

# institution watch



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Monitoring the progress toward a vision of full community living for *all* persons with intellectual disabilities.

*Institution Watch* is a quarterly production of the People First of Canada CACL Joint Task Force on Deinstitutionalization.

This international edition is a joint effort of CACL, People First of Canada and Inclusion International.



Canadian Association for Community Living  
Diversity includes.



***“An institution is any place in which people who have been labeled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day to day decisions. An institution is not defined merely by its size.”***

*Deinstitutionalization Task Force*

## MESSAGE FROM THE PFC-CACL TASK FORCE ON DEINSTITUTIONALIZATION

**Norm McLeod and Shane Haddad,  
Task Force Co-chairs**



This Task Force is most pleased, in partnership with Inclusion International, to present this international edition of our newsletter, *Institution Watch*. We present this edition to commemorate the 50<sup>th</sup> anniversary of CACL, and to coincide with the International Gatherings of Self Advocates and Families to be held in Ottawa Canada. A time when we will share stories of success and joy, of challenges still to be faced, and to further confirm our shared vision for the future.

A time also however when we must remember that throughout the world today there are still several hundred thousand people with intellectual disabilities who remain trapped in institutions. Trapped in facilities that deny their citizenship, their fundamental human rights, their very personhood; often in conditions that are simply and undeniably appalling, dehumanizing and abusive. Our collective global struggle to live full and inclusive lives in community must ever remain mindful of these people. They cannot be forgotten or overlooked. Our collective efforts must include them – indeed must begin with them. We cannot / will not allow the practice of institutionalization to continue or to be seen as somehow acceptable or needed in any part of this world. We cannot be free, cannot truly live inclusive lives in community, cannot enjoy the full rights of citizenship until and unless the rights of all are equally protected and preserved.

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The stories and updates in this newsletter should not be viewed as a comprehensive commentary on the status of institutionalization on a global level. We have merely attempted to provide brief illustrative examples from various countries. Clearly all the various regions are not equally represented – but this does not indicate that the use of institutions is any less in these countries but rather that less information is readily available. To lesser or greater extents the horrors of institutions continue to exist throughout the world.

## **MESSAGE FROM BENDINA MILLER**

**President, Canadian Association for Community Living**



In 2008, the Canadian Association for Community Living celebrates its 50th anniversary. Celebrates 50 years of working with and on behalf of individuals with intellectual disabilities and their families. Fifty years of effort toward advancing and entrenching the rights of persons to live in community as full citizens of Canada. While we have, together with individuals and families, achieved much in these 50 years regrettably we have not yet achieved the full and final closure of institutions in this country. Despite knowledge gained from national and international experience that demonstrates the benefits of community living for all persons with intellectual disabilities, institutions remain open. Even as we celebrate the historic signing of the UN Convention on the Rights of Persons with Disabilities, we are saddened by the fact that there are still several thousand people residing in large institutional facilities in this country. The Institution Watch newsletter has been a remarkable vehicle by which to monitor and in many ways advance our efforts toward full deinstitutionalization in Canada, and with this international edition we affirm our commitment to assisting persons with intellectual disabilities in taking their rightful place in community, in Canada and throughout the world. We encourage you to join with CACL in demanding that governments across Canada, and internationally, take action to close institutions and ensure that appropriate supports are in place within the community.

## **MESSAGE FROM RICHARD RUSTON**

**President, People First of Canada**



I would like to welcome delegates from around the world to our nation's capital city, Ottawa. We are pleased to co-host the Global Forum on Self-Advocacy along with Inclusion International. What an opportunity for self-advocates to learn about issues people are facing around the world. One thing we know for sure – the face of poverty looks the same everywhere.

While People First of Canada has many goals and objectives, the primary focus, the essential core of People First is to close all institutions in Canada. This task has been a long road with many bumps along the way. We have had success in some provinces and setbacks in others. It's hard to believe that in 2008, we still have to convince Canadian citizens that warehousing people simply must stop.

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People First of Canada, along with provincial groups in Manitoba, Saskatchewan and Alberta have recently finished a three year project with the National Film Board of Canada called “The Freedom Tour”. A 53 minute documentary of survivors sharing their experiences of what life was like while living in an institution. This film portrays both a historical point of view as well as recent experiences. The result is a powerful, horrific film that dispels any myths that may remain for anyone who may believe that this kind of setting is acceptable.

The UN Convention states that human rights and basic freedom are really important for all people, and we should have them by right. We need to acknowledge the fact that incarcerating people for no crime other than being born with a disability is a mistake, a huge mistake. We must right the wrong. People’s lives depend on it.

## **MESSAGE FROM DIANE RICHLER**

**President, Inclusion International**



Inclusion International is pleased to have an opportunity to collaborate with the Canadian Association for Community Living and People First of Canada to draw attention to the situation of people with intellectual disabilities living in institutions around the world. This international edition of *Institution Watch* provides a snapshot of the history of institutions and current efforts to support people to live in the community.

As the UN Convention on the Rights of Persons with Disabilities comes into effect Inclusion International will support initiatives to share information about good practices and lessons learned in Living in the Community (article 19); develop resources for our members who are working in this area; support the development of reports to the Committee of Experts by national groups and begin to track progress towards the goal of community inclusion.

The CRPD contains monitoring provisions which create opportunities to work with governments to develop practical strategies to provide supports in the community and transitions from institutions to community. Each country that ratifies the Convention will be required to report regularly on their progress towards implementation of the Convention. It will be essential that each of these reports contain data and information about people living in institutions.

This snapshot of institutions in different parts of the world is a first step in beginning to track the current situation of people living in institutions.

The Task Force wishes to express its appreciation to all those who contributed to the development of this edition of *Institution Watch*, in particular we thank Inclusion International and Inclusion Europe. We also wish to acknowledge and sincerely thank Ulrich Eigner for permission to use his wonderful photographs. The full photo-story (pictures and text on Social Care Houses in Bulgaria) and other of his works can be viewed at [www.ulricheigner.com](http://www.ulricheigner.com)



Photo courtesy of Ulrich Eigner

## TRANSFORMING RIGHTS INTO REALITY

Submitted by **Connie Laurin-Bowie**  
Director, Policy and Programs, Inclusion International

Inclusion International and its member organizations fought hard ensure that the right to live in the community was included in the UN Convention on the Rights of Persons with Disabilities (CRPD). The challenges we face in transforming this right into a reality around the world are multiple and complex. We need not only to move people out of large institutions but we need also to build communities that are welcoming, inclusive and where families are given the support they need.

The move towards deinstitutionalization began in most parts of the world over 40 years ago and yet there are hundreds of thousands of people with intellectual disabilities who still live in institutions. The impetus for returning people or keeping them in the community came from families. Forty years ago families in places like Scandinavia, Canada, New Zealand, the United States or Western Europe were given no options, no support was provided to them to care for their family members and institutions were the only option provided. In many parts of the world today that continues to be the reality. In Eastern European countries where extreme poverty means people are unable to feed their families, institutions are the desperate and bleak option presented by government. Parents begrudgingly

accept to send their children away knowing that at least they will be fed and clothed. In Africa or Central America where many families live in poverty and economic infrastructure is very poor, the large style institutions were never built but families were left with no support, no services and no hope.

The process of moving people out of institutions and back into their communities has had very different contexts in different parts of the world but many of the lessons we have learned in those efforts have been shared. In Canada the move to close institutions was set in the context of the Charter of Rights and Freedoms which prohibits discrimination based on mental or physical disability. Using a human rights framework meant taking a stand on moving people with the highest needs out of institutions first as a way to build community supports that would meet the needs of all people. In the United States over the 80s and 90s, families, disability advocacy groups and state policymakers worked to serve more people with developmental disabilities in the community rather than in large, state-operated facilities.

In June 1999, the U.S. Supreme Court (in *L.C. & E.W. vs. Olmstead*) ruled that states are required to provide community-based services for people. The result has been that the fight to move people into the community has been often fought in the courts and in grievance systems one person at a time. In Eastern Europe the process of accession to the European Union has meant that countries that want to be included in the EU must make efforts to improve their human rights records. Attention to the number of people living in institutions and the poor conditions that they live in has created pressure on governments to develop alternatives in the community. In New Zealand where they have officially closed the last institution, there will be a unique opportunity to watch as a generation of individuals, families and communities will live institution free.

We have learned many things over these past years about supporting people, about changing communities and about the role that public policy can play in our success or failure in the process. We know for example that during the process of closing an institution we must have funding for a period of time that pays for both systems to run at the same time (institution and community supports) while we build supports in the community and move people. Sometimes we simply replaced large institutions with smaller ones or created institutional conditions in our communities. We also have learned that attaching budgets to individuals as they leave the institution by itself does not create community supports. We've learned about building new families and about personal supports and much more. These lessons however have not been translated into knowledge that can be accessed by governments which are faced with their obligations under the Convention yet do not know how to proceed. It is our job to be the source of knowledge and expertise for those who are beginning the journey and to work together globally to continue the work in those places where the job is not done.

In some places we face the risk that the obligations to provide services and support that are outlined in the Convention will result in governments mistakenly believing that the construction of new institutions will help them to meet their obligations. Adding to this danger is the fact that many multilateral agencies and non-governmental organizations continue to invest in the building of "residential hospitals" and buildings otherwise known as institutions as a part of their development assistance plans. With no other offers of support, many families will accept these efforts in the belief that it will be an improvement on what they currently have (nothing). Families and self-advocates working in solidarity across borders can build awareness of alternatives to institutions and prevent the creation of new systems that exclude people.

Finally, we face the challenge of finding ways to

*The UN Convention on the Rights of Persons with Disabilities (CRPD)* recognizes the right of all people to live in the community:

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

measure our progress. Under the monitoring provisions of the Convention governments will be required to report on their progress towards implementation every four years. At a national level we must be asking how many institutions remain and how many people live in them? What investments are being made in communities to support families and individuals to be included? We must also ensure that no new capital investments are made in institutions by governments; by International NGOs nor by multi-lateral or development agencies. By collaborating internationally, we can develop a global platform for monitoring progress towards full inclusion.

We now have a new tool to help us in our progress towards community living and full inclusion. We have a critical role to play in keeping this agenda moving: as experts with real knowledge about what works; as a family movement in supporting each other globally to make demands for what we need to support and live in the community; and as watchdogs to ensure that the pressure for change does not diminish.



Photo courtesy of Ulrich Eigner

## **WORKING TOWARDS COMMUNITY LIVING IN EUROPE**

**Submitted by Ines Bulic, ECCL Coordinator**

The European Coalition for Community Living (ECCL) is a cross-disability initiative bringing together organizations and individuals committed to the promotion, development or provision of quality community-based services for people with disabilities. ECCL was established in 2005 by Autism Europe, the Center for Policy Studies of the Central European University, the European Disability Forum, the European Network on Independent Living, Inclusion Europe, Mental Health Europe and the Open Society Mental Health Initiative. Since January 2008, ECCL has been under the leadership of the European Network on Independent Living (ENIL), a European umbrella organization run by disabled people (more information is available at [www.enil.eu](http://www.enil.eu)). ECCL engages in lobbying activities at the European level, provides opportunities for exchange of good practice

among its members and other stakeholders and, together with the members, monitors developments in different countries. ECCL Newsletter, with good ideas and practices on community living, is published three times per year and is available at [www.community-living.info](http://www.community-living.info).

Across Europe, at least 1.2 million disabled people still live in long-stay residential institutions. The number is likely to be even higher, considering that many countries cannot provide accurate information about the number of disabled people or the kind of services they are using.

Having looked at the situation in 28 European countries, a recent study by Mansell J, Knapp M, Beadle-Brown and Beecham, J (2007) found that in 16 out of 25 countries for which information was available, state funds (local or regional) were being used, at least in part, to support institutions with more than 100 places. In 21 countries state funds were being used to support institutions with more than 30 places. When looking at the obstacles to development of community-based alternatives to institutions in Europe, the same study identified two major challenges: how to organize community-based services for disabled people so that their independence, integration and participation in the life of the community is successfully achieved; and how to manage the transition from institutionally-based systems of care to new models in the community.

In many countries, the problem is not that the necessary policies and strategies are not in place, but that there is no political will to see them implemented. The existing national deinstitutionalization policies are also reinforced at the European level. Both the European Union and the Council of Europe Disability Action Plans promote independent living and encourage Member States to develop person-centered support services in the community, which will facilitate independence and social inclusion of people with disabilities. Despite this, progress

towards the development of quality community-based services is very slow.

Moreover, in some countries in Central and Eastern Europe, the number of people in long-stay residential institutions is rising and new institutions, albeit smaller, are being built. A major concern that ECCL is addressing is the use of the EU Structural Funds (and other funding) for modernization or building of new institutions for people with disabilities. Such use of funding could delay development of community-based models of services even further.

On the positive side, in many countries where large long-stay institutions are still the only alternative for many disabled people, quality community-based services are being provided by non-governmental organizations. ECCL members in Central and Eastern Europe, such as the Association for Promoting Inclusion in Croatia and Pentru Voi in Romania, are examples of such good practice which should be supported and promoted.

Another major development is, of course, the adoption of the UN Convention on the Rights of Persons with Disabilities. While most European countries have signed it, only six have ratified it until now (Austria, Croatia, Hungary, San Marino, Slovenia and Spain). The European Union is also expected to ratify the Convention, and the proposal to do so has already been submitted to the European Council for approval. ECCL is aware that a lot of work will have to be put into ensuring implementation of the Convention, but it is a powerful tool we can use to encourage development of the much needed support services in the community, that will allow for the closure of existing institutions. The starting point for this work will be ensuring that community living (or independent living, as it is referred to by many groups) is seen as a human right of all people with disabilities and that no institution, regardless of its size, can give disabled people the opportunity to enjoy their rights on an equal basis with others.



Photo courtesy of Ulrich Eigner

## GERMANY

Submitted by **Dr. Corina Zolle**,  
European Network on Independent Living

Germany has 16 federal states. In our federal state Rhineland-Palatinate (RIP), there are 4M inhabitants, Germany as a whole has 80M. In RIP, 425,000 people are considered “disabled”, which means legal authorities have classified them. In the 60s and 70s a lot of institutions were founded. So a structure of homes, nursing care, special schools and kindergartens was set up. Today, 10,500 disabled people in RIP live in institutions, 13,000 work in sheltered workshops where their average income is 160 EUR per month. Only 13% of children with disabilities go to mainstream schools.

It is difficult to reverse this. If you want to get people out of the institution, there are objections from the authorities, from disabled people’s parents, from staff members of the institutions and sometimes even from disabled people themselves. The latter are often afraid to leave their sheltered homes and need positive role models. Authorities object because institutionalization seems to be the cheaper way and because the “outside environment” is not similarly accessible. Staff members are afraid that the appropriate care cannot be provided for outside the institution (and also fear for their jobs). The independent living movement in Germany started at the beginning of the 80s. The first Center of Independent Living was founded in 1986. The movement has been successful in many areas.

Ten years ago, a number of laws were reformed in Germany to guarantee full participation in society to people with disabilities. But legislation for personal assistance is still missing. One exception is assistance at the work place. The new SGB IX (Social Code) gives the possibility to get a fixed budget for an assistant at the work place: But our experience during the last year has shown, that there are still many problems with the administration that grants the money for assistance.

In 1998, RIP started a pilot project on “personal budget” which shall help disabled people to move out of institutions. But this project is targeting people with a psychological or mental disability. The budget is very tight, so that is it impossible to pay for personal assistance for people with a severe physical disability. The personal budget is also income based. In June 2008, 3,300 people were using it in RIP. In the first six month of 2008, about 500 disabled people started using it, so the number of recipients is growing rapidly.

Those persons who live independently and have a job have to pay for their personal assistance (beyond the work place) from their own pockets. They can only keep about 700 or 800 € in addition to the rent. Even the wives or husbands of disabled people have to give their income to pay the personal assistance of their partners. Sometimes even the parents have to pay although the disabled child is already an adult. When you choose to hire and pay for your personal assistants, you become an employer with all the rights and obligations of a “boss”.

***I don't care what size it is, it can be a residence with two people or it can be a massive place with 500 people, an institution's a state of mind at the end of the day as far as I'm concerned...It's the narrow mindedness of it all. And it's not having the energy or the motivation to take full advantage of everything that's around you.***

**From 'And people said they will never do it!' Staff Stories of Resettlement from Institutions for People with Learning Disabilities in the North West of England**

## **DEINSTITUTIONALIZATION IN GERMANY**

**Submitted by Dr. Bernhard Conrads**

**I**n Germany, before the big wars of the last century, persons with intellectual disabilities were accommodated mostly in large institutions, meaning many thousands of children, youngsters and adults behind institution walls. These walls were no protection. On the contrary: In the time of the Nazi terrors more than 200.000 persons with intellectual disabilities were taken away from there and were killed.

In 1958 the federal union Lebenshilfe – Life Help – was founded by parents of children with intellectual disabilities. It was their purpose that their children could remain at home with their parents, as long as they were young and wanted this. Later they should be able to live in residential options in the community, very independently and similarly to families.

Also the right to vote and the right of persons with intellectual disabilities to select, for instance, the environment of living and working is a matter dear to our heart. They should have – like every other citizen – the possibility to choose the place where they will live and work. Small homes similar to families can also belong to it. Nevertheless, even today we have a need to catch up in so-called “cared living”.

In more than 500 local unions of “Life Help” more and more residential options are being developed that allow a life in the midst of the community. The “Life Help” pays attention to the fact that the necessary support and the desired security is guaranteed.

Through the organisation (Aktion Mensch - Action Human Being) the “Life Help” is involved in a program of closing down big complex facilities. The purpose of this program is to close big institutions over the course of the time, and also to decentralise. This program also runs successfully because the operators of such

institutions recognise more and more that decentralisation is a good thing. In this respect the "Life Help" philosophy has spread more and more.

Nevertheless, we are still on the way. Hence, the "Life Help" has provided a vision paper 'How people with intellectual disabilities want to live in 2020'. It is written, by the way, also in an easy to read language. There one says for instance that "everybody can determine for himself or herself where he or she would like to live", whether in his or her own flat, or whether he or she likes to move into a residential home. Every person can determine with whom he or she would like to live. Every person gets the help they need.

So that we can better reach these purposes, we also learn from international collaboration. Hence, the "Life Help" is a member in "European Coalition for Community Living". From there we find out how persons with intellectual disabilities live in other countries and the progress made in the area of deinstitutionalisation. With pleasure we also learn from you in Canada and we will be pleased to hear from you.

## SWEDEN

Submitted by Davide Pipino and Sussann Johansson,  
People First Sweden

In Sweden the big institutions are forbidden by law from 1st of January 2000. This means there are no big institutions. People got help to move out to their own apartments in group homes and in their own apartments with support and service from the social office.

The number of people living in a group home can not be more than 4-6 persons. Each person has his/her own apartment including at least one room, kitchen and bathroom. The support and service should be adjusted to the individual needs. Many persons with more severe disabilities live in apartments with support from personal assistance.



Photo courtesy of Ulrich Eigner

In Grunden we are not satisfied about how the group homes and the service are organized. They still are organized in the institution culture and people are not free to live their own lives. Because of that we run a campaign: "Smash the Institutions!" and "Never again institutions for children!"

In 2010 we plan a big demonstration and procession in Berlin, in Germany, in connection with the Inclusion International Congress taking place there – to demonstrate our determined claim: Close the institutions and free the people. We hope to organize this demonstration together with our friends in People First Europe. Maybe you want to join?

## THE CLOSURE OF INSTITUTIONS IN ENGLAND AND WALES

As published in *Included in Society: Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People*.

Alternatives to institutional care in Britain began to be seriously considered in the 1950s when the demand for residential care appeared to be steadily increasing. A Royal Commission recommended that more provision should be made for people with mild intellectual disabilities in residential homes in the community, partly in order to relieve pressure on hospital places. The responsibility for community services lay with



Photo courtesy of Ulrich Eigner

local, rather than central, government and little was done until, in the mid-1960s, a series of public scandals in institutions revealed extensive ill-treatment and neglect in squalid, over-crowded surroundings.

In response to this a Government White Paper reinforced the goal of providing community services for people with mild or moderate intellectual disabilities, and set clear targets for local authority services. This initiative applied to England and Wales, Scotland has a different legislative framework. Also at the beginning of the 1970s, a new lobby, for the first time, called for the complete abandonment of hospital care and its replacement by housing-based services in the community. This lobby drew its inspiration partly from the first community services in the United States and Scandinavia. In the early part of the 1970s, most new developments in the community were of large (20-25 person) units including some for people with severe and profound intellectual disabilities. By the middle of the decade, however, there was increasing pressure for housing-based services for all and the first examples of supported housing for people with severe or profound intellectual disabilities appeared.

Policy in Wales and England diverged at this point. In Wales, criticism of institutional refurbishment led to a demonstration project to serve a whole sector of the city of Cardiff with community-based services. The shift in thinking this entailed was later reflected in a national

policy of developing community-based services and closing institutions. Review of this policy after a decade showed substantial development of community services by local authorities using earmarked central government funds, though with little impact on institutional numbers. In the second decade closure was identified as a key priority.

In England, the main policy initiative in the 1970s focused on transferring funds from the health service (responsible for institutions) to local government. By the beginning of the 1980s, another official committee had recommended housing-based services as the main future model of care and several reports outlined the necessary elements of community services. These initiatives were followed by a national demonstration project that signaled central government's overall acceptance of the policy goal of deinstitutionalization and gave many local service agencies experience of the work involved. In the second half of the 1980s the first large-scale institutional closures happened and the process gathered momentum, with deinstitutionalization becoming tacitly accepted as a general policy goal.

## DUBLIN, IRELAND

There are about 330 people with intellectual disabilities housed in Ireland's psychiatric hospitals. Officials say that 307 of them have no mental illness, and should be living elsewhere. According to a brief article in the Irish Examiner, 218 of the residents with intellectual disabilities are housed at one facility.

Deirdre Carroll, general secretary for the National Association for the Mentally Handicapped of Ireland said her organization is urging the Department of Health to create separate housing for these people. "The people I am talking about are living in awful circumstances and they shouldn't be," she said. "These people are not mentally ill and should be in appropriate housing, based in the community or in smaller units rather than in big psychiatric hospitals."

A spokesperson for the Department of Health said the 307 have had an alternative residential facility "identified" for them. The others, she said, require day services, residential support services, or increased support within a psychiatric hospital. The spokesperson added that a relocation program has been underway for many years. Five institution residents have been moved out recently under the program and 28 more are expected to move to "more appropriate facilities" by the end of this year.

Officials are reviewing Ireland's National Disability Strategy and Disability Bill to determine how they might affect people with intellectual disabilities in psychiatric hospitals.

## **DENMARK, FINLAND, ICELAND AND NORWAY**

As published in *Included in Society: Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People*.

In Norway, it was not until after the Second World War that particular interest was shown in institutions. A period of extensive building was initiated after 1949 with legislation on the development of institutional services, to be financed with state funds. This process continued until 1976. Since then, the number of places in institutions has not increased. Towards the end of the 1960s, a period of institutional improvement began, concentrating on developing the services within these institutions. This period was characterized by an ambition to reduce the size of institutions, to introduce a greater degree of decentralization, to make the wards more home-like and to develop their educational and occupational facilities. These suggested improvements were a response to criticism of institutions and demands which originated in the Normalization Principle. The beginning of the 1990s has seen the start of a period of closure, furthered by a law which states that county specific services for persons with intellectual disability should be discontinued from 1992.



Photo courtesy of Ulrich Eigner

The dissolution of institutions has also become a reality in Finland where, from 1977, legislation pointed in the direction of community services, breaking a trend, which had existed since the 1940s, and which had led to an increased number of places in institutions. This trend has now reversed and institutional closure has begun. In Iceland, early forms of services were institutional. Attitudes to these services changed in the mid 1970s when emphasis began to be placed on the importance of parents being able to keep their children at home while they were growing up and, as adults, being able to live in the local community, in housing with adequate support. Today, the process of dissolution has begun. In Denmark, services for persons with intellectual disability have always been dominated by large institutions, though changes have taken place to reduce their size. Work has also begun on the dissolution of some of them, with some closures having already been achieved.

In Scandinavia, the overall picture is that the 1970s primarily involved projects aimed at the development of institutional services, whereas the 1980s was the decade in which their dissolution began. This process has affected everyone involved in services for persons with intellectual disability throughout these countries, and the dissolution of institutions is recognized as a task of fundamental socio-political importance in Scandinavian societies.

## MILICA C.

Croatia

As published in *Include, Inclusion Europe*, 2/2007.

Milica recalls it raining on the day she and her Melder 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." Čičić was 15 years old on that rainy day in 1977. She had never been to school, and the Center provided her no schooling she can remember. Even now, Čičić knows little about numbers. She cannot even scrawl the letters 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 pajamas 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.

The general finding of the 'Included in Society' project is that in many respects large residential institutions in Poland, Romania, Hungary and France are similar to those that have been studied elsewhere. People – especially those people who need most support – often live lives characterized by hours of inactivity, boredom and isolation. Staff numbers are frequently too low to provide habilitation, rehabilitation and therapy. The physical environment is relatively impersonal and does not provide the kind of privacy and homeliness that the general population would expect. Contact with family, friends and community is limited. In this situation, where the organization becomes relatively isolated from the wider community, practices develop that should be unacceptable, such as keeping people in bed all day or the use of cage beds to confine people.

## END OF LARGE INSTITUTIONS IN THE EU?

By Joanna Gill

As published in *E-Include* (the e-Journal of Inclusion Europe), May, 2008.

On the 4th March 2008 MEPs along with EU Commission representatives and NGOs gathered in the European Parliament to discuss the disturbing human rights abuses occurring in institutions across Europe. Heading the panel was MEP Kathy Sinnott, Vice President of Intergroup for the Family and Protection of Childhood. As a focus of the discussion a film was shown by controversial documentary director Kate Blewett (*The Dying Rooms*). 'Bulgaria's Abandoned Children' has been causing public outrage in the UK, Netherlands and Belgium where it has aired. Centered around a worst case example, Mogilino in Bulgaria, the film led the discussion towards solutions for Europe in moving away from large-scale institutions towards community-based support services.

MEP Kathy Sinnott chairing the meeting began with a personal memoir of her experience in Ireland during the 1960s, where children with intellectual disabilities were treated as second-class citizens. After introducing the documentary 'Bulgaria's Abandoned Children' she reiterated the point that this is not a problem unique to Bulgaria but a Europe-wide phenomenon.

The documentary, edited to 28 minutes, followed three 'inmates' of Mogilino. The stories covered different disabilities, among them intellectual disabilities. The most harrowing case being that of Didi, described as 'mildly autistic.' She is shown after nine months in the institution as rocking and without speech with concerns voiced over her deteriorating mental health. The concluding scenes show the director of Mogilino absolving herself and the government of Bulgaria of all responsibility.

Following the documentary, Kate Blewett spoke of her dismay at worst case examples such as Mogilino, but made clear that it was by far not the only example, and the problem shouldn't be seen as geographically isolated to Bulgaria. In fact, she had seen cases of good practice in Bulgaria and this demonstrated the will to change.

The panel discussion ('Ensuring social inclusion for children with disabilities in the EU: The need for deinstitutionalization') began with passionate calls for change from the NGO representatives Slavka Kukova of the Bulgarian-Helsinki Committee, Laura Parker of Absolute Return for Kids, Luk Zelderloo of EASPD. The calls ranged from an outright ban on institutionalization to money and resources being put towards making the shift from institutions to community-based services. Richard Howitt voiced his disappointment with MEPs who still didn't see disability rights as human rights, and admitted to not forcing the issue of human rights abuses in institutions in newly acceding countries to the EU as a higher priority within the Parliament.

Jan Jarab representing the Cabinet of



Photo courtesy of Ulrich Eigner

Commissioner Spidla, was visibly moved by the documentary and commented that change is crucial and should not merely constitute material assistance but a respect for human dignity. Ultimately, he argued that change rests on political will. Questions from the floor largely attacked the Commission's lackluster approach to social issues, and forced the question to be focused on Europe and not merely Bulgaria. Various Bulgarian NGOs were represented and made the point that change had already happened, and that it was possible even in worst case scenarios to make a difference, thus echoing Ms Blewett's comments that 'where there's a will, there's a way'. Godfrey Bloom (MEP) summed up the discussion arguing that the State cannot be relied upon to solve problems of education and healthcare. It will take a multilateral approach to deinstitutionalize Europe.

***So the first ward, children's ward that I went on, nobody had a toothbrush, nobody had any shoelaces. So it meant they couldn't walk anywhere because they had no shoes, everybody had hospital issue lace up shoes so they couldn't go out anywhere. So, one of the first things that I did when I got there was to go to the stores and ask for 25 toothbrushes and 25 sets of shoelaces and the store man said, we've never had an order like that, it's not on the supplies list, you know, so there wasn't any expectation, and there hadn't been, nobody bothered, the expectation was that well somebody eats shoelaces on that ward so we're not bothering replacing them because they'll get eaten again. So it wasn't, I don't think it was malice, it was just that expectations were absolutely rock bottom.***

***From 'And people said they will never do it!' Staff Stories of Resettlement from Institutions for People with Learning Disabilities in the North West of England***

## BULGARIA

By Joanna Gill

As published in *E-Include* (the e-Journal of Inclusion Europe), May, 2008.

The national Bulgarian organization of people with intellectual disabilities and their families, BAPID, demands a dignified life with full social inclusion for all disabled people. With the release of a key publication on de-institutionalization, BAPID shows that change from large residential institutions that violate the human rights of their inmates to community-based services is possible. Change: A Journey to Inclusion is the title of the publication that documents the development of alternative residential options for people with intellectual disabilities by committed social NGOs.

This publication supported by Inclusion Europe comes at a key time, with the entry into force of the *UN Convention on the Rights of Persons with Disabilities*. The European Union has signed the Convention, thus making it an important legislative document for all people with disabilities in EU Member States. As the international human rights lawyer Gerard Quinn



Photo courtesy of Ulrich Eigner

notes, 'Deinstitutionalization is above all else a human rights issue.' Article 19 of the new Convention clearly states that people with disabilities have the equal right to live in the community, to choose their place of residence, and with whom they live and to have access to a range of support services.

Change: A Journey to Inclusion shows how basic human rights can be applied in real life. Using examples from community services in Bulgaria, the book shows vividly what can be done to include people with disabilities in the community. Mr Quinn remarks, 'it is living proof of what the values of the UN Convention can achieve.' It is also proof that there can be no excuses for the Bulgarian or any other government in Europe to maintain large residential institutions where human rights and dignity of disabled people are violated.

It is worth mentioning that the changes shown in the book were not expensive and did not involve magic, but merely the dedication and perseverance of the NGOs working in this area. By using stark contrasts of institutional life and comparing them with examples of successful deinstitutionalization in Bulgaria, it is a testament to progress. It also provides an important example that should be applied across Europe to ensure that the rights and values set down in the UN Convention become a reality.

***No way would these guys resettle, there's no way they would settle in a house after living in hospital for 15/20 years, you have got no chance of it. After the first few weeks, months, we thought 'yes, you're probably right.' Then after a while we were amazed how quickly they became accustomed to the way things were. Not every door was locked in the building. That people knocked on the door. People were able to have a key if they were able to use one. That was one of the best times in my life. I really enjoyed that it felt like we were doing something that was cutting edge. They were going back to their roots - they came from (the City), the guys, and they went back to their family again... they were able to go on buses and do things differently... As far as I am aware now they've moved into different houses and they are much happier.***

***'And people said they will never do it!'***

**From 'And people said they will never do it!' Staff Stories of Resettlement from Institutions for People with Learning Disabilities in the North West of England**

Governments should now take action in order to realize fully the human rights of persons with disabilities:

- Ratify the UN Convention on the Rights of Persons with Disabilities and the Optional Protocol and start implementing it. Use the European Action Plan as a tool to make the standards a reality.
- Develop action plans to remove physical, legal, social and other barriers that prevent persons with disabilities from participating in society. Consult with and include persons with disabilities and their organizations in the planning and monitoring of laws and policies which affect them.
- Adopt non-discrimination legislation covering all relevant areas of society.
- Set up independent Ombudsmen or other equality bodies to monitor that persons with disabilities can fully exercise their rights.
- Develop program to enable persons with disabilities to live in the community. Cease new admissions to social care institutions and allocate sufficient resources to provide adequate health care, rehabilitation and social services in the community instead.
- Review the laws and procedures for involuntary hospitalization to secure that both law and practice comply with international human rights standards.
- Set up independent mechanisms equipped to make regular, unannounced and effective visits to social care homes and psychiatric hospitals in accordance with the Optional Protocol to the UN Convention against Torture.
- Tackle hate crime against persons with disabilities through proactive policing and prompt prosecutions.

**Thomas Hammarberg**

**Commissioner, Human Rights Council of Europe ([www.commissioner.coe.int](http://www.commissioner.coe.int))**

## REFLECTIONS ON INSTITUTIONALIZATION

**Oliver Lewis**  
**Executive Director of the Mental Disability Advocacy**  
**Center ([mdac@mdac.info](mailto:mdac@mdac.info))**

**W**hy do institutions exist? I'm referring here to the several million children and adults with actual or perceived disabilities who are forced to spend much of their lives in institutions. I exclude acute psychiatric beds or institutions for people who have committed criminal offences.

To the question "Why do institutions exist?" I've heard the following answers over the years from policy-makers and service providers in several European countries. Institutions are the best form of care. Institutions are cheap and our country is poor. There's nowhere else for these people to go.

There is such stigma out there in the community: thankfully we are here to take care of these people. Our residents have no skills and could not cope out there. Institutions are the only option. These people need 24 hour supervision. We will lose our jobs if this institution closes. Our country is not ready for these people to live in the community.

I struggle to find any of these answers convincing. They are based on prejudices and ignore the evidence that with appropriate support everyone can live in the community. They ignore that it is actually a person's human right to live in the community and that the State has obligations to ensure community living. And they reveal a mindset which clings onto the view that social care homes are actually social, caring or homely. If you have visited one of these institutions you will see – hear, smell, taste and touch – that they are not.



Photo courtesy of Ulrich Eigner

The answers are excuses for politicians to fail to take a step. They may fear that disgruntled staff who don't accept change will not vote them back into office. Corruption is another reason why some politicians and directors of social care institutions resist change. You can imagine what happens when one person controls the budget of a large institution as well as the finances of possibly several hundred people and there are no financial audits or other checks and balances.

What's wrong with institutions in human rights terms? To start with, institutionalization itself is a human rights violation: just read Article 19 of the UN Convention on the Rights of Persons with Disabilities. Institutions make other abuses likely. People are detained arbitrarily without court review. Inmates may be injected with mind and body-altering chemicals without their consent. They may have their property removed and be denied access to their own bank accounts. Access to telephones and other forms of communications may be restricted or censored. Healthcare may be denied. Staff may sexually or physically abuse or neglect inmates. The right to challenge these human rights violations before courts may itself be denied.

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*Deinstitutionalization is probably one of the major challenges left for society and is a severe test of just how much or how little we value human life.*

– deHaan, 1981

## UNITED STATES OF AMERICA

In the United States, in the early part of this century, the majority of people with developmental disabilities received services in large public institutions or were cared for by their families with very little support from government. In the 1960s and 1970s, the appalling conditions and the poor treatment of individuals living in these institutions came under increasing public scrutiny. Public policy began to move toward one of deinstitutionalization and the development of a more comprehensive community based service system. These initial legal challenges sought not only to improve the conditions in public institutions, but also to eliminate the unnecessary institutionalization of people with developmental disabilities who are capable of living in their own communities.

Since the US Supreme Court's 1999 landmark decision (in *L.C. & E.W. vs. Olmstead*) the unjustified institutionalization of people with disabilities is a form of discrimination. The *Olmstead* decision established two legal principles fundamental to public policy for persons with disabilities. The first is that the medically unjustifiable institutionalization of persons with disabilities who desire to live in the community violates Title II of the Americans with Disabilities Act (ADA), which applies to publicly funded services. The second is that States have a legal obligation to affirmatively remedy such discriminatory practices through reasonable modifications to public programs and services.

In this decision, the court ruled that states are required to provide community-based services for people with mental disabilities if treatment professionals determine that it is appropriate and the affected individuals do not object to such placement. The Court further concluded that states are responsible for community-based placement if they have the available resources to provide community-based services. States that

maintain waiting lists must make a good faith effort to move those on the list to community programs at a reasonable pace.

Many States have responded to the desire of people with developmental disabilities and their families for a range of options for care and independent living by increasingly replacing institutional care with community-based services. However, there is wide variation throughout the country in the rates of deinstitutionalization, funding for community-based services and social and political commitments to developing a community-based delivery system.

In 1991, New Hampshire and the District of Columbia became the first state and jurisdiction to close their only public institutions for people with developmental disabilities and develop a delivery system based entirely on community-based services. Once dominated by large state-run institutions, systems of care for people with developmental disabilities are undergoing continued change, with community services increasingly replacing institutional care.

The following States do not have institutions for persons with intellectual disabilities:

Alaska	New Hampshire
District of Columbia	New Mexico
Hawaii	Rhode Island
Indiana	Vermont
Maine	West Virginia

Throughout the US there remain more than 25,000 persons with intellectual disabilities living in large institutions, ranging from a low of 9 persons in Minnesota to a high of more than 4,900 in the state of Texas.

*(Braddock, D. State of the States in Developmental Disabilities, 2008)*



Photo courtesy of Ulrich Eigner

## INSTITUTIONALIZATION SHOULD BE ABOLISHED

By: Katie Dunne

<http://media.www.dailyillini.com/media/storage/paper736/news/2008/10/07/OpinionColumns/III-Institutionalization.Should.Be.Abolished-3473291.shtml>

Posted: 10/7/08

Imagine that your home is an old brick building that houses 300 people. You've grown accustomed to the stark white hallways and dull living spaces, but you'll never get used to that stench of urine. Meal times are scheduled, rules are posted, and dissent is not tolerated. During the most intimate activities of daily life – showering, using the bathroom, having sex – you are supervised by a complete stranger, and there is nothing you can do about it. Imagine your life without a voice.

There are thousands of citizens in Illinois that don't have to imagine; this is their reality. They are not prisoners. They committed no crimes. They were simply born with developmental disabilities.

In 2004, the state of Illinois spent nearly \$350 million (about \$120,000 per person) operating public institutions for people with developmental disabilities. Most residents did not choose this living arrangement and do not need 24-hour care. Many could live in the community with appropriate support and services for less than \$40,000 per year.

But Illinois refuses to progress. It refuses to do what makes sense, both economically and

ethically. It refuses to close large, state-operated facilities, as many other states have done. Instead, Illinois relies entirely on institutionalization, which leaves us ranked 51st in the nation for providing community living arrangements for people with disabilities (out of 50 states and Washington, D.C.). Providing humane and dignified services is simply not a priority. Legislative victories are far more important.

In 2004, Gov. Blagojevich agreed to reopen Lincoln Developmental Center, which had been closed for poor treatment of its residents, in exchange for votes on his pension plan in the General Assembly.

Lincoln, which was described by the Chicago Tribune as a "monstrous, money-chomping, isolated institution," is a gem compared to Howe Developmental Center in Tinley Park, Ill. Between September 2004 and July 2008, 23 people died at Howe, and autopsies were never conducted. The institution remained open. The neglect and abuse continued. One resident at Howe was sent to the hospital with a mouthful of cigarette butts and treated for nicotine poisoning.

The federal government soon got involved, federal funding was pulled, and the U.S. Department of Justice launched an investigation of human rights abuses. Finally, the state declared its intention to close the facility. Twenty-three deaths we can handle, but we'll do whatever it takes to avoid bad press.

In Illinois, people with disabilities are treated as second-class citizens. They are herded into institutions and given remedial jobs in "workshops" that are often far below their ability levels. They are paid less than minimum wage, often less than one dollar a day.



Photo courtesy of Ulrich Eigner

So what can we do to change?

The state of Illinois must end its policy of segregation. The ultimate goal of the state should be closure of publicly operated institutions in favor of community-based living options, which are more cost efficient and provide a better quality of life for people with disabilities. In addition, the state should comply with national standards for care and services.

"Money Follows the Person," a federal funding program, should be implemented in Illinois. Today, if an individual chose to move out of an institution, he would lose his state funding. If money followed the person, he could use his funding to pay for an apartment, transportation, and a personal assistant. A "Money Follows the Person" program would give individuals more options and allow for greater independence.

Many people with disabilities imagine achieving this independence. They imagine living on their own, working in the community, hiring their direct support staff, and leading a fulfilling life. They imagine having a voice. The state of Illinois can make this a reality if it reexamines its priorities and makes a commitment to systemic change. Let's stop imagining and give people with disabilities the rights they deserve.

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*Our lives begin to end the day we become silent about things that matter.*

– Rev. Martin Luther King, Jr.

## WELLINGTON, NEW ZEALAND

Disability advocates gathered with members of the New Zealand government on November 14, 2007 to mark the end of an era: The closure of the last institution in the nation housing people with intellectual disabilities.

Several hundred people -- many of them former residents of the 13 state-run institutions that have closed over the past 40 years -- gathered in Parliament to celebrate with song, cake and speeches. Government officials called the successful deinstitutionalization of New Zealand an indication of the country's 'maturity' and an example of it being a world leader in providing community-based services to people with disabilities.

Disability Issues Minister Ruth Dyson said: "The deinstitutionalization process was about ensuring people with intellectual and physical disabilities can live in the community and do day-to-day things most of us take for granted."

People First New Zealand's Graeme Parish, who was institutionalized at age 6, said people with disabilities just want to live ordinary lives. "When you see a person with a learning disability serving you petrol, making you coffee in a cafe, walking down the street with their partner, walking their dog – this is ordinary, this is what we want."

## TASMANIAN GOVERNMENT DECLARES 'NEVER AGAIN' TO INSTITUTION DAYS

From a press release by the Government of Tasmania.

Deputy Premier Lara Giddings and Human Services Minister Lin Thorp welcomed tripartite support in the House of Assembly for a motion on Willow Court and the development of a new Disability Services Act. Willow Court, which provided institutional care in New Norfolk for people with disabilities, closed in October 2000.



Photo courtesy of Ulrich Eigner

The motion requests the Joint Standing Committee on Community Development to consider the objectives, outcomes and principles that should form the basis of a new Disability Services Act to ensure the institutional care approach experienced at Willow Court cannot happen again.

"I thank the Liberal Party Shadow Minister Brett Whiteley and the Greens Spokesperson for Health Cassy O'Connor for their support for today's motion and look forward to continuing a tripartite approach to this important issue," Ms Giddings said. "We were all shocked and saddened as we went through the process of revealing the tragic treatment and circumstances of vulnerable children in State Care in Tasmania's past.

"It is widely accepted that institutional care such as that experienced at Willow Court is no longer appropriate for people with disabilities. "All parties now recognize that the primary care and support for people with disabilities should be provided in the community," Ms Giddings said.

Ms Thorp said she was delighted at the cross-party approach being taken to such a sensitive and significant issue. "We need to look at how a new Disability Services Act could ensure the institutional approach taken at Willow Court cannot happen again,"

"New legislation could protect the human rights of people with disabilities and ensure our quality

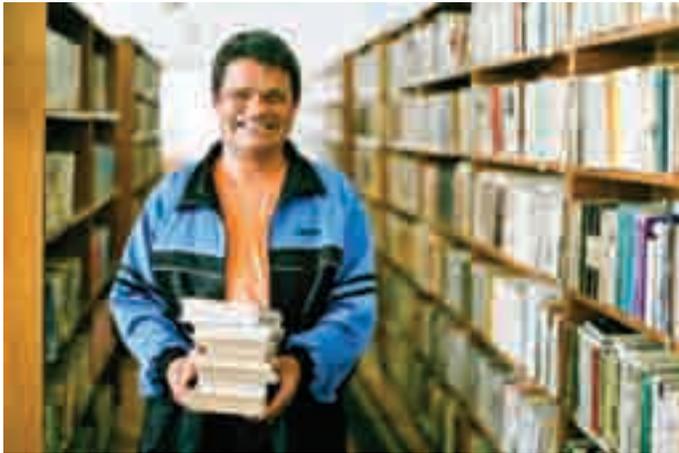


Photo courtesy of Ulrich Eigner

and safety framework is consistent with modern approaches to service provision.

“This motion came about as the result of a submission by National Disability Services and its State Manager Margaret Reynolds.

“I commend Ms Reynolds’ commitment to people with disabilities and acknowledge her efforts to ensure we continue to improve the lives of people with disabilities, their families and carers around Tasmania.

“Tasmania has led the way in recognizing the suffering of former wards of the State. We were the first jurisdiction in Australia to make amends for adults who were abused as children while in State care, and we aim to continue to lead the way as we develop new Disability Services legislation,” Ms Thorp said.

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*In an institution your rights are taken away and you are devalued. it is time to take a step ahead to inclusion and have all people brought into community with supports.*

– Shane Haddad, Former President,  
People First of Canada

## **GHIZELA G.**

**Romania**

**Submitted by Nicoleta Foica**

**A**bandoned by her mother at the age of 4, Ghizela spent 25 years of life in various institutions. She did not embark on any educational program or a job coach program. Therefore Ghizela did not gain knowledge of the basic social abilities. Seven years ago Ghizela and three of her colleagues were deinstitutionalized. Pentru Voi Foundation offered a new life providing constant support and accommodation in a protected house. She learned to cook, to clean her room and the flat she is living in, to sew, to travel unaided by public transport, to make new friends and to trust people.

Without any formal training it was more difficult to position her in a line of work, but she enrolled in a “chef helper” course. She successfully finished the course, and since 2001 she is working at Pentru Voi Day Centre. Ghizela firstly started as a janitor but afterwards she continued as a “chef helper” in the kitchen of Pentru Voi.

Gradually Ghizela made remarkable progress at the work place but also in her private life, becoming more sociable and friendly with her colleagues. Her first workplace was not the only challenge for her: moving into another protected house, moving in with two other colleagues – all coming from institutions, where they have a great deal of independence.

Presently Ghizela is working as a cook helper. She can choose how to spend her money, she knows how to make use of the public transport, she pays a part of the apartment expenses and she has lots of friends. As a self-advocate, Ghizela attended various national and international conferences – an unattainable fact in institutions.

## CANADA

In 1997, all provinces and territories of Canada committed to a common vision and a set of principles as articulated in the In Unison document. Among those principles was a stated shared belief that “citizenship for Canadians with disabilities means a full recognition of equality rights, inclusion and independence for people with disabilities.”

Despite this lofty vision, there are still thousands of Canadian citizens with intellectual disabilities inappropriately housed in institutional facilities. This reality represents the most basic form of exclusion and denial of citizenship and certainly stands in sharp contrast to a vision of “equality, inclusion and independence.”

As a country, we know that institutional environments are not appropriate places for persons with intellectual disabilities to live. Yet in many jurisdictions we have ceased efforts to close these facilities, and more tragically, in some instances, have allowed new admissions to occur. We acknowledge and applaud the past efforts in this country that have assisted many people to leave institutions and take their rightful place in our communities.

We contend, however, that such efforts must continue, indeed must be accelerated. It is simply unacceptable that a society so rightfully proud of its diversity and tolerance would allow many of our fellow citizens to be exposed to the “life wasting” associated with institutional care. As citizens of this country, persons with intellectual disabilities have the same rights as other citizens; surely this must extend to the right to choose to live in the community.

In Canada today, most provinces and territories have accepted that large institutions are not an appropriate response to the needs of persons with disabilities. During the past two decades we have witnessed a significant decline in the population



of large residential care facilities for people with intellectual disabilities. Yet we also know that approximately 1600 persons with intellectual disabilities still reside in facilities designed to house more than 100 individuals. We know that institutions for people with intellectual disabilities and housing more than nine persons still exist in Nova Scotia, Prince Edward Island, Quebec, Ontario, Saskatchewan, Manitoba, Alberta and British Columbia, housing many thousands of people.

## ONTARIO

Ontario, the largest province in Canada, has over the past several years undertaken a process to close the last of its three institutions and to assist the almost 1000 people in these institutions to return to the community.

The Community Living Ontario Working Group on Deinstitutionalization has been working closely with Government of Ontario officials to monitor the closure of these facilities and ensure an excellent outcome for all those leaving the three remaining facilities. As of October 30, 2008, the Southwest Regional Centre near Chatham closed, having successfully supported all former residents to move to new homes in the community. A historic occasion!

There are now just three people left in the Huronia

Regional Centre in Orillia, the oldest institution for people who have an intellectual disability in the Province. While there are still 49 people in the Southwest Regional Centre in Smith Falls, plans are being developed to have that facility closed by the target date of March 31, 2009.

Congratulations to all those who have successfully supported this effort for the past several years. Community Living Ontario is developing plans to mark the closure of the institutions with a provincial celebration – to which you are all invited!

## MANITOBA

A complaint was filed with the Manitoba Human Rights Commission (September 2006) on behalf of the 380 people with an intellectual disability who live at the Manitoba Developmental Centre in Portage La Prairie, Manitoba. The complaint came after many attempts by Community Living–Manitoba to negotiate with the Manitoba Government for the development of community living alternatives, and in response to a government announcement to invest significant new funds in the institution. The complaint outlined that the Manitoba Government had taken the wrong direction on services for people with intellectual disabilities. It was filed on behalf of those people living at MDC and with support of the many agencies



Community Living-Manitoba works and plans with throughout the province: service agencies, People First of Manitoba, People First of Canada, coalitions of social justice groups and families.

Since 2006, the HRC Investigator has completed an investigation of facts of the case and prepared a report for the Human Rights Commission. In October of 2008, an interim assessment from the Manitoba Human Rights Commission regarding the Manitoba Human Rights Complaint was released. This report presents a favorable ruling that discrimination exists in continued placement at MDC. This ruling means that sufficient grounds exist to further proceed with this complaint, and it is fully expected that the matter will now be referred to an independent adjudicator to conduct a full hearing into the matter. We anxiously await the final outcome of this landmark case.

## COMMUNITY LIVING IN SLOVAKIA

The Land of Harmony Foundation in Slovakia provides two small flats for one woman and four men with physical and learning disabilities. All of them are living, for the first time, independently from family or an institution with the support of social workers and the local community. They are able to make decisions about all aspects of their lives: what to eat, what to buy, how to spend the money, what to do, where to work, whom to meet, etc. The individual approach, trust and the principle of providing support only when needed, make this service exceptional in Slovakia. When the clients make mistakes, these are considered to be learning opportunities for them.



Photos courtesy of Ulrich Eigner

## COMMUNITY — WHERE PEOPLE SHOULD LIVE

Often times demands for deinstitutionalization are dismissed as being too idealistic; not practical; a view held only by a few radical parents and well intentioned advocacy organizations out to destroy a perfectly good system. Opponents to deinstitutionalization assert that persons with intellectual disabilities are better served in institutions, that they cannot be supported in the community, and that institutions represent the only appropriate place in which they can live.

What those opposed to deinstitutionalization fail to acknowledge (or accept) is that evidence gathered during the past 25 years clearly demonstrates that community living is superior to institutional care, that persons with intellectual disabilities are better supported in the community. An analysis of research findings (Conroy 2006) based on deinstitutionalization efforts implemented in the U.S. over the past three decades provides the following conclusions:

### **Research Shows Multiple Benefits of Community Placement**

On movement from institutional to community settings people experience major enhancements in their quality of life. They are more independent, they display less challenging behavior, their homes are more pleasant, and their families believe that they are far “better off” than they were in institutions.

### **Family Attitudes Change Dramatically**

When people move to the community, the families’ attitudes change from support of continued existence of those institutions and the continued placement of their relatives in them toward acceptance and support of community living. Even the most vocal opponents of community placement have become ardent supporters of community living once it has been experienced.

### **The Theory of the “Must Stay” Group is Not Supported**

The classic four reasons given for keeping people in large segregated settings (severe disability, challenging behavior, medical fragility, and advanced age) have been convincingly discredited by carefully controlled studies of community placement, by the evidence from total closures during the past 25 years, and by the fact that many jurisdictions are now entirely free of public institutions as an option.

### **Deinstitutionalization means having:**

- The right to choose where one will live, and with whom;
- Services/programs that are directed and controlled by the person and that are respectful of the right to make choices, and take risks;
- The right to individualized living arrangements and control over the required individualized funding;
- The necessary disability related supports needed to fully participate in the community;
- Support, as necessary, from friends/family/advocates to assist in decision making;
- Services that meet all identified needs and are of high quality, portable and accessible.

## A NEED FOR GLOBAL ACTION

As members of a global community, we must take action to ensure that institutions no longer represent an option forced on persons with intellectual disabilities. Clearly, persons with intellectual disabilities, throughout the world, have rejected any role for institutions in their lives. We must help give voice and urgency to this message and work together to ensure that the right to live in community is both respected and made real – for all people no matter where that may live in this world.



We know that the issues, regardless of geography, nationality or economic status, are basically the same. We know, through knowledge gained from previous efforts in countries throughout the world, how to assist people to leave institutions. We know that people can live inclusive and contributing lives in community if they are given opportunity and necessary support.

What we must now do is translate our collective 'lessons learned' into widespread policy and practice. We must continue to identify the atrocities of institutionalization and accelerate our demands that these places be closed. We must, together, help create the international political will that transform systems in all countries into ones that provide the necessary supports to make community living a reality for all people.

We can – we must – we will!



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