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Editorial

Dear Readers,

The main topic of the second issue of Include is "living in the community". At the end of 2007 the results of a European research study were published, explaining how to replace institutions with community-based services. People with intellectual disabilities have the right to choose where they want to live. They have the right to have possibilities for living in the community.

Le sujet principal de la seconde édition d'Include est "Vivre dans la communauté". A la fin de l'année 2007, les résultats d'une étude de recherche européenne ont été publiés, expliquant comment remplacer les institutions par des services de proximité. Les personnes handicapées mentales ont en effet le droit de choisir où elles veulent vivre. Elles ont le droit d'avoir la possibilité de vivre dans la communauté.

Das Hauptthema der zweiten Ausgabe von Include lautet "Leben in der Gemeinschaft". Ende 2007

FOR THIS SECOND ISSUE of our new Include, Inclusion Europe has decided to focus on the topic of Deinstitutionalisation and Community living. The end of 2007 has been marked by several alarming reports in the media about residential institutions focusing on Central and Eastern Europe. These reports highlighted the violations of most basic Human Rights among vulnerable people, mainly children and adults with intellectual disabilities.

In parallel, in November 2007, a European research study released successful strategies for replacing institutions with community-based services. These are not only beneficial for people with learning disabilities, but are also advantageous from an economic perspective.

These events reinvigorated the campaign for the creation and the promotion of alternatives to institutions.

We cannot be satisfied with the policies of some governments and international donors who continue to invest money to renovate institutions. People with intellectual disabilities have the right to live in the community and they have the **"right to choose** their place of residence and where and with whom they live" (Article 19 of the UN Convention). To reinforce this right, the only solution is the creation of alternatives. We hope that this

issue will recall and strengthen the position of all the organizations in our movement. We need to continue lobbying. We need to ensure that government funding and private funds are used to create alternatives to institutions, which should be based on long-term comprehensive strategies, as well as well-balanced transition plans.



Ivo Vykydal, Secretary General of Inclusion Europe

We hope you enjoy reading this edition of Include, and we wish you success in your future actions to promote community living,



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of Inclusion
Europe

wurden dazu die Ergebnisse einer europaweiten Studie veröffentlicht, die zeigt, wie man Anstalten durch gemeindeorientierte Dienste ersetzen kann. Menschen mit geistiger Behinderung haben das Recht zu wählen, wo sie leben wollen. Sie haben das Recht, die Möglichkeit zu wählen in einer Gemeinschaft zu leben. ★

Deinstitutionalisation and Community Living:

Outcomes and cost

By Julie Beadle-Brown, Jim Mansell, Martin Knapp, Jeni Beecham and the DECLOC group

The UN Convention on the Rights of Persons with Disabilities gives all people with disabilities the right to live in the community. Deinstitutionalisation means more than just closing institutions – it requires the development of community-based services and options for independent living so that people can choose where they want to live. It also means that people have access to more support, support which is tailored to the needs and wants of the individuals. The present study aimed to influence the policies towards the change from institution to community-based and independent living. In order to do this, the researchers have:

- 1. conducted an analysis of current living situation of people with disabilities in Europe, illustrating that at least 1 million people with disabilities still live in larger institutional services.
- 2. analysed the financial and organisational arrangements necessary for the successful transition from institutions to community life.
- 3. provided recommendations for the optimum transition to community based living for all people with disabilities.

La Convention des Nations Unies sur les Droits des Personnes Handicapées donne à toutes les personnes handicapées le droit de vivre dans la communauté. La désinstitutionnalisation signifie plus que juste fermer des institutions – elle exige le développement de services de proximité ainsi que des options pour une vie indépendante de sorte que les personnes puissent choisir où elles veulent vivre. Cela signifie également que les personnes ont accès à davantage de soutien, soutien qui est adapté aux besoins et souhaits des personnes. Cette étude vise à influencer les politiques vers un changement des institutions à la vie communautaire et indépendante.

Afin d'y parvenir, les chercheurs ont:

- 1. mené une analyse de la situation actuelle des personnes handicapées en Europe, illustrant qu'au moins 1 million de personnes handicapées vivent toujours dans de grandes institutions.
- 2. analysé les orientations financières et organisationnelles nécessaires pour une transition réussie des institutions à la vie communautaire.
- 3. proposé des recommandations pour une transition optimale vers la vie communautaire pour toutes les personnes handicapées.

Die Konvention der Vereinten Nationen über die Rechte von Menschen mit Behinderungen gibt allen Menschen mit Behinderungen das Recht, in der sozialen Gemeinschaft zu leben. De-Institutionalisierung bedeutet mehr als Anstalten zu schließen: es verlangt den Aufbau von gemeindeorientierten Diensten und Möglichkeiten unabhängiger Wohnformen. Nur so können Menschen frei wählen, wo und wie sie leben wollen. Es bedeutet auch, dass Menschen Zugang zu Unterstützung haben – Unterstützung, die auf ihre Bedürfnisse und Wünsche zugeschnitten ist. Die aktuelle Studie möchte politische Entscheidungen beeinflussen: Weg von Anstalten, hin zu gemeindeorientierten Diensten und unabhängigen Wohnformen. Um dies zu erreichen, haben die Forscher:

- 1. eine Analyse der gegenwärtigen Lebenssituationen von Menschen mit geistiger Behinderung in Europa durchgeführt. Sie zeigt, dass mindestens eine Million Menschen mit Behinderungen immer noch in größeren Anstalten leben.
- 2. die finanziellen und organisatorischen Grundlagen erfasst, die für eine erfolgreiche Umgestaltung von der Anstaltsversorgung in gemeindeorientierte Wohnformen notwendig wären.
- 3. Empfehlungen erarbeitet für den optimalen Übergang zu gemeindeorientierten Wohnformen für alle Menschen mit geistiger Behinderung. ★

Introduction

SUPPORTING PEOPLE WITH DISABILITIES to live in the community rather than in institutional settings is an issue of human rights. The UN Convention on the Rights of Persons with Disabilities gives all people with disabilities the right to community living. Previous work such as the Included in Society project (ref) has illustrated that segregating people with disabilities in institutions is a violation of their human rights. Good practice in the provision of support for people with disabilities has been characterised not as the provision of a certain model of building but as the provision of flexible support and resources that can be provided wherever the person chooses to live and in the way that they choose to have their needs met. The UN convention also requires governments to collect and make available official statistics which will allow the transition from institutional to community-based services to be tracked.

The present study aimed to provide scientific evidence to inform and influence the political processes necessary to move forward the transition from large scale institutional to community-based living. The project aimed to do three things:

1. Collate, analyse and interpret existing statistics on the number and living situation of people with disabilities in 28 countries across Europe.
2. Analyse the economic, financial and organisational arrangements needed for the transition from institutional to community-based and independent living, using three countries as case studies (England, Germany and Italy) to illustrate the issues.
3. Report on the findings including a commentary on the adequacy of the data and the provision of recommendations for the cost-effective transition from institutions to community based services.

Method

PHASE 1: collation and analysis of existing official data on the number of people with disabilities living in residential care.

The first task in this phase was a review of existing international data sources for relevant information. Project partners in Spain, Germany, Belgium, the Czech Republic and the UK collated the data for between 4 and 7 of the 28 countries included using a template designed specifically for this purpose. The template aimed to collect information on descriptions of each type of residential service available within each country, the numbers in each type of service, with a breakdown by size of setting, age group, disability ground and gender provided where possible. In addition, a commentary was written for each country providing background and an analysis of the accuracy and completeness of the data available for each country and including any data available from other (non-official) sources.

PHASE 2: Analysis of the economic, financial and organisational arrangements necessary for the best transition from institutional to community services.

The phase involved several tasks. The first of these was the description of the sequence and process of service development in three countries – Italy, Germany and England, including the roles of different actors in the service development process. Secondly, evidence about the economic implications of shifting from institutions to services in the community was collated from available research in England, Germany and Italy. Thirdly, the available evidence was examined to understand the extent to which transitional cost (eg 'double-running' expenditure) issues were important and finally, the different strategies used in each of the three countries used as case-studies to manage the cost and wider economic issues arising during the transition from institutional to community-based care were examined.

Findings and conclusions

REVIEW OF EXISTING SOURCES OF INFORMATION

Data at national level, albeit of limited quality, was collated for 24 of 28 countries. No national level data was obtained for Greece, Cyprus and Austria and data on only one service type in Germany was included. For most other countries, there were substantial variations in the completeness and accuracy of the data collated, with data for most countries being incomplete in one way or another. From the data which were available, it was clear that at least 1.5million people with disabilities live in residential care, with at least 1 million in institutional care (settings of over 30places). However, this is likely to be a substantial underestimate due to the lack of complete data for most countries.

It is clear from this analysis that the countries included in this study still have some way to go to be able to fulfil the requirements of Article 31 of the UN Convention on the Rights of Persons with Disabilities. Current information systems are inadequate to help Member States plan and monitor the transformation of their disability services from institutional care to services in the community. At present, comprehensive information is not available for all types of residential services provided nor for all the client groups involved, nor is there clarity about the definition of kinds and characteristics of services provided or people served. Where such information exists, it is not always collated at national level. The report recommends creation of a harmonised data set at European level that will enable review of Member States' progress in the closure of institutions and of the growth of independent living and services in the community.

The change process in England, Italy and Germany

The review of the change process in the three case studies illustrated the importance of co-ordination of the different agencies involved in the transition process – the number of agencies involved, the geographical spread and the involvement of different levels of government make good co-ordination essential. The report indicates that there is

a need for national and regional governments to take a strong leadership role in this transformation, working closely with disabled people and their families. Study of transformation of services in other countries shows clearly that this cannot be left to residential institutions or to local authorities acting on their own because of the range of new services needed, the need to transform services for the whole population and the complexities of funding and administrative arrangements.

It also recognises the need to create new roles for actors in the process. It is important that thought is given to the role of traditional service providers at the end of the transition process – these organisations and those who work in them should be offered new roles either within community based services or in other fields. New actors, in particular users and their families, NGOs and public authorities where they haven't been involved before, will need to be involved.

The report recommends that Member States take action to strengthen the vision of new possibilities in the community (through legislation, policy, a stronger voice for disabled people and their advocates and learning from good practice on other countries), sustain public dissatisfaction with current arrangements (through independent inspection and scrutiny and publication of comparative studies of institutions and community services), create some practical demonstrations of how things can be better (by creating innovative services, especially for people with severe disabilities) and reduce resistance to change by managing incentives for the different actors in the process (through removing obstacles to change, creating new funding opportunities and making funding contingent on quality).

Cost effectiveness of community versus institutional models of residential care and change over time

Review and analysis of the literature and available information on costs of institutional and community-based provision, identified many important elements in the transition process. Here we outline just four - Firstly, it was identified that the transition from institutions to community based services should have a national mandate, with a plan which is agreed between all potential service provider sectors. Secondly, it is important to note that whilst families may be able to provide support for people, they will need help to do so and for some this option will not be available nor indeed desirable. Ensuring that staff are recruited and trained to staff new services before people move out of institutions, is an important consideration for those planning the transition process. Thirdly, the need to find ways to finance the transition process is outlined in the report, including issues such as "hump" costs and double-running costs. Finally, the importance of taking a long view is emphasised: even with the additional costs needed at the beginning of the process, over time the costs of community-based provision and independent living do not need to be more expensive than institutional care when level of resident need and quality of care are taken into account.

The report points out that the current lower cost of many institutions is achieved because they offer poor quality care. Member States will have to improve quality and therefore costs will rise over time. The choice facing Member States is not therefore between inexpensive institutions and more expensive community services but between institutions that cost as much as community services to run but achieve poorer results, or services in the community that cost the same but do a better job.

Recommendations

The report from the project puts forward a series of recommendations for the optimal transition to community based services. These are based around 4 key elements of the change process

- **1.** Strengthening the vision of new possibilities in the community by: adopting policies in favour of inclusion; developing legislative support for inclusion; strengthening the voice of disabled people their families and advocates; requiring professional bodies to make their policies consistent with supporting inclusion, encouraging media interest in and support of inclusion; and learning from best practice in other countries.
- **2.** Sustaining public dissatisfaction with current arrangements through opening institutions to public scrutiny, creating inspectorates to protect and promote the rights of individuals and emphasising comparisons of quality of life in community based services compared to institutional care.
- **3.** Creating some practical demonstration of how things can be better both through creating innovative services in the community and through including everyone from the start so that services gain experience of meeting the needs of those with more severe disabilities right from the start.
- **4.** Reducing resistance to change by managing incentives for the different actors in the process – this requires the creation of new funding opportunities, in which personal/individual budgets are likely to play an important role. It also requires the removal of obstacles to the development of services in the community such as unhelpful rules around service provision but also around other related services such as housing, employment etc. Finally it is suggested that funding of new services should be contingent on quality so that only good quality services gain public funding. It is important that governments resist the temptation to redevelop institutions or build new ones as an interim measure and that international bodies, especially those providing funding, do not create perverse incentives for institutionalisation by allowing their money to be used to renovate or build new institutional services.

These elements are not a sequence – attention needs to be given to all four elements throughout the process to ensure the optimal transition. A focus on human rights and a

person-centred approach to supporting people with disabilities to live the life they choose, provides both the framework and the motivation for change. ★

The project report can be downloaded from the European Commission website (http://ec.europa.eu/employment_social/index/7002_en.html) or from the Deinstitutionalisation and Community Living: Network for Change website (http://www.kent.ac.uk/tizard/research/DECL_network/index.html)

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A Long journey from an institution to community in the Czech Republic

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“Deinstitutionalisation and community living” is a research project that was undertaken between 2004 and 2007. The aim of the project was to collect information on the number of disabled people living in institutions. This project took place in 28 European countries. A Czech research team was responsible for 5 countries: Romania, Hungary, Bulgaria, Poland and the Czech Republic. This article presents the main results for the Czech Republic and the recommendations made by the research team.



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“La désinstitutionnalisation et la vie au sein du tissu social” est un projet de recherche entrepris entre 2004 et 2007. L'objectif du projet était de rassembler des informations sur le nombre de personnes handicapées vivant dans les institutions. Ce projet s'est déroulé dans 28 pays européens. Une équipe tchèque de chercheurs étaient responsables de 5 pays : la Roumanie, la Hongrie, la Bulgarie, la Pologne et la République tchèque. Cet article présente les résultats principaux pour la République tchèque ainsi que les recommandations émises par l'équipe de recherche.

“De-Institutionalisierung und Leben in der sozialen Gemeinschaft” ist ein Forschungsprojekt, das von 2004 bis 2007 lief. Das Ziel des Projekts war, Informationen über die Anzahl all der Menschen zu sammeln, die in Anstalten leben. Die Studie wurde in 28 Ländern durchgeführt. Ein tschechisches Team war für fünf Länder zuständig: Rumänien, Ungarn, Polen und die Tschechische Republik. Dieser Artikel präsentiert die wichtigsten Ergebnisse für die Tschechische Republik und die Empfehlungen, die das Forschungsteam daraus entwickelt hat. ★

The Czech Republic as a living laboratory

THE POLITICAL, ECONOMIC AND SOCIAL STRUCTURE of the Czech lands has changed rapidly in the last hundred years. The Czech Republic therefore gives a unique opportunity to

study a climate where changes and their consequences have occurred in a relatively short time period. The Czechoslovak Republic was an independent state since 1918 when a federation of two states, Czechia and Slovakia was formed. After World War II, the state became socialist where the communist party ruled under the Soviet Union's influence. In 1989 the “Velvet Revolution” restored independence from the communist government and democracy was

re-established. In 1993 the state was divided into two sovereign countries, the Czech Republic and the Slovak Republic. Since 2004, the Czech Republic has been a member of European Union.

Social Care for people with disabilities

THE CZECH REPUBLIC is a transitional country moving from a model of residential services; based on segregation and congregation of people with disabilities, towards community based services. This process was expressed in *Preliminary National Report on Health and Long-term Care in the Czech Republic (2005)*: "A general trend in social services has been a shift from the institution-based care towards the community-based care, promoting the idea of an individual care provided in a home-like environment. This trend puts emphasis on the individual approach to clients and their human rights". Also, strategic documents published by the government call for the prevention of institutional care for people with disabilities (Nation Plan Support and Integration for Persons with Disabilities 2006 – 2009, Government Resolution 1004/2005). However, there remains a deeply rooted structure of segregation apparent in social services, which is also evident in public perception regarding disability. There are known cases, besides the Czech borders, where "cage beds" are used in care homes for people with intellectual disabilities.



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Despite a significant effort from the Czech central government to assure quality standards in social services, problems in residential services in particular still remain.

Public administration

PUBLIC ADMINISTRATION AND THE MANAGEMENT of public services, has been decentralized in the Czech Republic since 2003. Subsidiarity is the key principle for

further development as it sets basic criteria for dividing competences between the state, its administration and regional and local governments. This principle should ensure that all issues are solved at the lowest possible level and also considers effectiveness. The territory of the Czech Republic is divided into 13 regions and the capital city of Prague. The basic territorial units are municipalities (6,249) and corporate towns. According to Law on Social Services No. 2006 Coll. Regional governments carry out the main responsibilities in quality assurance in residential services for people with intellectual disabilities.

Residential Services for Persons with Intellectual Disabilities

IN LINE WITH THE HISTORY of many other industrial countries, social policy in the Czechoslovak Republic tended to segregate people with disabilities by placing them in residential institutions. The past few years have witnessed the fall of communism and the peaceful division of the Czech-Slovakian Federation, where the country has undergone a radical transformation within political, economical and social areas. In the early 1990s, an important shift took place with the de-monopolisation of the central state role in delivering social services. Accompanying this was the transfer of responsibility to local authorities. The process continued in 2003 when regional authorities assumed responsibility for institutions. NGOs have grown in CR as new providers of social services with the aim of supporting people with their families and local communities. Laws on Social Services (entered into force on January 1, 2007) are based on three principles: quality, accessibility and security. This is revolutionary as it empowers services users and their families. The laws are based on the principles of direct payments. However, there is no independent advisory body to support people with intellectual disabilities in their decision-making with regards to their services.

Social service institutions still exist in the Czech Republic.

THESE INSTITUTIONS were established mainly during the communist era, with the first being established in late 19th and beginning of the 20th century. These residential facilities are *pensioners' homes, boarding houses for pensioners and social care institutions for disabled people*. They are divided according to the types of disability, both for adults, children and young people. It is not an exception to find pensioners' homes with 300 beds, and social care institutions with 350 beds. There are about 140 institutions for people with intellectual disabilities (children & adults). Most of these facilities are still open and the living conditions have not changed much over the last decade. Only a few of them have undergone reconstruction. Some bedrooms have between six and ten beds, although in newer institutions

(20% of these institutions were built in the last 10 years) bedrooms have from three to five beds, with modern furnishings. The number of people in the institutions has diminished very little since the beginning of 1990s.

Transformation of institutions?

THERE ARE FEW ATTEMPTS from central and regional governments to transform institutions to sheltered housing. Their conception is to organize institutions into small units or individual houses for 6-8 persons and to also provide supported living or halfway flats within the institutional walls. The author of this paper argues that such a transformation plan is not feasible because it is based on "building centred planning" and not on "person centred planning". In comparison, the Czech attempt to move to community-based services still shows some features of institutions. This can be different clothing for staff or a huge dining room where all inhabitants come to have lunch with different sections for staff and clients. On the other hand, until 2006, the large net of institutions has been the only provider of financially stable residential services of handicapped people.

Sheltered/supported housing

SHELTERED AND SUPPORTED HOUSING are examples of new service types in the Czech Republic, which started in the 90's and are provided typically by NGO's or charities. In 2006, there were 212 places in these facilities. Sheltered housing is usually provided in special facilities resembling households. Support is provided flexibly according to client need and homes may resemble a group home (community living, 8-15 residents) or small individual flats (1-2 residents). These types of services are usually offered to people with mental illnesses, particularly younger clients from 18 to 35, where their placement in these facilities is usually limited to 2 years. After this time they are expected to live in their own flat and their consultant or case manager, can support them if necessary. Supported (assisted) housing allows people with disabilities to stay in a home environment (in his/her own flat, rental flat etc.). Users of this service only receive assistance when it's necessary. It is often not clear and possible to distinguish between these two types of housing, as the terms are not well established in Czech yet. Group homes are the most typical facilities for people with intellectual disability, while individual flats are more common for people with mental illnesses.

Social hospitalisation

People with disabilities sometimes also live in pensioner's homes. There is a lack of places in these homes and as such this situation is often resolved by using "social hospitalization". This means that a patient, who is not self-sufficient, can temporarily get social care while being hospitalized in a health care facility. This is typically provided in hospital for



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long-term patients. Formally this type of social/health care service was legal, but it is still a subject of discussion. For example, its funding should be from more sources: public sources (Ministry of Health, MoLSA), providers' budgets (regional and local authorities) and patient's allowances (from social benefits and pension). There are some cases that document 1059 patients staying in health institutions for more than a year and others that report stays for longer than 10 years (99 patients). From the statistics, it is not clear why these patients stay in the facilities for so long. It is only estimated that 1/3 of the bed capacity of the psychiatric institutions is used by patients in difficult social situations (they are on waiting list for a social care institutions, some of them are hospitalized for more than 1 year).

Conclusions

THE RESEARCH PROJECT DECLOC revealed that the available data about residential services in most European states is far from satisfactory. The Czech Republic is not an exception. There is a clear need to establish a comprehensive methodology for data collation. Furthermore, the following recommendations are particularly significant for the Czech Republic:

- Strengthen the vision of new possibilities in the community
- Abolish the building of new institutions or new buildings in existing institutions, and to spend the majority of available funds to develop services in the community.
- Create some practical demonstrations of how things can be better

The Czech Republic, as well as other transforming European countries has a unique opportunity to learn from the mistakes of other countries during process of deinstitutionalization. We can only hope that BBC and Mrs Rowling will have soon other subjects for bad news than living conditions in care home for people with disabilities in the Czech Republic. ★

People with Developmental Disabilities:

Living as Everyone Else Does

Chuck Sudetic

a senior writer for the Open Society Institute's Communications Office

People with intellectual disabilities should not be excluded from our society. So throughout the last few years, many people have been fighting for their inclusion. This was also the case in Eastern and South Eastern Europe. This fight entails attempts to change the attitudes of parents, professionals, political leaders and general public. Milica Čičić and Zdenka Petrović live in Croatia. Their personal experiences show why this fight for inclusion is so important.

Les personnes handicapées mentales ne doivent pas être exclues de notre société. Aussi, ces dernières années, de nombreuses personnes ont lutté pour leur inclusion. Cela a également été le cas en Europe de l'est et du Sud-Est. Ce combat implique des tentatives pour modifier les attitudes des parents, des professionnels, des hommes politiques et du grand public. Milica Čičić et Zdenka Petrović vivent en Croatie. Leurs expériences personnelles montrent pourquoi cette lutte pour l'inclusion est si importante.

Menschen mit geistiger Behinderung dürfen aus unserer Gesellschaft nicht ausgeschlossen werden. Daher haben sich in den letzten Jahren viele Menschen zusammengeschlossen, um für ihre Einbeziehung zu kämpfen. Auch in Ost- und Südosteuropa ist dies der Fall. Dieser Kampf umfasst die Bemühungen, die Einstellungen der Eltern, Experten, politischer Wortführer und der Öffentlichkeit zu ändern. Milica Čičić und Zdenka Petrović leben in Kroatien. Ihre persönlichen Erfahrungen zeigen, warum der Kampf für die Einbeziehung so wichtig ist. ★

MILICA ČIČIĆ RECALLS IT RAINING on the day she and her elder sister entered the main gate of the Center for Rehabilitation. On their right, beyond the rim of their dripping umbrella, were a guardhouse of dirty white stucco, a watchman's eyes, and a statue of a woman cradling a child. Čičić was afraid. Her sister was crying and tried to be reassuring: "It's a school, Milica. They'll teach you to read and write."



Milica Čičić

MILICA ČIČIĆ. And because she cannot gauge the passage of time, from the moment of her sister's farewell, Čičić's days mashed together like lumps of clay in the activities room. Wake-up at six; Breakfast, crafts, perhaps music. Lunch; Maybe a walk around the grounds. Dinner; Arguments and catfights. Punishments: head shavings, days of lock up, days of having to wear pyjamas instead of clothes. Once an

inmate tried to fix an iron without unplugging the cord and died of electrocution. After that it was; "Don't touch the irons." "Don't touch the television." "It's nine." "Everyone to bed."

Čičić cannot say exactly how long it has been since she left the Center for Rehabilitation. (It was during 2001.) She is one of more than 100 people who have built new lives in the world beyond the front gate of the center and other institutions like it across Croatia. They were assisted by the Association for Promoting Inclusion, an organization working to close the Center for Rehabilitation and similar state institutions and to redirect their public funding into programs that reintegrate former residents into society with full human rights.

A professor at Zagreb University who specializes in rehabilitating people with developmental disabilities, Borka Teodorović, manages the Association for Promoting Inclusion, which receives support from the Open Society Mental Health Initiative. Teodorović says that for centuries people like Čičić suffered terribly. Some families rejected them; other families were unable to give them adequate protection and care; some loving caregivers died and left them with no one. And in the world outside the family, the disabled endured mockery, abuse, homelessness, hunger, and castigation as vessels of demons or souls condemned by god. During World War II, Nazi Germany chose to exterminate them in an attempt "to strengthen the nation." After the war, communism came to Eastern Europe. Efforts

began to institutionalize and educate the developmentally disabled with a view toward someday allowing them to return to society. In too many instances, however, these institutions failed to educate, train, and return their residents to society. Too often, they cut their residents off from their families and barred them social contacts in the outside world. In many cases, these institutions became expensive life-long warehousing facilities for human beings.

Several decades ago, the developed countries of the West began undertaking successful efforts to reintegrate developmentally disabled people into society. Now, the countries of Eastern and South Eastern Europe are following the same course, and the Open Society Institute is assisting their efforts. "The developmentally disabled are among the most marginalized and neglected segment of the population of these regions," said Judith Klein, director of the Open Society Mental Health Initiative. She has carried the idea of inclusion into Eastern Europe and the former Soviet Union, where tens of thousands of people are locked away. "These people have significantly less ability to advocate on their own behalf," Klein says, "and this, in part, has led to a history of massive institutionalization that is contrary to the principles of an open society and a violation of human rights."

Liberating the developmentally disabled from institutions requires altering the attitudes of parents, some professionals and members of the government bureaucracy managing these institutions, political leaders, as well as the general public. "We are about 30 years behind," Teodorović says of Croatia, which has about 4,500 developmentally disabled people in institutions countrywide. "The ministry here has not reached the conclusion that it has to change things. The bureaucrats say they favor inclusion, but they create barriers. They have a plan, for instance, to build five new buildings at the Center for Rehabilitation to house about 125 residents who have the most severe disabilities; the remaining 260 or so residents, they would like to deinstitutionalize. We disagree. We believe it doesn't matter that the institution is great, if it is new and clean. None of these people should be locked away."

"The people living with the worst disabilities will need more assistance in a community setting than the others," Teodorović says, "but the community can and should bear the costs, because the alternative deprives them of their human rights."

Čičić remembers a team from the Association for Promoting Inclusion asking whether she wanted to leave the Center for Rehabilitation: "They said I would have my own bed, that I would work, that I would earn money and be able to keep it."

"I understood that when I came out I would have to try hard but that I could live as everyone else does," she says. In the center, "they treated us all as if we were children. They used to call us children. But we are not children. I am a grown woman. But there any relationship with a man was considered shameful."

Čičić's integration proceeded in steps. At first, she shared an apartment with a round-the-clock attendant. Later, she

married and moved into a flat of her own. Today, she holds the keys that unlock the main entrance to the apartment house where she resides. A social worker makes periodic visits. An assistant takes Čičić and other members of the program to shop in groups. Her husband, another former resident of the Center for Rehabilitation, works for a company, placing labels on retail body-care products. Čičić handles the cooking: "I like to make everything, fried chicken, soup, strudel, eggs. And my husband is very satisfied."

Milica Čičić and the other citizens of Croatia with developmental disabilities have an advocate in Zdenka Petrović. She is president of South Eastern Europe's first non-governmental organization run by developmentally disabled people dedicated to lobbying on their own behalf and demanding respect for their human rights. Petrović knows the loneliness, fear, mistrust, of life inside an institution. The 24 years she spent in one did not mash together like balls of clay in the activities room.

Petrović was abandoned at birth in 1965 and placed in a home for children. She eventually lived in a foster family for several years before being institutionalized in 1974. She wanted to go to school, but never got a chance. In 1998,



Zdenka Petrović

Borka Teodorović approached Petrović, one-on-one, and asked her whether she would like to attempt to live outside the institution. Now, after eight years, Petrović has her own apartment. She works. She has friends and relationships with men. She can read, write, and do arithmetic. At age 41, she is tackling fifth-grade grammar, reading, math, geography, and history. "I buy what I want," she says. "I pay my own rent. I receive

some social assistance, but I can work and earn money on my own. They always told me I was incapable of working. They said we were of no use to anyone else."

On July 13, 2005, Petrović appeared as a witness before the Committee on Human Rights of Croatia's national assembly. She wore a business suit. She enunciated her words clearly, slowly, and with resolve. "My friends who are still in the institution today would also like to come out, they want our help," Petrović testified. "They want to live independently. And I would recommend that a decision be taken to close down all these institutions and give these people the ability to live independently and work."

Someday—she hopes it is soon—Petrović will approach the front gates of the Center for Rehabilitation with Čičić and other former residents. They will walk up the driveway alongside an imposing new metal fence and pass the guardhouse of dirty white stucco, the watchman's eyes, and

the statue of a woman cradling a child. And once inside the center, Petrović will approach residents one at a time. She will explain to them the possibilities of life outside. This is exactly how this woman who was told she had nothing to contribute described what she will say:

"I'll ask them whether they want to go outside. If they say no, I'll ask why."

"If they say they don't want to leave, I'll ask them why it is fine in the institution. If they say it is fine because they have something to eat and a place to sleep, I'll ask whether they would like to have a place to sleep and something to eat outside.

"If they say they can't leave, I'll ask them why they can't leave. I'll ask them whether they would like to work and be paid for it. I'll ask them if they want friends, men and women friends.

"If they say the staff won't let them, I'll explain that, once they're outside, they'll have their own friends, they'll decide what to do, what to eat, when to wake up, when to go to bed.

"People are afraid of what they do not know."

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The Role of Families in Deinstitutionalization and Beyond

Marty Ford

The Arc and United Cerebral Palsy Disability Policy Collaboration

The government of the United States has always supported people with intellectual disabilities. They have done so by providing services. However, the way services are provided has changed a lot in 25 years. Today, the government supports this group of people more in the community than in the institutions. More funds are spent on community-based services and less on institutional services. Family members can be key partners in deinstitutionalization. But they need support. Moreover, to ensure full implementation of the UN Convention for people with severe intellectual disabilities, State Parties should give even more support to the families.

Le gouvernement des États-Unis a soutenu les personnes handicapées mentales en finançant des services. Néanmoins, la manière dont les services sont fournis a beaucoup changé ces 25 dernières années. Aujourd'hui, le gouvernement soutient davantage les personnes dans la communauté que dans les institutions. Plus de fonds sont consacrés aux services à caractère communautaire et moins aux services institutionnels. Les membres de la famille peuvent être des partenaires clés dans la désinstitutionnalisation. Mais ils ont besoin de soutien. En outre, pour assurer la mise en œuvre complète de la Convention des Nations Unies en incluant aussi les personnes avec des handicaps mentaux graves, les États doivent apporter encore plus de soutien aux familles.



Die Regierung der Vereinigten Staaten unterstützt Menschen mit geistiger Behinderung durch Förderdienste. Dennoch - die Art der Bereitstellung dieser Dienste hat sich in den vergangenen 25 Jahren verändert. Heute unterstützt die Regierung mehr Dienste in der Gemeinde als Anstalten. Mehr Fördermittel werden für Gemeinschaftsdienstleistungen verwendet als für Anstalten. Familien können die Hauptpartner für die De-Institutionalisierung sein. Aber sie brauchen Unterstützung. Mehr noch – um die volle Umsetzung der Konvention der Vereinten Nationen auch für Menschen mit schwerster geistiger Behinderung zu erreichen, müsste die staatliche Seite die Familien noch viel mehr unterstützen. ★

OVER THE LAST 25 YEARS, the United States has experienced a revolution in the way government funded long term services are provided to people with severe intellectual and other developmental disabilities. Through the 1960s and 1970s, large congregate residential services were the major service funded by federal and state governments and these services were primarily provided in large state institutions.

With the advent of the state and federal Medicaid partnership, many states began to use the new source of federal funding to improve the conditions in their institutions. It was in the 1980s, with the new Medicaid home and community-based waiver, that states began to spend Medicaid dollars in community settings. By 1995, there were more people receiving home and community



based waiver services than institutional services through the Medicaid program, and spending in the home and community-based waiver soon surpassed institutional spending. Today, state and federal funds continue to support more people with intellectual and developmental disabilities in the community than in the institutions, and, by far, more funds are spent on community-based services than on institutional services. There are long waiting lists for community based services and fewer people ever enter institutional settings.

Many factors played a role in this revolution, including lawsuits by families and advocates to close the large state institutions; leadership of state and national governments; improvements in the measurement of quality of services; and evolution in the understanding of how best to serve people with significant cognitive impairments and medical and behavioral challenges.

The family role included systemic change and establishment of grass-roots organizations like The Arc of the United States and its state and local chapters. As their organizational priorities evolved, by the 1970s many of these chapters were responsible for the class action lawsuits to close the institutions and grass-roots efforts at the state level to provide services to individuals in their own homes and communities.

While advocacy by parents and families has been critical in achieving systemic change, the family role is also intensely personal for many individuals. Where there is an active family involved in the life of an individual with disabilities, the family has a major impact in the individual's deinstitutionalization or avoidance of institutionalization. It is critical that families be given active help and encouragement in their efforts to support the individual. This is the case for families when an individual returns to the community from an institution; it is also necessary to support families in order to prevent future institutionalization.

Many people who have been institutionalized have family members who remain involved in their lives and who can provide support as the individual moves into the community. On the other hand, experience in the United States also shows that many family members of people who have been institutionalized, especially for long periods of time, are fearful of a move to the community and resist such change, often placing obstacles in the way of deinstitutionalization. Many older parents, knowing they are no longer able to handle day-to-day caregiving responsibility, are afraid that they will be required to provide for their adult sons or daughters in their own homes and community. However, many of these family members have become strong advocates for community services when their loved one has successfully transitioned to a community setting. Clearly, these families will need support.

Family members can be key partners in making deinstitutionalization work for people with severe disabilities and in developing community alternatives. Due to the unique needs of each individual with severe intellectual disabilities, family members' involvement in their lives can be critical in furthering the implementation of the United Nations Convention on the Rights of Persons with Disabilities.

The Preamble Statement to the Convention states that "The State Parties to the present *Convention*, ... (x) *Convinced* that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities, ... *Have agreed* as follows..."

The Preamble statement recognizes the importance of the family's role in the lives of people with disabilities. For many, it will be through the support of family members that the UN Convention's promise for people with severe intellectual/cognitive impairments is realized.

In situations where people with severe intellectual disabilities historically have been institutionalized as a regular practice, it will be necessary to work with families



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medical choices; end-of-life treatment; and life or death decisions.

For children, families will need support in early diagnosis and in learning about and understanding the extent of the child's disability; addressing educational opportunities and barriers; and supporting the child in growing up in the family home.

For adults, families can assist the individual in ensuring that services reflect their individual values and preferences and in exercising their rights in areas such as living arrangements; religious expression/choice; use of public supports or benefits; work; everyday functioning; decision-making; mobility and access; access to assistive devices or accommodations; marriage and children; health care coverage and medical decisions; quality and monitoring of services; and increased supports due to aging.

As parents age, siblings often take on increasing advocacy and support roles and should be encouraged to do so. Because they are likely to live longer than the parents, siblings can play a very significant role throughout the lifetime of an individual with severe intellectual disabilities.

To ensure full implementation of the Convention for people with severe intellectual disabilities, State Parties should support the family in the various roles described.

In addition, State Parties should consider how the State can protect the individual and the exercise of his/her rights when the family is not acting in the individual's best interests, or where there is no family, and what barriers must be dismantled. In such cases, the State Party may need to ensure the availability of adult and child protective services; informal supported decision-making; health care and financial powers of attorney; and guardianships where necessary, including limited guardianships and less restrictive alternatives, with appropriate government oversight and monitoring. ★

and assist them in supporting their family members once those individuals move out of the institution and back into their home communities. A supportive family can aid in a positive transition to the community, even if the individual will not be living with the family.

Supportive families may also be key for those who have never been institutionalized. To maintain the family in a supportive role will require that the family's needs are met, in addition to the individual's needs. Services like respite care will assist the family in its supportive role.

For people with severe intellectual or cognitive disabilities, the family role will also change over time as the individual moves through life. Families and service systems should support individuals to become self-advocates and to voice their own concerns to the extent possible.

The challenge for State Parties to the Convention will be how best to support individuals with severe intellectual disabilities and their families in meeting the goals of the individual and in making decisions that are in the best interest of the individual regarding education; where to live; recreation; with whom to spend time; activities; religious worship; choosing guardians/support groups where necessary; long term planning; financial arrangements;

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Inclusion Europe is a non-profit organisation that campaigns for the rights and interests of people with intellectual disabilities and their families throughout Europe. Respect, Solidarity and Inclusion are the fundamental values shared by all members of our movement of and for people with intellectual disabilities and their families.

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