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Introduction

On 1 May 2004, ten new countries joined the European Union. The process of accession negotiations provided important opportunities to work for the Human Rights of people with intellectual disability in those countries. Inclusion Europe and ten of our members from accession countries have seized these opportunities and worked since 2000 on using the accession process for the benefit of people with intellectual disabilities and their families.

Supported by the European Initiative for Democracy and Human Rights of the European Commission, Aktion Mensch, Lebenshilfe Germany and a donation by the late Dr. Rosemary Dybwad and Prof. Gunnar Dybwad, Inclusion Europe has produced National Reports on the Human Rights of people with intellectual disability in Bulgaria, the Czech Republic, Estonia, Latvia, Lithuania, Hungary, Poland, Romania, Slovakia and Slovenia. We have also looked at the situation in two neighbour countries of the enlarged European Union, Belarus and Macedonia. The objectives of these activities were

- to strengthen the political capacity of NGOs and to ensure more active participation in decision-making processes concerning persons with intellectual disabilities;
- to introduce NGOs to the European disability policy and make sure that persons with intellectual disability from Central and Eastern Europe are part of it;
- to raise awareness of the Governments at national and European level about the human rights of persons with intellectual disability in Central and Eastern Europe.

At the date of accession of eight of our partner countries to the European Union, we can say that these activities have been an outstanding success. This was due to the fact that we have not only produced reports, but that our members have engaged in active political lobbying to improve the situation of people with intellectual disability in their country. The findings of the National Reports have later been confirmed by organisations like Amnesty International, the European Disability Forum, and the Open Society Institute's Mental Disability Advocacy Programme.

The policy engagement of the national associations for people with intellectual disability in our partner countries at local, national and European level has led to significant improvements of the situation of people with intellectual disability and their families. It has also strengthened the recognition of disability NGOs in policy work and brought the situation of disabled people on the policy agenda of the enlargement of the European Union.

Günter Verheugen, European Commissioner on Enlargement, said at a meeting with Inclusion Europe: "We have already undertaken a number of initiatives to ensure that this group of people and their families are not forgotten in the enlargement of the European Union but will belong to the winners of enlargement in the medium and long term. Inclusion Europe contributed to this policy. Its excellent reports, both by Inclusion Europe and also by its member organizations in seven accession countries and in the former Yugoslav Republic of Macedonia have provided us with important information for action and I wish to express my gratitude and my appreciation for the close co-operation we have established."

This updated Comparative Report between the different countries involved in this important exercise shows that the situation of people with intellectual disability and their families in the new Member States, accession countries and neighbouring countries is far from satisfactory. While also in the past European Union with 15 Member States much remains to be done, it can be concluded that significant political commitment and investments are necessary to achieve similar conditions for disabled people in the new Member States. Inclusion Europe and our members will actively participate in the creation of better conditions for people with intellectual disability and their families in Central and Eastern Europe.

Françoise Jan, President, Inclusion Europe

Executive Summary

This report presents a comparison of twelve National Reports about the Human Rights of people with intellectual disability, thus giving an overview of the situation in all participating countries. It underlines the similarities in the situation of people with intellectual disability living in this part of Europe, but also points out the differences between particular states, resulting from their political and economic development, their geographical and historical position and their size and population. The basis of the research for the National Reports were the United Nations Standard Rules on the Equalisation of Opportunities for People with Disabilities, the worldwide accepted benchmark for services and legislation for disabled persons. The report concludes that the UN Standard Rules are not fully met in any of the countries.

A fundamental problem is that the national governments have no policy of awareness raising about the abilities and the situation of persons with intellectual disability and hence the attitude of these societies is still characterised by prejudice. The access to quality intervention services remains also a problem, especially in rural areas. People with intellectual disability and their parents often have negative experiences of contacts with medical staff who are not adequately trained to deal with disability-related issues.

It is mainly at the initiative of NGOs that alternative living facilities are set up. The legislative framework and the governmental policy in this area are rather declarative. Hence, the majority of people with intellectual disability continue to live in institutions or with their families.

Some steps have been taken to improve legislation in terms of architectural accessibility in these countries. Nevertheless, the practical implementation of these changes remains very slow. Also, there are no normative acts regulating the access to information and communication for people with intellectual disability.

The integration of children with intellectual disability in mainstream schools is still limited, most visit therefore special schools. Many children with profound and multiple disability do not attend school at all. Also employment of persons with intellectual disability is problematic. In general, the legislation does not support inclusive employment for people with intellectual disability.

Disability allowances remain extremely low, which constitutes an obstacle to the provision of community-based living facilities. The process of de-institutionalisation is only at the beginning. Many of people with intellectual disability in these countries are still forced to live in large residential institutions, which are often overcrowded, understaffed and seldom meet the minimum required living conditions.

The last part of this report provides common regional recommendations for the actions of national and international NGOs, national Governments and European structures. A number of measures need to be taken urgently in order to improve the situation of persons with intellectual disability in these countries. A new approach to intellectual disability should be promoted in the society, highlighting social inclusion. The medical profession should be trained in dealing with intellectual disability, especially with early intervention.

Alternative community-based services must be developed to replace large residential institutions. All children with intellectual disability should have access to education and should have the possibility to be included in mainstream classes with adequate support and well trained teachers.

A supported employment model must be developed, including accessibility of occupational training and adequate preparation for work for everyone. Adequate financial support should be ensured to persons with intellectual disability and their family carers. Also, the equal status of persons with intellectual disability as citizens of their countries must be assured.

Region Description. Data Resources and Definitions

Region Description

All the twelve countries which took part in the project belong to the Central and Eastern European post-communist states. Their democracies date from the end of the 80s to the beginning of the 90s. Nowadays, they are all constitutional republics with a free market economy. However, the political and economic changes in these countries took place at varying various speeds. The richest among these countries are: Slovenia, Hungary and the Czech Republic with the poorest being: Bulgaria, Romania and Macedonia. Also the size of each country differs: Poland with around 39 million inhabitants and 312,685 km² is the biggest one, followed by Romania with 22.546 million inhabitants and 237,500 km² and by Belarus with 10 million inhabitants and 207,000 km². Much smaller are Bulgaria (110,993 km² and 8.992 million inhabitants), Hungary (93,030 km² and 10.300 million inhabitants) and the Czech Republic (78,865 km² and 10.330 million inhabitants). The smallest are Lithuania (65,303 km² and 3.480 million inhabitants), Latvia (64,589 km² and 2.35 million inhabitants), Slovakia (49,025 km² and 5.380 million inhabitants), Estonia (45,227 km² and 1.446 million inhabitants), Macedonia (25,700 km² and 2.100 million inhabitants) and Slovenia (20,251 km² and 1.960 million inhabitants). The countries vary also in religion (from the almost completely catholic Poland, protestant Estonia and orthodox Romania and Belarus, to the large Muslim minorities in Macedonia or Bulgaria) and in ethnic composition (from the ethnically homogenous the Czech Republic, Poland and Slovenia, to more than 30% of population being made up of ethnic minorities in Estonia, Latvia or Macedonia).

Data Resources

The surveys were made according to a common questionnaire and used various sources of information. They described the existing legislative acts concerning persons with intellectual disability. The members of national governmental bodies were contacted (even if they were not always ready to provide any data). The representatives of the national NGOs of persons with intellectual disability and their parents were interviewed. In each country at least five locations (differing in geographical, economic, ethnic or other points of view) were chosen for the data collection on a local level. Then the interviews were carried out with the members of local governments, representatives of local NGOs of persons with intellectual disability and their parents, and also with self-advocates and parents themselves. In each country at least three large institutions (of more than one hundred residents) for persons with intellectual disability were visited. The greatest difficulties in all countries there were with statistics and budgets, as they were often not accessible, not specific for persons with intellectual disability, or even non-existent.

Definitions and Differentiations

All twelve countries accepted the definitions and levels of intellectual disability formulated by the World Health Organisation (WHO). They interpret *intellectual disability* as a complex disturbance in the abilities which emerge during the developmental period and which contribute towards the general level of intelligence (cognitive, speech, motor and social skills). There are usually four different levels of intellectual disability distinguished according the IQ results: *mild, moderate, severe and profound*. However, it is the case that the intellectual disability definitions and qualifications are different in various legal acts of the same country (Bulgaria, Latvia or Poland).

Awareness Raising (UN Standard Rule 1)

In reality the National Governments have no policy of awareness raising in the society about persons with disabilities, especially with intellectual disability, even if in some countries there are legal acts regulating this obligation. The main role is played by the NGOs. But still the attitude of their societies is characterised by prejudice.

Only in some of the countries there is a legal act making it an obligation of the National Government to ensure the existence of an awareness-raising campaign about persons with disabilities (Belarus, Bulgaria, Hungary, Poland or Slovenia). However, even these acts are non-operating: they are not fully implemented (Slovenia) or serve as general declarations (Bulgaria, Hungary, Poland). And what is more important – they are never specifically directed to the persons with intellectual disability (either all disabilities are treated homogeneously, or intellectual disability is considered as a part of psychiatric health issues).

In the majority of these societies, people do not get enough information about persons with intellectual disability that results in prejudice towards them. This attitude, even although it has improved during last ten years, is always very strong, often characterised by fear and rejection. The situation does not seem likely to change in the near future, as nowhere are disability issues part of schools curriculum.

Usually the presentation of persons with intellectual disability in the media is a negative one: they are shown as a social problem, focusing more on charity and much less on their potential and the right to live as full citizens, however this attitude slowly changed during the year 2003. Recently in some countries, NGOs, sometimes with the financial support of the Government, started to promote the idea of Human Rights of persons with intellectual disability (the Czech Republic, Poland, Slovakia, Slovenia), usually by different publications and translations of international human rights documents. Still the idea of integration, social inclusion and mainstreaming in all areas of life is rather poor.

In general, the National Governments have no systematic and long-lasting strategy for persons with intellectual disability. They prefer singular and specific actions, such as sponsoring the Day of Disabled People, patronising the different competitions for NGOs, professionals and disabled persons, or co-financing sporting or cultural events with the participation of persons with disabilities. However, with the European Year of Persons with Disability, they started some promotion campaigns against discrimination and for equal opportunities. Some of them adopted even the 2003 National Action Plan with awareness rising as one of its priorities (Lithuania).

All the countries need a systematic, overall strategy promoting equalisation of opportunities for persons with disabilities, and especially with intellectual disability, in all areas of life. This campaign should be directed and adapted to different receivers: children, general adult society, professionals, and families of the disabled persons and the disabled persons themselves. It should show the persons with intellectual disability as full members of society with all their potential, underlining their human rights. The National Governments should work out this strategy in the partnership with the NGOs and assure its stable financing.

Ensuring the equalisation of opportunities for persons with intellectual disability is not possible without changing the attitude and values of society.

Medical Care (UN Standard Rule 2)

The access to early intervention services of optimal quality is still a big problem, especially in rural areas. People with intellectual disability and their parents often have negative experiences of contacts with medical staff who are not adequately trained in disability issues or in communication techniques.

In all twelve countries the legislation assures an equal access to free health care for all citizens through the framework of compulsory health insurance. But these uniform regulations create a risk of overlooking the specific needs and costs connected with medical treatment for people with intellectual disability. Access to medical care and its quality vary according to the economic position of the country. The worst health care conditions have been observed in Romania, where the hospitals are frequently confronted with lack of medicines and hygienic materials. However in the remaining countries the situation is not much better. For example, in Estonia the quality of health care for people with disabilities is so poor, that more and more parents decide to take their children abroad to get medical care. The best situation is in Slovenia, but even there, the additional specialist care for intellectually disabled is not free of charge.

There is commonly too small a number of early intervention centres with highly qualified multidisciplinary specialist staff for new-borns. Especially people living in rural areas have to travel many kilometres to such centres (for example: in Macedonia there are only two of them). In Belarus families living in the countryside have no access to any specialist medical care in their neighbourhood and they are therefore forced to send their children to distant institutions. And even if a disabled child gets such care, the number of visits covered by insurance is so limited that they are too rare to assure an adequate rehabilitation. Therefore the disability tends to be diagnosed very late and the child is not adequately rehabilitated. The medical care for adults is even poorer. There is almost a total lack of services providing constant and complete treatment and medical rehabilitation for intellectually disabled people throughout their life, corresponding to their age. Access to specialists is very difficult, especially for the severely disabled. Some NGOs try to resolve these problems by creating their own early intervention centres or medical care services for intellectually disabled people (Belarus, Hungary, Poland, the Czech Republic or Slovakia).

There is no governmental programme of training the medical and paramedical staff in providing adequate medical care for people with intellectual disability and a support for their families. Unfortunately there are still specific cases of medical help being denied to persons with intellectual disability on the grounds that such help is overly time-consuming or too expensive.

In general, doctors/dentists are not trained in communications and counselling abilities. Very often they do not treat the intellectually disabled persons or their parents as partners in the health care and medical rehabilitation processes. Usually they have no knowledge how to communicate the disability diagnosis to the parents and often they do not explain its reasons, gravity or rehabilitation possibilities. In some cases the parents get the advice to abort a disabled foetus or abandon a disabled newborn and "make a new one". Because of such attitudes of medical staff, in Belarus there are still many intellectually disabled children abandoned by their families and put into isolated closed-type residential institutions.

In all the countries the system of health insurance should be changed in order to cover the specific medical needs of the intellectually disabled people so that the families are not forced to pay the supplementary costs of the medical services and medicines on their own. The network of high quality multidisciplinary services should be widened to assure quick, complex and long-term access to free health care and medical rehabilitation for people with intellectual disability of all ages. The medical staff should be trained how to inform and advise the parents about their

child's disability and to give them psychological support, but also how to communicate with an intellectually disabled patient in order to treat him/her as a partner in the health care process.

Knowledge about intellectual disability among the majority of medical staff is still very poor and their attitudes discriminatory.

(Re)habilitation (UN Standard Rule 3)

The main components of rehabilitation such as: early intervention, physical and psychological rehabilitation, vocational training and occupational therapy do not form one complete, synchronised system. The access to different rehabilitation services is poor especially in rural areas.

In the majority of countries, different types of rehabilitation are dispersed in various legal acts and they do not form any coherent system. There are also the cases in which some very important components of the rehabilitation are not regulated at all (for example: vocational rehabilitation in the Czech Republic, early intervention in Slovenia). Usually the law does not differentiate the rehabilitation services for intellectually disabled people from those provided for all sorts of disability, or at least from the rehabilitation for persons with psychiatric illness. There is also, in general, no co-operation between ministries to ensure such a coherent rehabilitation system for all ages of intellectually disabled people exists.

The number of the services provided is too small and often they are only partly funded (Latvia, Poland). In all twelve countries there are entire regions totally lacking such services, especially in rural areas. The most neglected are the persons with severe disability. The existing rehabilitation services are usually under the responsibility of the local governments, but they are often of poor quality, as the Governments have not a complete and long-term plan for their financing. However, in Belarus, where the rehabilitation services are just at the beginning stages, the State has implemented a Programme on Disability Prevention and Rehabilitation for the period 2001-2005, aimed at the development of rehabilitation services, and has allocated a substantial budget for it.

Because of this often-dramatic situation, more and more NGOs are starting to organise different rehabilitation centres for people with intellectual disability (Bulgaria, Hungary, Latvia, Poland, Romania, Slovakia, Slovenia). Nevertheless, they experience big difficulties because of insufficient and unstable funding (for example: in Macedonia the total lack of governmental funding made it impossible till now for national NGOs to organise any rehabilitation services at all).

A complex system of rehabilitation for people with intellectual disability with stable and adequate financing should be created at governmental level. The availability of rehabilitation programmes should be expanded and brought closer to the location of the users. The rehabilitation programmes should be based on individual plans for every person with intellectual disability, taking into consideration his/her personal needs, abilities, life style, age and family situation. It is necessary to establish complex development centres for people with severe and multiple disability. NGOs need stable resources from the Governments to continue their rehabilitation services and to open new ones. A good and accessible information system about available services should be also created. More highly qualified specialists in all types of rehabilitation should be trained, including psychologists for family support.

The components of rehabilitation are disparate from each other. Therefore a comprehensive rehabilitation system for people with intellectual disability needs to be set up and stated clearly in legislation. Rehabilitation services must be available on the local level.

Community-Based Support Services (UN Standard Rule 4)

Alternative living facilities, such as small group homes, are established only on the initiative of NGOs. The current legislative framework and governmental policy in this field are rather declarative. The majority of intellectually disabled people still live in institutions or with their families.

The legislative framework concerning community-based support services in the twelve countries is usually very general and not directed specifically to the persons with intellectual disability. Even if the law or national policy plan declare de-institutionalisation (in Romania concerning only children), in reality the process of transformation from the big closed state institutions into alternative community-based small living facilities is very slow, if not non-existent. The main role in establishing such facilities, especially group homes and daily activity centres, is played by disability NGOs (Bulgaria, Hungary, Lithuania, Poland, Romania, Slovakia, Slovenia). This is a very expensive task to carry out and the financial assistance of the state is rather limited and unstable (the Czech Republic, Hungary, Macedonia, Poland, Romania). Therefore, the majority of intellectually disabled people still live with their families or in institutions.

The best situation is in Slovenia, where the Government since 1999 has started to encourage new forms of community-based support services for intellectually disabled people to be developed by different contractors as part of a framework of public services. But even there the number of services is too small in comparison to the needs of people. The biggest deficiencies are for persons with profound intellectual disability and elderly persons with intellectual disability. In Slovakia where the programme of developing small assisted living facilities had already been started, many established facilities have been transformed into homes of social services because of financial reasons. The other countries face the same problems, but to a larger extent. For example, in Romania there is only one day-centre for adults with intellectual disability; in Macedonia there are no residential facilities for intellectually disabled people with less than a hundred inhabitants; in Lithuania only 12 of 1000 disabled people (of different disabilities) residing at home receive any community-based support services.

The financial support received by families with an intellectually disabled member is too low to cover the supplementary costs of the disability in every country studied. Paradoxically, this support is sometimes based on the age of the disabled person, as for example in the Czech Republic, where some benefits are paid till this person is 26 years old. In the majority of countries there is no personal assistance for an intellectually disabled person assured by the social services (even if in Romania the law gives the disabled people the right to get such help). For example the Belarusian social services system, which is responsible among others for covering assistance for home visits of physicians of retired persons, refuses to provide social services to intellectually disabled persons. Therefore, the practice is that one parent resigns from his/her work and stays at home to support the disabled child, even if the pension offered to him/her is minimal.

It is necessary for the governments to prepare, realise and finance a long-term programme to ensure the complex support for persons with intellectual disability and their families, which would allow them to live in the open society. Everywhere there should be introduced a legal act on personal assistance to all intellectually disabled persons, adequately financed by the state and ensuring an active participation of the disabled person in the social life of their age group. Protected housing and other forms of community-based services should be one of the main tasks of the local public administration. On the other hand, NGOs must get adequate and stable financing for the services they manage in order to create an open market of such services with the right of concurrence, high quality standards and their control. The state social administration should at the very least change the attitude towards the disabled persons and their families who should become real clients of their services, choosing them according to their needs and wishes.

Community-based services give a real opportunity for an independent life with dignity, but up till now there has been an alarming lack of day centres, care services, personal assistance and supported living facilities.

Accessibility (UN Standard Rule 5)

Although legislation in terms of architectural accessibility has been significantly improved in last years, the practice changes very slowly, even if constantly. On the other hand there is a total lack of legal regulations ensuring barrier-free access to the information that creates the most important obstacle in the life of people with intellectual disability.

Access to the physical environment

In all twelve countries the law regulates the architectural standards for a barrier-free physical environment. It is concerned with access to the public offices, schools, hospitals, cultural buildings and other places, but also public transport and construction of the streets and pavements (including pedestrian crossings with sound signals). However, the enforcement of these regulations varies from state to state. The most important factor in their practical implementation is of a financial nature, and therefore the most significant changes may be noticed in the countries with stronger economy (Slovenia, the Czech Republic, Hungary, Lithuania, Poland). But, even there, the transformation is very slow and far from accomplished.

Access to information and communication

There is no legal basis for providing information in an adequate way to persons with intellectual disability, even if, as in some countries the law generally declares that all citizens have access to public information (Belarus, Bulgaria, Hungary, Latvia, Lithuania, Poland or Slovakia). With the exception of Slovakia there is neither a legal obligation on public bodies to provide television information in sign language, nor to publish public documents in Braille. In none of the twelve countries is an easy-to-read system known to public administration. NGOs have just started to translate guidelines in how to prepare easy-to-read written documents and to publish brochures in this language. However, the Governments are not interested in promoting easy access to information, and they have no policy plans in this field.

In general, parents of intellectually disabled persons and self-advocates complain that they have little information about their rights, available services and diagnoses. They also find public information inaccessible. One important barrier are also social workers who are sometimes unwilling to spend more time and use easier language to talk to their clients.

Therefore, the Governments should organise an awareness-raising campaign among public institutions and staff working with or for intellectually disabled persons to promote the idea of easy access to information as necessary for a full life in civil society. They should be taught how to communicate difficult (legal or medical) issues in an easy way. It should be obligatory for all public documents to be written in an easy-to-read language version. A network of information centres should be organised to provide the practical information about available services, counselling centres, possible financial benefits, etc.

There are no normative acts regulating the access to information and communication for people with intellectual disability. The information regarding diagnoses, rights, services and programmes for them is not provided in an accessible form.

Education (UN Standard Rule 6)

The integration of children with intellectual disability in mainstream schools is still limited. Furthermore, not all children with profound and multiple disability attend schools even if they have a constitutionally granted right to do so.

The constitutions and the national education legal acts of the twelve countries declare that all children have right to education, without any discrimination. They state that school attendance is compulsory till a certain age. Furthermore, on paper, these laws seem to promote the mainstreaming of intellectually disabled children regardless the level of the disability, leaving the choice of the school.

But in reality, all these countries provide a very strong system of special and individual education and there is very strong pressure on parents to send their intellectually disabled children to special schools or teach them at home. The problem is that the mainstream schools have no obligation to accept an intellectually disabled child, even if his/her parents wish him/her to attend this school. Therefore the process of mainstreaming is very slow, concerning up till now only singular cases and it has had a rather strong opposition on the part of teachers and parents of other children. There is no integration for children with severe and multiple disability. The best situation is in Slovenia, where the integration process is the mostly advanced. But even there, parents are not allowed to decide the school and education methods for their disabled child (the opposite system has started to be introduced in Lithuania and Poland with the right of a child and his/her parents to choose the form of education). Recently there were some important international pilot projects for mainstreaming in Romania. Also, in Slovakia a big programme of integrative education, called Millennium in being prepared. It should be implemented between 2010 and 2015. A similar project has already started in Belarus. In Poland, in response to difficulties with mainstreaming in public schools, NGOs (or parents) started to open semi-private integrative schools and special revalidation schools for persons with severe and multiple disability.

There are also some objective barriers to the full and optimal integration of intellectually disabled children which lie in the organisation and financing of support services such as: personal/teacher assistance, transport, teaching instruments for pupils of special needs. There is too small a number of high quality special education teachers educated in new approaches towards disability and the regular teachers often have no knowledge about intellectual disability and work with such children.

In general, the intellectually disabled persons attend only a primary school. Few of them have access to vocational secondary schools. There is almost no education for adults with intellectual disability.

Nevertheless, in Bulgaria and Romania the majority of children with moderate and severe disability living with their families or in institutions are deprived of education. Similar singular cases happen in Lithuania, Macedonia or Poland. In Belarus, because of poor access to education for children with severe or profound disability, their parents often decide to teach them at home.

The co-operation of the disability NGOs with schooling system varies from state to state. It is rather good in Slovenia, Hungary, Romania, and Slovakia, but poor in other countries.

All children including children with all levels of intellectual disability should have equal access to appropriate education, with preference given to integrative education. This should include children living in the institutions. The curriculum of all teachers should include intellectual disability issues and methodology of teaching an integrative class. The education of intellectually disabled children, both in the integrative schools as in the special schools, should be based on an individ-

ual programme enforcing the strong abilities of the child, the programme being evaluated continuously by a group of specialists. Every disabled child should have free personal assistance at school of a good quality. The education system for intellectually disabled people should be life-long, assuring different kinds of trainings.

No all children with severe and multiple intellectual disability have access to education. Mainstreaming is just at its beginnings but with good results.

Employment (UN Standard Rule 7)

The area of employment of persons with intellectual disability is one of the most problematic: the majority of them stay without any work, as there is almost no possibility to be employed on the open market and the number of places in sheltered workshops is strongly limited.

In all twelve countries the rate of unemployment is high (in general about 14-16%, but there are also such extreme cases as Romania and Macedonia where it exceeds 30%; the official rate in Belarus of 3% is much underestimated). Everywhere this rate is much higher in the case of people with disabilities. For example in Slovenia where the unemployment figure is 14,5% in general population, it increases to 32% for the population with disabilities. The real statistics for persons with intellectual disability are unknown, but it seems that the rate of employment of this group is even lower (the Belarusian NGOs estimate that this rate in their country as high as 99%).

None of the countries has specific legislation on employment of people with intellectual disability. This field is regulated by general provisions of labour law and sometimes (as in the cases of Lithuania, Latvia, Macedonia, Poland, Slovenia) by legal acts on vocational rehabilitation and employment of persons with disabilities. In such a legal situation the special needs of persons with intellectual disability on the labour market tend to be forgotten. The law generally promotes the system of sheltered employment rather than inclusive employment on the open labour market. There is no budget allocated either for inclusive employment, or for working assistance.

In the majority of the studied countries a quota system exists (in Slovenia a new law on employment of persons with disabilities intends to introduce such a system). According to this system employers who employ more than a certain number of workers should employ among them a certain percentage of persons with disabilities, otherwise s/he is obliged to pay a fine to a special fund. However, the reality shows that the employers prefer to pay a fine than to employ the persons with disabilities, which seems to be cheaper.

Even the special financial support for creation of and protection of the work places for persons with disability does not seem to be very persuasive for employers to employ such workers. Nevertheless, if they do it, they prefer to employ the persons with other kinds of disability, rather than with intellectual disability. Also, the social security system is not favourable to working of persons with intellectual disability, as in such a case they lose their pension or it is at least diminished.

In the transition period, a large number of sheltered workshops have been closed and the employees with intellectual disability were first to be dismissed. The NGOs are usually still too weak to manage the sheltered workshops, however there are examples of doing so (many in Poland, but also singular in other countries as Belarus). They do also promote inclusive employment by organising job-seeking and job-coaching services (Latvia, Romania or Slovakia).

Another problem is the too small number of vocational training places. The existing vocational therapy workshops do not get an adequate and stable financial support (in Poland the new law

decreased the support by national government and obliged local governments to finance them without giving them any budget for it).

An intensive promotion of the work abilities of persons with intellectual disability should be organised, since social attitudes towards their capacities to participate in social society and open labour market is still negative. A general employment strategy for persons with intellectual disability should be developed taking into account both the sheltered employment and the inclusive employment on the open labour market with an adequate assistance. This strategy should include also accessible vocational training adequate to the market needs and the possibilities of the intellectually disabled persons.

In general the legislation does not support the inclusive employment of intellectually disabled people. The national Governments have no active policy in this field. Neither persons with intellectual disability nor their families believe that they can be employed on the open market.

Income Maintenance and Social Security (UN Standard Rule 8)

The intellectually disabled persons and carers who are obliged to stop working have the right to financial support from social security. However, these benefits are not nearly enough to compensate either the supplementary disability costs or unemployment of the parent.

The benefit systems for persons with intellectual disability and their carers vary throughout the studied countries. However, they have some points in common. Firstly, the system is very complex and the legislation governing this field is enormous and complicated (for example in Czech Republic it consists of 25 laws and 85 lower acts). Usually the system engages at least three different ministries and combines the allowances from social care system, health insurance and social security, including pensions and unemployment allowances. Secondly, the organisation of the benefit system is not clear, there is a lack of information which allowances are accessible for a concrete intellectually disabled person and their family. Very often even the administration is not well informed and helpful. There are various disability assessment systems, even inside one country for the needs of different administration offices in order to get different allowances.

And last, but not least, there is the problem of poverty. In all studied countries the multiplicity of various allowances aimed at persons with intellectual disability, according to their age, disability level, family income, working abilities, give a completely false picture that the needs are met. On the contrary, everywhere the allowances are too small. They do not cover the costs of a normal life, without regard on the supplementary disability costs. The allowances are calculated as a percentage of a minimum salary. Therefore they are never equal even to this minimal income. Very often they depend on the whole family income – if one of the family members earns good salary, the benefit is lowered. Such regulations are contrary to the approach of independent living of persons with intellectual disability, as they force people to be dependent on their family or dependent on institutions as the allowances allocated for their residents are usually higher as for people staying at home (in Belarus, a large residential institution gets about three times more money to cover the living expenses of an intellectually disabled person living there, than such a person would get living at home).

Parents who have to stop working in order to take care of their disabled child do not have a right to allowances in all of the countries (Macedonia or Slovenia). Even if they get any, it is often so small that does not compensate for the unemployment. Only in the Czech Republic, Slovenia, Slovakia and Romania there are some services in kind of personal assistance for persons with

intellectual disability. However, in Romania it is a rather misleading concept, as one parent can be such an assistant. In this case s/he does not work, but gets money for being the assistant. However, there are huge difficulties in getting this money, as the local authorities have not always had enough resources to distribute it. This is unfortunately the case with all allowances in the majority of the studied countries. The recipients get these poor benefits often with delay, and sometimes not at all.

The other problem with personal assistance is that in all the above-mentioned countries the personal assistant is very poorly paid. Even in one of the best-developed systems of personal assistance that has recently been introduced in Slovakia, the State rate for an hour work of personal assistant is established at the amount of 1,35 Euro. Such assistance is granted on the basis of medical assessment to people with severe disability from the age of 6 years up to 65 years. A person with disability can have up to 10 personal assistants for a number of hours, set by the respective local department of social affairs. The client concludes a contract with the assistant and pays him/her monthly for the actual worked hours. The contract must be accepted by the municipality and confirms each month the required number of assistant hours. If the assistance contract suits all above conditions, the client is reimbursed by the State. However, in reality this form of compensation has been awarded only to a small percentage of people with intellectual disability. Also social affairs officials do not believe in the philosophy of personal assistance – they say that people with intellectual disability are not capable of managing such a contract and therefore they offer them nursing services as a substitute.

The system of social security must change in order to assure an easy, comprehensive and stable access to adequate financial benefits for persons with intellectual disability and their carers. The allowances must be calculated in order to cover the needs of a real person. Alternative forms of day care should be created to allow parents to keep their work. The service of a personal assistant should be assured for everyone for free.

Financial support for persons with intellectual disability is not correlated with life costs. People cannot survive with the disability allowance without the support of their family. This is an obstacle to de-institutionalisation.

Family Life and Personal Integrity (UN Standard Rule 9)

There are no services to support the marriages of persons with intellectual disability. The number of intellectually disabled persons who are married or have children is extremely small. There is almost a total lack of independent housing options – the intellectually disabled adults are obliged to live with their families or are sent to big institutions.

In all twelve countries the majority of persons with intellectual disability live with their families, even during their adult years. Parents of intellectually disabled adults are legally obliged to assure them financial support, especially given that their pension is usually inadequate. The only alternative for a family house in general is a big institution – protected housing is almost non-existent. Even if NGOs try to organise group homes, the places in such facilities are very limited and such homes usually do not get enough financial support from the state.

The civil law of all studied countries provides the means to declare adult persons with intellectual disability legally incompetent. In such cases the tribunal appoints a guardian who takes all decisions on behalf of the disabled person. There is still a strong pressure on the authorities to declare persons with intellectual disability legally incompetent, especially these living in the institutions (the Czech Republic, Hungary, Poland). During these procedures the most important is the

role of psychiatrist who often does not know the person. Nowhere can the disability NGOs participate in court proceedings. Usually it is the parents or other family members who are appointed guardians. There are unfortunately cases where the members of the family ask courts to declare intellectually disabled persons incapable in order to take advantage of their property, salary or inheritance rights (Lithuania, Poland). It also happens that intellectually disabled persons do not possess an identity card.

According to the family law of the majority of the studied countries persons without legal capacity, but also often persons with profound intellectual disability who are legally capable, cannot marry (Bulgaria, Romania, Slovenia) or can do it only with consent of the tribunal (Poland, Slovakia). Even there where such marriages are possible there are only few couples living in a formal civil union. In some countries the intellectually disabled persons who are parents are deprived (by law, or in practice) of their parental authority (Romania, Poland). There are no special legal provisions or programs concerning sexual education of persons with intellectual disability. The Governments have no policy in this field. NGOs try to fulfil this lack by organising family-life counselling services and sexual education trainings for persons with intellectual disability and their parents, but these actions are insufficient.

In the field of medical experimentation, no abuse of the rights of persons with intellectual disability was noted. However, the criminal law does not usually provide any regulations assuring a higher protection of persons with intellectual disability who are victims of crimes. On the other hand – the persons with intellectual disability who have infringed the penal law are excused of liability, if they were not able to understand the meaning of their acts.

It is necessary to establish a control system of the judicial procedures of declaring legal incompetence and realisation of the guardianship to avoid any abuse. Some instruments of personal support more adequate to the needs of persons with intellectual disability, such as personal assistance should also be introduced.

Awareness-raising campaigns about the rights of intellectually disabled persons to a full family life – marriage, parenthood and sexual relationships should also be introduced – as well as the education programs and support services in these fields sufficient for all intellectually disabled and their families.

Persons with intellectual disability have no access to the necessary counselling on opportunities for sexual relations and the right to parenthood. They get no real possibility to have a family of their own. But they are also often deprived of other human rights, among them the right to autonomy, by being declared legally incompetent.

Culture (UN Standard Rule 10)

There are only a few cultural events where persons with and without intellectual disability participate together and they are organised only by NGOs. There are two major barriers for intellectually disabled people to take part in the open cultural activities – one is the architectural inaccessibility, the other is the often discriminatory attitude of the general public.

The disability NGOs are rather active in organising cultural events for people with intellectual disability according to their financial capability and fundraising successes. They organise painting, handicraft and music or theatre workshops for persons with intellectual disability, but also make them attend cinema, theatre, concerts, parades, etc.

However, intellectually disabled people from poor families, especially from the rural regions or those living in institutions are often deprived of culture. All cultural buildings are still not accessible for persons with disability.

The local and state governments do not take any initiative to organise any cultural events for this group of people nor to include them in the regular events. Their work in this field is limited to partially sponsoring such events organised by NGOs, but usually the level of financing is not very high (or even diminished in recent years, as in the Czech Republic and Slovakia). The difference was noticed only in the year 2003 when the Governments decided to allocate more funds for cultural events of disabled people in order to prove they were celebrating the European Year of People with Disabilities. This was because during this year, some politics and media celebrities gave their names as patronage for various disability cultural events.

However it is still the case that the presence of people with intellectual disability accompanied by their parents during any cultural activities gives rise to interest, curiosity, laughter, compassion and even discrimination.

The national and local authorities should develop a long-term strategy to ensure the inclusion of disability groups, among them the intellectually disabled in the cultural life of the civil society. NGOs should get stable financial support in their work on this field.

People with intellectual disability should be more present in the public cultural life, as common cultural activities improve social integration and raise awareness.

Recreation and Sports (UN Standard Rule 11)

The Government finances only international sporting events, therefore the regular sporting and tourist activities should be organised and financed on a local level as a part of rehabilitation process.

The national Governments are usually interested only in sponsoring Special Olympic teams who are famous for their international performances, but these are very selective organisations (positive exceptions are Hungary and Lithuania where the budget for sport of disabled persons is quite high). Therefore, the majority of the sporting and recreation activities for persons with intellectual disability are organised by NGOs. The number and quality of these activities depend on the financial ability of the NGO (thus quite good in Slovenia, but almost non-existent in Bulgaria), as the local governments or private donors seldom sponsor them. There is also rather a poor cooperation with public sport halls, swimming pools and community sport centres. Therefore the persons with intellectual disability have limited access to sport and recreation activities, in reality it is assured only for children in schools as part of their curriculum. The people living in rural areas and those who have severe and multiple disabilities are almost totally deprived. There are also no qualified training personnel for the needs of disabled sportspeople.

Since sport and recreation activities are the areas in life which encourage people more to be more active, special programmes for children and adults with intellectual disability in this sphere should be included in the local governments' annual activity plans. Such programmes should include both the activities organised by the local governments and the financing of activities organised by NGOs.

The national and regional sports and recreation agencies should allocate financial means for activities for people with intellectual disability.

Religion (UN Standard Rule 12)

Persons with intellectual disability have the possibility to participate in the religious life of their parishes.

The law in all twelve countries guarantees the freedom of religion. The co-operation between disability NGOs and churches is rather poor (with exception of Romania where the Orthodox Church plays a very important role). In general, people with intellectual disability do not face barriers to participating in religious ceremonies in accordance with their family tradition, even if unfortunately, singular cases of discrimination still take place. The understanding of religious activities by persons with intellectual disability depends on their disability, as there are no easy-to-read religious documents and only seldom have churches organised special activities for this group with a qualified personnel.

Religious education should take into consideration the specific needs and abilities of people with intellectual disability.

Organisations of Persons with Disabilities (UN Standard Rule 18)

With the political changes of the beginning of the nineties the movement of NGOs has started in the post-communist countries. The disability NGOs try to fill in the gaps in the social governmental and provide missing modern services. However, their situation is not very stable as they often lack sufficient financial support from the State and are only seldom recognised as equal partners for local or national authorities.

In all twelve countries the law recognises the rights establish and NGO and recognises different legal forms of NGOs. After the collapse of the communist system the movement of civil society in the studied region has developed with a great enthusiasm. Nowadays there are many organisations working in the disability field, also in the intellectual disability field, and most of them provide social services. However, the third sector is still not strong enough. There are three main problems: co-operation between NGOs, partnership with authorities and financial support.

The huge number of disability NGOs means that they are often forced to compete for limited financial resources, trying to protect the specific interests of the disabled group who they represent. This is often the case for small local organisations that are dependent on local authorities. But it is also the case for big organisations that apply to the same sponsors for grants (ministries, international institutions or international grant foundations). Therefore the co-operation between the disability NGOs is not always perfect. However this situation varies from country to country, or even from region to region in the same state. Nevertheless, in all countries the NGOs attempt to create a national umbrella of intellectual disability organisations and of all disability NGOs (Estonia, Lithuania, Macedonia, Romania, Slovenia or recently Poland).

Such an attitude is justified by need to have one strong representation of the disability field to be recognised by the state authorities on local, national and international level, as up till now the co-operation with government has been rather poor. The legislation in the majority of studied countries puts the obligation on the government to consult the civil society and its representatives before adopting new laws concerning a specific group of citizens. However, these consultations are usually sporadic, and even if they take place they are only formal – the NGOs have no legal in-

struments to make their recommendations the government accept their recommendations. The lobbying force of intellectual disability organisations is still too weak. Continuously changing governments often provoke the NGOs to lobby the same problem over the course of many years, repeating the same actions and the same arguments over and over to different politicians.

This is the case because the financial position of the NGOs is not assured and even the limited resources are not stable. The state does not have a legal obligation to finance the organisations of public utility in every country (for example Belarus, Czech Republic, Lithuania; otherwise such a law was recently passed in Poland). Even there where such provisions exist the support is too small to the needs (Romania). Usually, the NGOs have to apply annually to the State and other sponsors for financial support by defining new grant projects, the evaluation of which by the sponsor usually takes some months. The problem with grant financing is also that grants are given with a concrete aim, for example for a particular event or service. Therefore, even the big NGOs with great annual budgets which provide many services have problems to paying management costs, staff salaries, offices costs and member's fees in international organisations, etc. The poverty of the societies means that parents cannot afford to pay such fees to cover these costs. The best situation is in Slovenia and Macedonia where the finances are at least stable i.e. assured by a percentage of a national lottery (Macedonia) or a special foundation (Slovenia).

The new democracies should give greater recognition to the role of civil society in the policy making and make provision for adequate and stable financing to the third sector working for public utility, especially if the services it provides are not assured by the state.

The intellectual disability organisations should lobby their country's decision-makers for the best interest of their members. They should promote self-advocacy. The State has the obligation to hear to the third sector and to adequately finance the services it provides.

Large Residential Institutions

The process of de-institutionalisation is only at the beginning, up till now there has been an almost total lack of alternative housing options. The large residential institutions still remain overcrowded, understaffed, with poor living conditions, no privacy and no employment possibilities for their residents.

In all twelve studied countries, a considerable number of persons with intellectual disability still live in large residential public institutions, the majority of which have more than one hundred residents. In some cases persons with different levels of intellectual disability and persons with mental health problems live together in the same institution (Belarus, Bulgaria, Czech Republic, Lithuania or Poland).

The national governments have already started the programmes for amelioration of living conditions in the big institutions (in Romania this is happening only in the case of institutions for children) and they have adopted the standards that the institutions must achieve in a certain period of time. The final objective of this programme should be de-institutionalisation. However, the main problem with its realisation is of financial nature. The budget spent on residential institutions is too small to assure dignity in every day life for their residents, there are almost no resources to make any positive changes in order to achieve the standards. The only positive exception is Slovenia, where there are already no institutions with more than a hundred inhabitants and the majority of persons living in existing residential facilities have a room of their own (on the contrary in Belarus there are only two institutions of less than 40 inhabitants).

The reality in other countries is quite different. The essential part of institutions assure only several bed rooms, where usually there is no spare place for other furniture. Therefore, even if the residents everywhere have the right to possess personal things, they have no real private living space. In Bulgaria there are still institutions where the toilets are outside. The only standard the institutions accomplish are regular meals (even if in Romania the portions for children are bigger than for adults, as the subventions for children are higher).

Besides the common lack of adequate physical living conditions, there is a problem concerning the activities organised for the residents of the institutions. The children living in them do not always have access to education. Access to work for adults is even poorer. In many cases persons (especially with profound or complex disability) spend their life in one room doing nothing. The lack of productive activities and of independent living education leads to even higher level of dependence. Such conditions are accompanied by a poor access to medical treatment and an often fatalistic attitude of personnel who do not treat the residents in a subjective way and do not give them the right to make any decisions about their every day life. The situation is much better than it was ten years ago, but still the majority of big residential institutions are of the old, medical, closed model (only in Latvia and Macedonia the access to the institutions is free for everyone, without the need for permission).

The process of de-institutionalisation is at its beginnings. However, in all studied countries there is a risk of the process being mishandled. The governments are looking at closing all big institutions, but the majority of countries has no real policy for the creation of the alternative housing for persons with intellectual disability – community-based services are still almost non-existent.

Therefore, a network of different community-based services with stable financing should be created as a priority, adequate to the needs of persons with different levels of intellectual disability . In the meantime, the most unacceptable living conditions in existing institutions should be improved – from all financial, physical, psychological and therapeutic points of view (including changes in mentality of the employed staff). However, this should never take the priority over the development of alternative living facilities. The biggest and most inhuman institutions should be closed soon as possible, leading to the disappearance of this kind of facilities.

The big institutions do not provide privacy and create no self-identity. The quality of life in them is still low and the approach mainly medical.

Recommendations

The following recommendations are common in the National Reports on the Human Rights of people with intellectual disability in all participating countries for the actions of national and international NGOs, national Governments and European structures. A number of measures need to be taken urgently in order to improve the situation of persons with intellectual disability:

1. A new approach to intellectual disability should be promoted to the public, highlighting positive examples of social inclusion of people with intellectual disability. The mass media must take an active role in such a campaign, but the issue should be also introduced in the curriculum of schools and the training of various professionals.
2. The medical profession should be trained in dealing with intellectual disability, especially with early intervention. They should be taught to inform and counsel the parents of the newborn children with disability. A free and quick access to high quality medical treatment (especially by specialists) and long-term rehabilitation should be assured for people with intellectual disability throughout their life.
3. Alternative community-based support services should be accessible to everyone. They should respond to the needs of all ages and disability levels as well as the needs of their families and include various counselling services, alternative housing, day centres with different activities, personal assistance, etc.
4. Laws and other useful information should be accessible in the easy-to-read format.
5. All intellectually disabled children should have access to education. They should be included within mainstream classes with adequate support and well trained teachers.
6. It is necessary to develop and legitimise a supported employment model, in which personal assistants help a person with intellectual disability to understand and cope with required operations and attains the expected degree of performance on the open labour market. Occupational training and adequate preparation for work should be accessible to everyone.
7. Financial support to persons with intellectual disability and their family carers should be adequate for their needs and cover the supplementary disability costs.
8. Equal status for persons with intellectual disability in all aspects of life, as for other citizens, must be assured. Legal incapacity should be an exception, under the supervision of disability NGOs.
9. The self-advocacy movement should be developed.
10. A network of alternative community-based services should be developed to replace large residential institutions.
11. The disability NGOs should be treated as equal partners by local, national and international governments, also in the legislation process. They should be assured stable and adequate financial support for their management and services they provide.
12. A coherent International Plan of action, focussing on the essential common needs for policy development in the twelve countries and meeting the essentials of the UN standards on Human Rights of persons with intellectual disability should be established. The existing differences between the twelve countries in political, social and economic development and the different stages of implementing a civil society based on legal human rights in general and for persons with intellectual disability, should be used for the mutual exchange of useful experiences, practices and knowledge for mutual exchange. During the development and implementation of such an international plan, pressure should be maintained to keep the national policy changes going.

