



***On the Record: Civil Society in Kosovo – Rebuilding After the War***

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**From the AP Editorial Desk by Iain Guest**

One of the questions asked at the outset of this series was whether international aid agencies understand civil society. This issue provides some answers.

Disability is not normally high on the list of priorities when it comes to rebuilding wartorn societies. Certainly, it ranks far below ensuring security, restoring the rule of law, rebuilding the economy, protecting minorities, and punishing war criminals.

The same applies to representative organizations. When aid agencies are selecting partners, they usually turn to human rights groups, women's associations, cooperatives, and student unions -- but not those who represent the disabled.

This betrays a profound misunderstanding of the strength and weakness of civil society. More than any other single group, disabled people show that the experience of war and repression can be a source of strength as well as suffering.

It is not that hard to understand. To be disabled in Kosovo over the last ten years was to be triply disadvantaged. First, there was the physical and psychological strain that faces any disabled person. Second, there was the dependence on a Serbian government that withdrew all social support from non-Serbians when the autonomy of Albanians was revoked in 1989.

And, third, there was war. War is hell on its victims, but it is particularly hellish for the sick, the young, the old, and the disabled. There is a description in the profile that follows of how paraplegic refugees in the Macedonian camps were tossed helplessly about like bundles and left to lie on the open ground without wheelchairs.

Anyone who rises above an experience like this and comes back stronger is truly remarkable. If the international community is looking for self-reliant partners, one might think they would look to people like Halit Ferizi and his organization HANDIKOS.

Halit has not been ignored. Handicap International and Oxfam supported his group from the mid-1990s. The unit of the Organization for Security and Cooperation in Europe (OSCE) that promotes democratization has made an effort to include HANDIKOS at its coordination meetings for local NGOs. But, as Halit observes in this profile, the disabled are classified as a 'minority' for administrative purposes by the OSCE. They do not even qualify as an identifiable category.

Because its mandate is to build democracy, the OSCE has more reason to appreciate a group like HANDIKOS than relief agencies. From the vantage point of an aid agency, disabled people will be high on the list of victims who need their help. Their representative organizations will only be useful to the extent that they can supply interpreters, drivers, guards, translators, or an outlet for emergency aid.

This accounts for the fact that agencies hired away ten of the most talented members of the HANDIKOS community network of supporters. These were people who had been trained and were performing a vital function in the villages. (None are themselves handicapped. So HANDIKOS was denied even the satisfaction of seeing one of its disabled members earn an international wage.)

Such things are not callously done. The kind of community support provided by HANDIKOS is simply not deemed useful for reconstruction.

There are solid practical reasons to change this. Any investment in the disabled is almost guaranteed to yield solid, long-term results because unlike the hungry and the homeless, disabled will not move on once their home has been built or food produced. They will make sure any assistance is used well. And such are their numbers, that any support for them is likely to have a major impact on the entire community. According to the World Health Organization, on average 3 percent of a population suffer from physical disability. Multiply that by seven to include family members, and one is talking of over a quarter million Kosovars. This is many times more than the province's entire minority population.

One other point needs to be made. Precisely because of their physical limitation, disabled people depend to an unusual extent on communicating with each other and with allies and friends abroad. This makes them a perfect candidate for an Internet connection and web-based advocacy.

But first they need some security. Two days before an associate of the Advocacy Project went back to talk to Halit Ferizi at the end of February, the HANDIKOS office was broken into and all

their office equipment was stolen. Halit was close to tears and close to calling an end to his brave initiative. The day of the break-in there were 30 robberies in Prishtina. Halit himself has been robbed three times at home.

It was hard to know who to blame most -- Albanians for turning against their own vulnerable people, or the international agencies for not providing better security. Either way, it was a depressing reminder that the disabled are not a priority in Kosovo.

From Iain's Diary:

Imprisoned by a wheelchair and framed against a montage of triumphalist graffiti on the wall, Halit Ferizi welcomes me to his shabby office in the Dardania suburb of Prishtina with a huge smile and a barrage of questions.

Halit has spent half a lifetime spent fighting disability, but he now concludes that life is looking up. He sees a huge opportunity in post-war Kosovo. He is convinced that the international agencies will be receptive to his message and his model of advocacy. After 25 years of campaigning for the rights of the disabled, his moment has come. This man is an inspiration. I am amazed that this dirty little corner of Europe, which has known such hatred, can produce such people.

### **Profile: Halit Ferizi and the Struggle Against Disability**

Halit Ferizi is president of HANDIKOS, the Association of Paraplegics and Handicapped Children of Kosova, a coalition for the disabled that was established in Kosovo 20 years ago. He is proof of the paradox that physical handicap can inspire reconstruction.

It has been a long and tortuous journey since the car accident in 1974, which almost cost Halit his life. Halit was fortunate; as a state employee he was entitled to medical care. After a spell in hospital in Belgrade, he went for rehabilitation at a seaside center in Montenegro.

The weather was good, but the company was better. They were, like him, disabled people from Scandinavia and the Balkans who refused to give up: 'Every night there was wine, and a party on the beach. They forced me to forget my disability. I started to feel normal and accepted. I realized that you can be a good lover, a teacher, a swimmer -- even a driver -- even if you are disabled.'

Finally it was time to return to his village in Kosovo. He came down to earth with a jolt. His family cried over him and commiserated. They turned him into a victim and made him feel deeply depressed. He decided that he would go mad if he remained, so he moved to Prishtina with his wife and daughter determined to take the initiative.

Scandinavian friends urged Halit to form an organization, but under Serbian law this required a board of ten disabled persons. He spent two years trying to find volunteers. One paraplegic had been bed-ridden for four years, and the wall in his bedroom was pock-marked from his despairing blows. 'Give up,' he told Halit. 'We're incontinent. We're not normal.'

Halit concluded that the man's problem was not disability, but his uncomprehending family. Together they persevered, and on November 28, 1983, the man agreed to join Halit in creating a new organization for the handicapped. There were 35 initial volunteers, included 12 of whom were handicapped.

They had to battle the mentality of centralized government. Several other organizations existed for the handicapped (blind, deaf, even World War II invalids). But all were state-run, and only one was managed by disabled persons. It took three years to persuade the organizations to work together under a single coordinating board, with Halit as president.

Even then, the decisions were made by the state. The organizations for the handicapped were entitled to lottery money, but it was the state that decided who got what and issued the licences. The state also insisted on creating special schools for the disabled. It was the antithesis of self-help.

### **Disability and the Parallel Society**

The mixed blessing of state support came to an abrupt end in 1989, when Belgrade suspended Kosovo's autonomy and cut government support to all organizations in Kosovo that were not run by Serbs. This forced six of the seven groups to close down. The one exception was the organization for the blind, which was taken over by Serbs. It had been supporting over 1,000 blind Albanians and only 20 Serbs. Nonetheless, the blind Albanians were struck off the list of beneficiaries.

For the next nine years, disabled Albanians received no financial support from their (Serbian) government. But Halit and his friends continued to meet, plan, and do what they could.

The needs were growing exponentially. The Serbian authorities revised the lists of socially needy and struck off all Albanians -- instantly depriving almost 20,000 disabled Albanians of state support. Albanian workers were dismissed from their jobs. It was particularly hard for those with a disabled child.

By 1993, as the crisis was getting worse, Halit had his first contact with a foreign agency, Handicap International. Several months later, Handicap International delivered a large consignment of wheelchairs, crutches, and hygienic parcels. Determined to update the lists of handicapped Kosovars (which were out of date by now), Halit and his friends turned to the main Albanian political party (LDK) and the Mother Teresa Society (MTS), which both had extensive contacts in the villages. Within weeks, they had identified a network of community representatives, whose task was to assess the needs of the disabled and visit homes. Twenty-five local groups were created.

Within two years, the network had produced a new nationwide survey. It registered the names of 6,970 disabled persons. This meant that at least 40,000 Kosovars were affected by disability, if one included families.

These families suffered on several different levels. Like all Kosovars, they were short of money

and food. Medical treatment was intermittent, which was particularly difficult for those with a medical condition. In addition, said Halit, parents were deeply depressed and unable to understand their children's disability: 'All they could think of was getting those small, deformed bodies taken abroad for treatment.'

Halit's organization HANDIKOS began to focus on the parents. It invited a group of 20 to Mitrovica and suggested that they should start meeting with each other in their own homes. Parents responded by setting up two community rehabilitation centers in Gjilan and Prizren. Handicap International increased its support and sent in experts in physiotherapy and psychosocial support.

Another group to help was Oxfam, which offered training in advocacy. This approach was different from a service. It asked the disabled to view their situation in terms of the human rights of disabled, which are clearly enunciated by U.N. standards and rules. It argued that segregating the disabled was a violation of these rules. It urged the disabled to lobby and to argue -- even if no one seemed to be listening.

The efforts paid off. By the time of the war, 320 volunteers were working for disabled throughout Kosovo. This seemed hardly sufficient for an affected population of 40,000, but it was a fantastic achievement given the obstacles thrown in their way by the Serbian government. Indeed, in terms of sympathy and support from their fellow citizens, handicapped Kosovars were much more fortunate than their counterparts in more developed societies. It was one of the unsung triumphs of the parallel society.

### **Disabled in the Refugee Camps**

All of the gains were washed aside in the war last year. For Halit, as for many activists, the crisis began in 1998 with the fighting in Drenica. There were disabled among the refugees that flocked into Prishtina. They were generously received, but it was impossible to find proper beds, wheelchairs, or crutches for them in the makeshift centers.

With the onset of the refugee crisis and the NATO bombing, all pretenses were thrown aside. Serbian forces treated disabled people with contempt and cruelty.

Paramilitaries came for Halit on March 30 and ordered him out of his home. There followed several days of extraordinary adventure. Halit drove to the border with his niece, who was expecting a child. They were separated, and he found himself in a massive convoy of cars that was diverted into a cement factory and then ordered to return to Prishtina. Somehow he managed to slip away and made it across the border.

Along the way he saw horror. 'Disabled people were picked up and tossed about like sacks. Wheelchairs were abandoned.'

Yet it was hardly surprising, given the vicious nature of the conflict. Halit was met at the border by Oxfam representatives. They visited the refugee camps and found desolation and despair -- disabled people curled up on the bare, cold ground. Halit threw himself into the emergency and

set about organizing emergency assistance. At least there was no shortage of money and international assistance here at the border.

### **The Postwar Challenge**

The challenge that faces Kosovo's disabled has shifted again since the end of the war. On the one hand, the number of disabled has risen alarmingly. Over 9,000 are now registered by HANDIKOS. In early December last year they included 340 persons injured by landmines and many more by cars. In one 80-kilometer stretch of road, Halit spotted eight accidents. 'Old cars and bad drivers are creating a new generation of paraplegics and spinal injuries,' he said sadly.

But if the crisis has grown, so have the possibilities presented by the large international aid mission. In the view of Halit, this offers a 'historic opportunity' to get the needs of the disabled integrated into the reconstruction of Kosovo.

Halit has thrown himself into the fray with customary vigor. He has tailored his advocacy to two different types of allies -- international nongovernmental organizations (NGOs) and intergovernmental agencies. He would like to see the NGOs doing more on long-term social problems and less on the short-term emergency. He also feels that too many NGOs gravitate to the part of the country where their national NATO contingent is based, instead of where the needs are. At the same time, he has nothing but praise for his two main NGO partners, Oxfam and Handicap International, which have continued to support the group. Handicapped International produces prostheses and provides physiotherapy for landmine victims. Oxfam continues to provide advice on advocacy (although Oxfam's specialist had just left when we talked, causing some concern at HANDIKOS).

### **The U.N. Mission in Kosovo: Indifferent to Disability**

The intergovernmental agencies are a different matter. In many respects, they are singularly insensitive. In their hunger for translators, the international agencies have snapped up at least ten of the most talented HANDIKOS (non-disabled) volunteers -- leaving large holes in the community network. But not a single disabled person has been hired as an interpreter, so benefiting from the large U.N. salaries.

UNMIK and its agencies pay far too little attention to the special needs of those in a wheelchair, said Halit. He cannot attend meetings of the UNHCR's community officers because they are held on the second floor of a building whose elevator is broken. When UNMIK arranged a meeting between local civic leaders (including Halit) and the visiting U.N. Secretary-General Kofi Annan, Halit had to be carried up two flights of stairs by guards. He remembers being pushed from behind by the Secretary-General's entourage on the way up.

The OSCE is establishing a 'democracy cafe,' where NGOs can meet and use the Internet. But Halit will not be able to access part of it, because it is built underground. Even the ramps that are built for HANDIKOS are often inadequate. One of the ramps built in the town of Peja, he said, is 'positively dangerous.'

But these are merely the latest in a long line of obstacles, and true to form Halit has tried to turn them to advantage. He aims to improve the standards for ramps and make sure that these are built into every public building constructed in Kosovo under the U.N. program. If this can be done early enough, it will cost no extra money.

Another goal is to ensure that disability is treated as a distinct issue by the international agencies. Of all the agencies, the OSCE is most sensitive, said Halit. He was elected to one of the 14 seats on a Council of NGOs chosen under the auspices of the OSCE. But he is dismayed that the council has not created a subgroup on disability, preferring to put the disabled in the category of 'human rights and minorities.' He plans to lobby hard with the OSCE and UNMIK in the months ahead.

HANDIKOS has grown, and for the time being his budget is secure. There are 160 persons on the payroll, receiving between 200 and 300 D-marks a month (Halit himself receives 700 D-marks). Seven people are on the staff in Prishtina, two of whom are disabled. But Halit wants to decentralize and reinvigorate the HANDIKOS network in the villages. He is thinking of converting all 25 groups in the countryside into independent NGOs.

### **Exciting Future**

When we met last December, Halit was upbeat, looking forward to an exciting few months. Everything was up for grabs -- from the design of wheelchair ramps to the drafting of laws.

In such a climate, a skillful advocate can go far. Halit knows it and is refining his skills. He wants to extend his international contacts. He was impressed by what he read of the anti-apartheid movement in South Africa. He has met other campaigners, like Faruk Sabanovic, the young Bosnian who was paralyzed by a sniper in Sarejevo and created an inspiring movement. Halit wants to organize a conference with others like Faruk, to exchange views and campaigning ideas.

As befits a restless man with limited physical outlets, he is hungry for ideas and news. He wants to hear from the European Commission, from the Forum on Disability, and from the Spinal Chord Injury Association, which provides useful practical information. He wants to hear from everyone who is interested. It is hard to think of anyone making better use of the Internet.

Unfortunately in early March, 2000 the Handikos offices were broken into and the donation of computer and office equipment they had just received was stolen. Although Halit was depressed about the loss for him it was just one more obstacle to overcome. Halit is starting again from scratch but with the knowledge that computers and communication are indispensable to his work. The Advocacy Project is working with Halit to develop a technology plan that will aid him and Handikos in fulfilling their mission and be accessible to all their constituents.

Despite his disability, he is in many respects, the personification of civil society, and an inspiring example of what is possible. 'Civil society means taking control of your own life,' he says. 'We are ready to assume our responsibility. They cannot make democracy without us.'

- Name: HANDIKOS, Dardania, Prishtina T +381 38 40834, 43 806 email: [handikos@eunet.yu](mailto:handikos@eunet.yu)

## **Battling the Apartheid of Disability: The View From Kosovo**

*The following analysis was written by Halit Ferizi, the director of HANDIKOS (Prishtina). It is reproduced here at Halit's request.*

### **Part One: Understanding a Society with Disability**

It is important to recognize that there are segments within the disabled community that have experienced greater discrimination than others. They also experience exclusion from social, political, and economic spheres of life. Special attention must be given to understanding and redressing the conditions that have made them vulnerable in this way.

It is important to achieve the paradigm shift from medical treatment to social support for the disabled. This only occurs when disabled people create a strong organization. Central to the concept of the 'social model of disability' is the principle of self-representation by people with disabilities. This must involve the creation of an NGO. One of its first tasks must be to articulate the claim to respect the human rights of those with disability.

The following are the most vulnerable groups:

#### **Women with Disability**

Kosovar society is still extremely narrow-minded. Although attitudes have changed, women are still treated as second-class citizens, subservient to man and in need of protection. Their role in society is seen as homemaking. Women with disabilities experience the same oppression as non-disabled women, but often without even enjoying the status that women traditionally receive as mothers or wives.

The consequent isolation of women with disabilities means:

Women with disabilities are more likely to be poor; Women with disabilities are more likely to be malnourished; Women with disabilities are more likely to be illiterate; Women with disabilities have a lesser chance of founding a family.

A woman who bears children with disabilities often faces rejection and even scorn. Such women, especially in poor areas, often find themselves excluded from social and economic activities due to the additional attention they have to provide to their disabled children and the lack of facilities. Stigma, or the fear of stigma, is likely to increase a woman's social isolation in society.

#### **Children**

Kosovar society still regards children with disabilities as incapable, ill, and a burden on society. This means that their problems are dealt with separately from other children's activities. Children with disabilities are unable to defend themselves. They are often alone at home and are undervalued. All this makes them particularly vulnerable to physical, sexual, and emotional abuse.

Children with disabilities fear being excluded from a very young age, yet they are often separated from family and society. On the other side, non-disabled children learn that the

exclusion of children with disabilities is normal and socially acceptable.

This exclusion has a particularly serious effect on other non-disabled siblings. These tensions are frequently exacerbated when professionals take over decision-making from the parents, and insist that 'they know what is the best for their child.' As a result, the mother may lose confidence in her abilities not only as a mother, but also as competent human being.

### **People with Severe Intellectual or Mental Disabilities**

The needs of people with severe mental or intellectual disabilities are often thought to fall outside the gambit of development. Such people are likely to be regarded as 'ill' and 'in need of constant care.' As a result, they are not provided with opportunities to participate in society to the best of their abilities. They are also particularly vulnerable during the period of transition from institutionalization toward community-based services.

Investigations in recent years have unearthed gross human rights violations in institutions for people with mental or intellectual disabilities. They are particularly vulnerable when confronted with the justice system. Their testimony is often not taken seriously. They are not regarded as reliable witnesses. They seldom have access to advocates through whom they can speak.

People with severe intellectual disabilities living in rural areas often have low life expectancy, due to lack of care support and access even to the most basic services. Families can seldom meet the cost of visits to hospitals, let alone the additional expense required for equipment, assisting devices, and other necessities.

### **The Elderly**

The percentage of disabled people in a society increases dramatically with the onset of old age, and the increase of the population in Kosovo has caused an increase in the prevalence of disability in its society. Poor access to home-based health and social services, especially in rural communities, means that elderly people with disabilities often live in the back rooms of their children's homes. Public transport is inaccessible, and barriers exist all around in buildings. This means that services aimed at the elderly seldom reach those with disabilities. This causes isolation and depression.

### **Rural Dwellers**

About 70 percent of those with disability in Kosovo live in rural areas without medical, institutional, social, or educational support. They lack security. Often, their houses have no sanitation in the form of bathrooms or toilets. Their houses have no water. There is no organized public transport.

### **Youth**

Youth with disabilities are less likely to access youth development programs than their peers, for the same reasons as other groups with disabilities. As with other groups, it is also important to note that there are specific sub-groups that experience particular difficulties.

## **Part Two: Causes of Disability**

Many factors are responsible for the rising number of people with disabilities and their consequent isolation from the mainstream of society:

### **Violence and War:**

Especially as they affect women and children; injuries as a result of landmines, and psychological trauma.

### **Poverty and Unhealthy Living Conditions:**

Disability feeds on poverty and poverty on disability.

### **Lack of Information:**

People do not have correct information about disability, which gets in the way of treatment. This is a consequence of poor knowledge about basic social, health, and education services.

### **Failure of Medical Services:**

Insufficient primary health care and genetic counseling services; weak organizational links between social services; faulty treatment of accident injuries; and the incorrect use of medications.

### **Lack of Health Education:**

Misuse and/or abuse of medication; abuse of drugs and other substances; deficiencies in essential foods and vitamins; stress and other psychosocial problems.

### **Environmental Factors:**

Epidemics; accidents and natural disasters; pollution of the environment and poisoning by toxic waste and other hazardous substances.

### **Accidents:**

Industrial, agricultural; transport- or sport-related accidents.

## **Part Three: International Programs**

### **The World Program of Action Concerning Persons with Disability**

The United Nations declared 1981 to be the International Year of Persons with Disabilities. This was promoted by nongovernmental organizations (NGOs,) who adopted the theme of 'Full Participation and Equality.' The most important outcome was the adoption of the World Program of Action Concerning Persons with Disabilities, during the U.N. decade of persons with disabilities (1983-1993). The purpose of the World Program was to promote effective measures for the prevention of disability, rehabilitation, and realization of equal opportunities for persons with disabilities.

## **Standard Rules on the Equalization of Opportunities for Persons with Disabilities**

The United Nations facilitated the drafting of the standard rules for the Equalization of Opportunities for Persons with Disabilities to provide governments with clear guidelines on action to be taken. The U.N. General Assembly adopted the standard rules on December 20, 1993. The rules imply:

- a strong moral and political commitment by the state to take action for the equalization of opportunities for persons with disabilities.
- offer an instrument for policy-making and action. The purpose is to ensure that all persons with disabilities may exercise the same rights and obligations as other citizens.
- outline crucial aspects of social policies in the disability field, and provide models for the political decision-making process required for the attainment of equal opportunities.
- propose national mechanism for close collaboration between the state, United Nations, NGOs, and private sector.

The aims of the standard rules are to:

- stress that all actions in the field of disability presuppose adequate knowledge and experience of the conditions and special needs of persons with disabilities;
- emphasize as a basic objective of socioeconomic development that every aspect of the organization of society is made accessible to all;
- outline crucial aspect of social policies in the field of disability, including where appropriate, the active encouragement of technical and economic co-operation;
- provide models for the political decision-making required to attain equal opportunities. This should bear in mind differing technical and economic levels and the cultural context. It should also ensure a role for persons with disabilities;
- propose national mechanisms for close collaboration among states, the organs of the U.N. system, and other intergovernmental bodies and organizations of persons with disabilities.

## **International Standards and Instruments**

International standards and instruments addressing the rights and needs of persons with disabilities include:

- The Universal Declaration of Human Rights (1948);
- The European Convention on Human Rights of November 4, 1950, with all later Protocols and Amendments;
- Declaration on the Rights of Disabled Persons (1975);
- The World Program of Action Concerning Disabled Persons (1982);
- The Vienna Declaration on Human Rights (1993); and
- The U.N. Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993).

## **Part Four: An Integrated Disability Strategy**

### **The Vision: A Society for All**

The needs of all citizens must constitute the basis for planning and policy. The general systems and institutions of society must be accessible to all.

By accommodating the structures of society so that they function in a way that meets the needs of all, society mobilizes the potential of all its citizens and, consequently, strengthens its developmental potential.

People with disabilities are a natural and integral part of society as a whole. They should have opportunities to contribute their experience, talents, and capabilities to national and international development.

The concept of a society for all encompasses human diversity and the development of all human potential. It captures the spirit of the human rights instruments of the United Nations.

The challenge is to translate the rights of persons with disabilities into specific measures and programs. The Standard Rules provide the main instrument for guiding public policy. They can assist governments in creating an enabling environment that will lead to the full participation and equalization of opportunities for persons with disabilities at all levels of society, both during and after the period of reconstruction and development. This includes the right of people with disabilities to assume full responsibility as members of society.

### **Objectives**

The objectives of such a strategy would include aim to:

- integrate disability issues into developmental strategies;
- develop an integrated management system for the coordination of disability planning, implementation, and monitoring in the various line functions at all spheres of government; and
- promote public education and awareness-raising, aimed at changing in the mental prejudices in Kosova society.

### **Principles**

A fundamental principle that informs the outlook of the disability rights movement in Kosova is the right to self-representation. This means that the collective determination of people with disabilities must be used to inform the strategies of the government. In recognizing this principle, government acknowledges the important advisory role played by the organizations of persons with disabilities and their representatives.

- The right to vote is restricted by inaccessible polling booths;
- The right of access to public information is restricted as a result of inaccessible public media;
- Failure to recognize sign language prevents deaf people from enjoying access to full

participation in the social, political, and economic life of the country.

## **Integration and Sustainability**

Historically, disability issues have been addressed in a piecemeal, fragmented way. This has been one of the key factors contributing to the marginalization of people with disabilities and to the poverty in which the majority find themselves. If their needs are to be effectively addressed, people with disabilities must be fully integrated. This will ensure that they no longer suffer from apartheid but are included in a sustainable process of reconstruction.

## **Strategy Guidelines**

An Integrated Disability Strategy needs to take place within a coherent program of reconstruction and development and must be planned and implemented in terms of strategic guidelines. It should be underpinned by the pursuit of goals of freedom from want, hunger, deprivation, ignorance, oppression, and exclusion.

Funding for the Integrated Strategy as part of reconstruction and development should link up with potential sources of finance and related policies, whether from the public or private sector. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the World Program of Action Concerning Persons with Disabilities, and Persons with Disabilities Rights charters will be the guiding documents in developing, implementing, and monitoring the Integrated Disability Strategy.

## **Prevention**

One of the cornerstones of a disability policy is prevention, because most disabilities are preventable. This starts with:

- The avoidance of conflict, war, and violence. This will include observance on the ban of landmines and the pursuit of peace initiatives;
- Improving the educational, economic, and social status of the poor;
- A reduction in occupational and environmental accidents through the adaptation of the environment. The adoption and implementation of legislation and regulations to prevent accidents at work, sport, and on the road.

## **Improvement of Health Services**

For persons with disabilities to realize their potential both personally and as member of the community, there must be improvement of health services in the following areas:

- Immunization;
- Early identifications of impairments and appropriate interventions;
- Mother and child health care;
- Family planning;
- Genetic counseling;

- Effective emergent and rapid medical treatment;
- Effective management and control of people with disabilities and degenerative diseases; and
- Development/decentralization of primary level of historically secondary level services (e.g., management and control of chronic diseases, diseases of older persons, and basic rehabilitation).

### **Involvement of Role Players in Society**

All role players should be involved to commit in policy objectives:

- Government, particularly the departments of health, social welfare, labor, sport, culture, and education;
- The disability sector of NGOs;
- Other key players that contribute to the improvement of disability issues;
- International organizations.

### **Public Education and Awareness Raising**

One of the greatest hurdles people with disabilities face when trying to access mainstream programs are negative attitudes. It is these attitudes that lead to the social exclusion and marginalization of people with disabilities. Negative attitudes are continually reinforced. Disability is treated as a 'problem.' People with disabilities are viewed as helpless and dependent; as ill and in constant need of care and medical treatment or as tragic victims. Culture also plays an important role in the way we relate to people with disabilities. This contributes to the perception of people with disabilities as different from the others.

Yet changing attitudes is not something that happens automatically or spontaneously. It is a complex process. Public education and awareness are central to the changing of attitudes.

### **Target Groups**

The groups to target for assistance are those most vulnerable in the society and least able to advocate for their rights, including:

- Very young children with disabilities (pre-school)
- Children with multiple/severe disabilities
- The girl-child
- Hospitalized children
- Woman with disabilities
- Adults with disabilities
- People living in rural areas.

### **The Advocacy Corner**

Halit Ferizi shows that disabled people can be resilient and imaginative in putting their lives back together -- and that this can galvanize and inspire the larger process of rebuilding societies

like Kosovo.

This is neither new nor surprising. Another casualty of the turmoil in the former Yugoslavia, Faruk Sabanovic, was crossing the infamous 'Sniper's Alley' in Sarajevo when he was hit by a sniper and paralyzed. The incident was caught on television. But instead of giving into despair and seeking welfare, Faruk started the Center for Self-Reliance in Sarajevo. He is campaigning for better access for wheelchairs in buildings and increased benefits for the disabled, as well as using his skills as a communicator to show that disability need not mean dependency.

Faruk has even used television footage of his own shooting in 1995 to embarrass the World Bank and other agencies into installing facilities for wheelchairs into Bank-supported projects. He has also translated the U.S. Disabilities Act in an effort to change Bosnian laws and press for tax incentives that will encourage firms to hire the disabled. There were 25,000 Bosnians disabled in the war, and as many as 70,000 Bosnians in need of physical rehabilitation. For more information, contact **Faruk**.

Halit Ferizi does not lack for contacts abroad. But in his discussion with On the Record, he also appealed for more information. He wants models of legislation, training, advocacy, presentation, lobbying -- everything. Perhaps because of the physical limitations, he has a hunger for information and practical experience. Above all, he wants to learn from the experience of others.

### **Voices That Matter**

*The following brief selection gives some idea of the range and variety of organizations campaigning on disability. Check out their websites for more links.*

- The Landmine Survivors Network (LSN) has formed to lobby around one of the most devastating forms of disability. It has much to teach Halit Ferizi, and also to learn from him.

LSN was founded by two Americans, Gerry White and Ken Rutherford, who both lost legs to landmines. LSN starts from the premise that any programs on behalf of landmine survivors must involve them: 'nothing about us without us.' LSN projects are locally run and owned by amputees, and involve outreach by amputees.

The best model is probably in Bosnia, where Plamenko Priganica, a veteran survivor, heads a group of nine outreach workers. This team has made hundreds of visits to homes and hospitals, accompanied by a social worker, to support and counsel survivors. LSN's work in Bosnia has received support from the **U.S. Institute of Peace** because it can promote reconciliation. Often survivors from different ethnic groups are brought together by the common enemy of the landmine.

**LSN** is now moving increasingly into advocacy on the Internet. It recently launched a second website which provides one-stop information on current research, including profiles of countries like Bosnia that have been affected by landmines. LSN plans to develop and promote a portfolio of good projects, which will be posted on the web, to attract support. This will need input from

advocates like Halit.

LSN has also distributed ten information kits on coping with the aftermath of a landmine accident. These are being translated into several languages. LSN is now preparing 'disability activism kits' aimed at helping advocates like Halit Ferizi learn from the experience of LSN.

LSN is good at exploiting 'news pegs,' without overstepping the boundaries of good taste. In one recent example, LSN marked the March 1, 2000, first anniversary of the entry into force of the 1999 (Ottawa) treaty banning landmines by inviting survivors from mine accidents in World War II to a press conference at the United Nations in New York.

- The International Center for the Advancement of Community-Based Rehabilitation (Queens University, Canada) works to promote community solutions to disability in wartorn societies. It began working in Bosnia in 1993 and also works in four Central American countries promoting the rehabilitation and the full reintegration of disabled people into society. It is also working in Bosnia and Russia to strengthen professionals that work to rehabilitate disabled people in Central and Eastern Europe. Contact Djenana Jalovic, program officer.

- Handicap International has provided support and rehabilitation to thousands of mine victims (including Halit Ferizi) throughout the 1990s. It is headquartered in France. Contact **Sylvie Brigot** (Paris), **Anne Capelle** (Brussels).

- The Committee for International Rehabilitation Research Information and Exchange (CIRRIE) at the University of Buffalo is engaged in three projects, with funding from the U.S. Department of Education. One involves preparing a database of rehabilitation research, culled from existing databases. It is expected to be posted on the project's website and available by May 2000. Project director **John Stone** says that it will allow practitioners like HANDIKOS and specialists to get a quick sense of what is being done by and for disabled people. CIRRIE provides travel grants that facilitate international contacts between rehabilitation research experts. Information available from the **CIRRIE website**. CIRRIE also publishes cultural information that can be used by therapists in treating immigrants to the United States.

Visit the CIRRIE website for information, and also to log into 'Rehab Talk!' a new interactive forum that allows researchers to share information. The website has links to scores of related organizations.

- Wemedia is a for-profit company that bills itself as 'the disability network' and is aimed at the estimated 54 million disabled Americans. The home page features an item on disability rights.

- Disability Radio Worldwide transmits a 30-minute radio program every week on the experience of disabled people to over 100 countries, from Costa Rica, via Radio for Peace International on short wave frequencies 6975, 15050, and 21460: Mondays at 19:00 UTC, Fridays at 17:00 UTC, and Saturdays at 22:00 UTC. Plans are also under way for Internet broadcasting. For information and cassettes of past programs, contact **Disability Radio Worldwide**, Colorado, US.

- **World Institute on Disability** (WID), based in Oakland, California, advocates to ensure that

disabled people have equal access and breaks down barriers to independent living by disabled people. Founded 16 years ago, WID has a staff of 30, over half of whom have some form of disability. One of its recent successes was passage of the Work Incentive Improvement Act (US), which seeks to open up work opportunities for the disabled.

WID also runs an international program, which promotes links between the United States and other countries. Since 1992, WID has worked with the **All-Russian Society of the Disabled (ARSD)**, helping to strengthen the capacity of ARSD's network and increase the profitability of 1,500 business that are owned by ARSD. Further information contact **Kathy Martinez**, Director, International Division.

- **The European Network of Independent Living** started after 80 persons with extensive disabilities attended a 1989 meeting at the Council of Europe in Strasbourg. The organization seeks to promote 'the opportunities of persons with disabilities to gain more personal and political power, self-determination, full participation, and equality through information, training materials, consultancy and technical assistance.' Also supports self-help groups in developing countries. Consult the web site for links, and free online services, ranging from a library to a holiday home exchange.

- **The Archimedes Project** at Stanford University was recently profiled in Wired magazine (March issue). This project aims to teach engineers how to build access for the disabled into computer design and creates product prototypes of its own.