and resources. However, this process has the inevitable resulting consequences of heightening stress for both parents and their children, as they experience deep envy and frustration that resources in other parts of the world are out of their reach.

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