

To: Health Professionals
From: Medical Office/Europe Program
Date: 14 November 2003

MEDICAL ACTION

Russian Federation: For a full and decent life – Action to promote the rights of children with mental disabilities

The sign on the door said: “Beware! Keep out!” This was the corridor where children are kept permanently in bed. There were 27 beds in six tight rows in a ward that was clean and bright. A television was switched on over the bed of an 18-year-old woman who could speak with an Amnesty International delegate visiting the *internat* (orphanage) and was excited about the visit. She was the oldest. The others were boys and girls from the age of four who were unable to speak.

The room was silent. Three of the children had Down’s Syndrome and the delegate was told the others were suffering from “imbecility” and “idiocy”. As the children had been in bed all their lives, their arms and legs were wasted and their skin covered in sores. One nine-year-old boy lay curled up, the size of a four-year-old.

“It is surprising they are alive,” the chief doctor mused loudly, within earshot of the children. “They are like vegetation. Their lungs and hearts work but there is nothing going on in their heads.” (Amnesty International report: *Rough Justice: The Law and Human Rights in the Russian Federation*” Index no: EUR46/054/2003, October 2003)

Summary

On 2 October 2003 Amnesty International (AI) launched its final report of the Russia Campaign (*Rough Justice: Law and Human Rights in the Russian Federation* (AI Index: EUR 46/054/2003), which examines reforms introduced in the legal system since the creation of the Russian Federation (RF) in 1991.

In the report, AI acknowledges that there have been improvements in certain areas, but describes how the administration of justice still offers poor protection to many sectors of society – particularly ethnic minorities, women and children.

This action focuses on chapter 6 of the report, which highlights the situation suffered by thousands of children with mental disabilities who are confined in children’s homes and *internats* (see below).

AI’s report includes a number of recommendations with respect to the institutionalization of children with mental disabilities. These include: **independent judicial oversight** of the decision to place children with mental disabilities in institutions; **impartial continuing review** of all such placements, with a view to discharging children where this is in their best interests; and the provision by the RF authorities of **greater educational, health and rehabilitation services and recreational activities**, appropriate to the age and abilities of the child.

Goals

- To raise international awareness of the issue
- To urge the authorities to improve the situation for children institutionalized with mental disabilities.

Relevant Materials:

- AI's report: *Rough Justice: The Law and Human Rights in the Russian Federation* (AI Index: EUR 46/054/2003, October 2003). Chapter 6 deals with the institutionalization of children with mental disability. Here is the link: <http://web.amnesty.org/library/Index/ENGEUR460542003?open&of=ENG-RUS>
- Action circular EUR 46/062/2003: *For a full and decent Life. Action to promote the rights of children with mental disabilities in the Russian Federation* (sent to all sections in July).
- Website action available in core languages and Russian, focussing on the plight of children with mental disabilities. This includes a standard letter to the RF authorities. Please link to this action or adapt it into your own languages for use on your site, and encourage other organizations working on mental health / child rights issues to run or link to it.
Here is the link:
<http://www.amnesty.org/russia/action.html>

Timing

This action will run until end March 2004.

Special instructions

AI Health Professionals Network coordinators should check with their sections before carrying out any of the recommendations suggested under **outreach** and **publicity** as they may already be organising related activities (action circular EUR 46/062/2003 relating to AI's report was sent to all sections in July).

Background

More than 19,000 children up to the age of four are housed in children's homes and around 29,000 children in internats (see below) in the Russian Federation (RF). Some of these children are orphans but a large number are confined purely because of their mental disability. These children have a range of disabilities including Down's Syndrome, autism, epilepsy and cerebral palsy.

There are few social services to help parents bring up children with mental disabilities at home, leaving parents to readily agree to institutionalization. Children are separated from their families on the word of a commission of doctors, without the benefit of judicial oversight or review of this decision. Presented with a diagnosis that their child's condition is hopeless, parents are often asked to sign a legally binding document renouncing their rights and are not even given the opportunity to request a review of the decision or recommendation. No independent information is available to parents that might put a different light on the medical advice they are receiving.

Children's homes and internats

A mentally disabled child whose parents have given up their right to parenthood will

be placed in institutions known as DDI from their Russian initials (*Detskie doma i internaty* – children’s homes and *internats*). The children’s homes are run by the Ministry of Health and are intended for children up to the age of four. *Internats* are administered by the Ministry of Labour and Social Development for children up to the age of 18. There are on average two *internats* in each of the 89 regions of the Federation with seven in Moscow Region, which is densely populated. At the age of 18, people with mental disabilities can be transferred to neuro-psychological nursing homes run as well by the Ministry of Labour and Social Development. No role is foreseen throughout this process for the Ministry of Education.

Interminably confined...

While conditions in the DDI are inspected by the state prosecution service and the State Centre for Sanitary-Epidemiological Inspection, there is no provision for regular, detailed and individual reviews of the children to assess their condition with a view to discharge at any point, nor to evaluate their care, treatment or education. At *Internat Z* visited by an AI representative, one psychologist was working with 205 children. She said that the children receive a thorough assessment at the age of 18, when a visiting commission decides where to place them next.

Ministerial directives for putting children with mental disability in DDI also determine their conditions inside. In children’s homes, two duty nurses on a 24-hour rota are assigned to 100 children, with an additional nurse to handle 50 children who are bed-bound. The directives state that ward orderlies should deal with the children’s moment-to-moment needs. This function, however, is not listed in their job descriptions, drawn up and confirmed in 1995 by the Ministries of Labour and Social Development and by the State Committee of Higher Education. These say that it is the orderlies’ job to clean premises to a hygienic standard; to assist the nurse in dispensing medication; to receive, store and dispense laundry and domestic equipment; and to tidy the bedside tables of bed-bound patients after each meal.

In internats for children over the age of four, the ratio of staff to children may be even lower. AI visited an internat which had only one psychiatrist and one part-time speech therapist for nearly 300 children. Children with very different needs were placed together in one group. There were about 50 children, who were considered “uneducable”. Section IV of the 1979 Directive states that no effort is to be made to teach or train “uneducable” children. The Ministry of Justice of the Russian Federation has just given an order to the Ministry of Labour and Social Development, that the directives from Soviet times, which still rule the treatment of children with mental disabilities should be changed.

During its research visit, AI’s delegate found that even children who are considered to be educable, live in close confinement in an environment that offered them little in the way of sensory stimulation, education or human interaction. While the children are being cared for, generally this is only in the sense of a basic, functional and custodial care. They are not encouraged to explore the world around them and although the internat has good books, toys and children’s games, most of it is locked away. Most of the “uneducable” children are left in their beds all day (in 1996, 5,600 children in internats were permanently confined to their beds, according to government information), as a result becoming more developmentally and physically delayed because of the lack of stimulation and education, rather than just the presence of Down’s Syndrome or other disability. Staff and doctors in these institutions routinely use outmoded terminology to refer to the children, who are labelled as “uneducable”, “imbeciles” or “idiots”. The perception that these children are “hopeless” determines their treatment, or lack of it.

...with no rights

Because their future is regarded as hopeless in the Russian Federation, many human

rights are automatically taken away from children with mental disability. Unlike other people who are put in institutions, they are confined only on account of their disability and not because they pose a threat to themselves, or to others, or because their parents are unfit to bring them up. They are consigned to an utterly aimless life – and unlike prisoners they have no chance of review.

In recent years the authorities have begun to acknowledge the damaging way that children with mental disability in the Russian Federation are treated. However, to date they have not taken decisive steps necessary to remedy the problem.

The UN Committee on the Rights of the Child made recommendations to the Russian Federation when considering its two periodic reports on implementing the Convention on the Rights of the Child in 1993 and 1999. In 1993 it “recognize[d] the legacy of certain attitudes which hamper the implementation of the rights of the child. These relate to, *inter alia*, the institutionalization of child care, the disabled and family responsibilities.” It urged the Russian Federation to set up a National State Committee to coordinate and monitor implementation of the Convention.

In 1999, the Committee expressed its serious concern at the scale of institutionalization of children in the Russian Federation and the conditions in which institutionalized children live. It recommended the authorities adopt appropriate procedures “to provide for the periodic review of all types of placement” and reform of the inspection system “in particular by reinforcing the role and power of independent inspection mechanisms and ensuring their right to inspect foster homes and public institutions without warning”.

The Committee expressed special concern about the plight of “children with mental disabilities and children living in institutions”, and in particular the “current diagnosis system and practices” and the “conditions for disabled children living in institutions.” The Russian Federation was due to report to the Committee for a third time in 2002. In its draft report which Amnesty International has seen, it says it has set up an Inter-Agency Co-ordinating Committee on the rights of the child, and has improved inspections of institutions through the establishment of Children’s Ombudsmen in 15 regions of the Russian Federation, including the Chechen Republic. The government’s draft report does not address the question of ensuring systematic review of placements, recommended by the UN Committee.

AI concerns

Amnesty International questions the legality of the procedures used for institutionalizing these children, which breach many international standards. Above all, the decision to institutionalize such children is taken without reference to any *law* passed by parliament, and without the informed participation of someone to represent the child’s best interests. Children caught up in this situation have no legal means of reversing it.

In Amnesty International’s view, the situation of children with mental disabilities in the Russian Federation poses questions of fundamental rights – including the rights to liberty, family life, education and access to justice. Amnesty International also believes that these children are living in conditions which do not respect their inherent dignity.

As a basic minimum, Amnesty International believes that the Russian Federation should adopt a law, whose primary concern is the best interests of children with mental disability. This should set down the procedures and criteria for placing a child in an institution and taking him or her away from their family. The child’s best interests should be represented by an appropriate independent expert, who seeks the child’s view and, where possible, articulates it and intervenes in his or her best interest. An independent and impartial court should review the substance of all such decisions.

This law should guarantee that the placement is automatically subject to a systematic and regular review, and where continued institutionalization is shown to be in the best interests of the child, should prescribe conditions for the treatment and welfare of the child. It should be drafted in consultation with qualified experts, the parents of children with mental disability, and with non-governmental organizations working in the field of mental disability.

Recommended Actions

Letter-writing

Please write **letters, faxes or e-mails** to the RF President and Ministers of Health, Labour and Social Development. Please include where possible, examples of the achievements and abilities of children with mental disabilities, and of “model” programs of mental health care operating in the Russian Federation (see for example: <http://www.amnesty.org/russia/disability-feature1-eng.html>) or in your countries.

In your letters, please make clear that **AI is not calling for the closure of children’s homes and internats**. Without the necessary community-based social support services, which are not presently in place in most regions of the Russian Federation, AI believes that closures would increase the plight and isolation of the children and their families.

We are asking for groups to organise one detailed letter to President Putin and individual members to write to one or more of the other ministers. Please write letters in your own words in Russian, English or your own language using the following points as guidelines.

To President Putin:

- Say that you are writing concerning AI’s recent report, “*Rough Justice: The law and human rights in the Russian Federation* (AI Index no. EUR 46/054/2003) and in particular, as a health professional, to express concern about the confinement of children with mental disabilities.
- Express your concern about the lack of appropriate treatment and education and legal guarantees for children with mental disabilities in state institutions in the RF.
- State your view that there is a consensus within the caring professions that children with mental disabilities benefit from stimulation and appropriate education.
- State that in your opinion, children with mental disabilities should only be confined where this is necessary for the well-being of the child.
- Urge him to ensure that where children are confined, they are treated with the care and education, and the dignity and respect to which they are entitled.
- Draw the authorities’ attention to the UN Convention on the Rights of the Child, to which the Russian Federation is a state party, and in particular to Article 23: “States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.”
- Urge him to adopt a law whose primary concern is the best interests of children with mental disability. This should set down the procedures and criteria for placing a child in an institution and taking him or her away from their family. The child’s best interests should be represented by an appropriate independent expert, who seeks the child’s view and, where possible, articulates it and intervenes in his or her best interest. An independent and impartial court should review the substance of all such decisions.

This law should guarantee that the placement is automatically subject to a systematic and regular review, and where continued institutionalization is shown to be in the best

interests of the child, should prescribe conditions for the treatment and welfare of the child. It should be drafted in consultation with qualified experts, the parents of children with mental disability, and with non-governmental organizations working in the field of mental disability.

- Urge him to carefully consider and implement all the recommendations included in AI's report.

Additional letters may be sent to the following:

To Dmitri Kozak, Director, State Legal Department of the RF Presidential Administration and Yurii Chaika, Minister of Justice:

- Say that you are writing concerning AI's recent report, "*Rough Justice: The law and human rights in the Russian Federation* (AI Index no. EUR 46/054/2003) and in particular, as a health professional, to express concern about the confinement of children with mental disabilities.
- Express your concern about the lack of appropriate legal guarantees for children with mental disabilities in state institutions in the RF.
- State that in your opinion, children with mental disabilities should only be confined where this is necessary for the well-being of the child.
- Welcome the decision of the Ministry of Justice to review directives which regulate the confinement of children with mental disabilities in internats. Urge them to ensure that where children are confined, they are treated with the care and education, and the dignity and respect to which they are entitled.
- Urge them to introduce legislation whose primary concern is the best interests of children with mental disability. This should set down the procedures and criteria for placing a child in an institution and taking him or her away from their family. The child's best interests should be represented by an appropriate independent expert, who seeks the child's view and, where possible, articulates it and intervenes in his or her best interest. An independent and impartial court should review the substance of all such decisions.

This law should guarantee that the placement is automatically subject to a systematic and regular review, and where continued institutionalization is shown to be in the best interests of the child, should prescribe conditions for the treatment and welfare of the child. It should be drafted in consultation with qualified experts, the parents of children with mental disability, and with non-governmental organizations working in the field of mental disability.

- Urge them to establish procedures and criteria governing the placement of children with mental disabilities in state institutions and separating them from their families. These should have the best interests of the child as their primary concern. In line with international standards, they should provide for court supervision of all placements and guarantee the children a systematic, regular judicial review of their confinement. The child's best interests should be represented by an appropriate independent expert, who seeks the child's view and, where possible, articulates it and intervenes in his or her best interest.

To Minister of Health, Yurii Shevchenko

- Say that you are writing concerning AI's recent report, "*Rough Justice: The law and human rights in the Russian Federation* (AI Index no. EUR 46/054/2003) and in particular, as a health professional, to express concern about the confinement of children with mental disabilities.

- Express your concern about the lack of appropriate treatment and education for children with mental disabilities in state institutions in the RF.
- State your view that there is a consensus within the caring professions that children with mental disabilities benefit from stimulation and appropriate education.
- State that in your opinion, children with mental disabilities should only be confined where this is necessary for the well-being of the child.
- Urge him to provide programs of appropriate professional training and development for mental health workers in state institutions. These programs should be informed by up-to-date international practice in mental health issues, and parents and people with disabilities should be actively involved in the development and implementation of the programs.

To Aleksander Pochinok, Minister of Labour and Social Development:

- Say that you are writing concerning AI's recent report, "Rough Justice: The law and human rights in the Russian Federation (AI Index no. EUR 46/054/2003) and in particular, as a health professional, to express concern about the confinement of children with mental disabilities.
- Express your concern about the lack of appropriate treatment and education for children with mental disabilities in state institutions in the RF.
- State your view that there is a consensus within the caring professions that children with mental disabilities benefit from stimulation and appropriate education.
- State that in your opinion, children with mental disabilities should only be confined where this is necessary for the well-being of the child.
- Urge him to change the directives regarding the placement of children with mental disabilities in internats, which still exist since Soviet times.
- Urge him to ensure that where children are confined, they are treated with the care and education, and the dignity and respect to which they are entitled.
- Urge him to take measures to bring RF medical terminology into line with terminology adopted by the World Health Organization, which does not include diagnoses like "imbecility" and "ineducability".
- Urge him to provide programs of appropriate professional training and development for mental health workers in state institutions. These programs should be informed by up-to-date international practice in mental health issues, and parents and people with disabilities should be actively involved in the development and implementation of the programs.

COPIES:

Please copy your letters to President Putin to:

- the Ambassador of the Russian Federation in your country.

Please send copies of letters sent to other ministers to:

- President Putin.

Please copy your letters to the Minister of Health to:

- the Russian Medical Society, urging them to make representations to the authorities that children with mental disabilities should only be confined where this is necessary for the well-being of the child and urging the authorities to improve care and conditions for such children where they are confined.

Publicity

Please alert specialized mental health media in your country to AI's action.

Outreach

Please check with your section before organising these suggested outreach activities. Coordinators of AI's Health Professional Network are asked to bring AI's report and campaign to the attention of their country's national medical associations as well as larger mental health NGOs/charities.

Other activities

Please liaise with your section concerning public campaigning events/embassy visits/home government lobbying/IGO lobbying.

ADDRESSES

President of the Russian Federation

Vladimir Putin

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You can as well send letters to President Putin via the website of the Kremlin

<http://president.kremlin.ru/pmail/report.shtml>

or send an e-mail to: president@gov.ru

Director, State Legal Department of the RF Presidential Administration (*responsible for the legal reform programme in the RF*)

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Please send any replies received to the Medical team at the IS as soon as possible.

Thank you for any action you are able to organise.

International Standards

The institutionalization of children breaches many international standards. These include:

The UN Convention on the Rights of the Child which states:

“States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child’s... disability, birth or other status.” (Article 2)

“States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.” (Article 23(1))

“States Parties recognize the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.” (Article 25)

“States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation... while in the care of parent(s), legal guardians(s) or any other person who has the care of the child.” (Article 19(1))

“The child shall be registered immediately after birth and shall have... as far as possible, the right to know and be cared for by his or her parents.” (Article 7(1))

“States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.” (Article 8(1))

“States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child.” (Article 9(1))

The **ECHR**, on review of the decision to institutionalize a child, states:

“Everyone who is deprived of his liberty... shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.” (Article 5(4))

On the right to education, Article 2 of Protocol No. 1 to the ECHR states:

“No person shall be denied the right to education...”

The International Covenant on Civil and Political Rights states: “No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence... Everyone has the right to the protection of the law against such interference or attacks.” (Article 17)