



DISABILITY RIGHTS INTERNATIONAL

**INTERNATIONAL COLLABORATION FOR INCLUSION:
Lessons from international experience in responding
to the urgent human rights needs of children with disabilities
in Ukraine's orphanage system**

A report by
DISABILITY RIGHTS INTERNATIONAL
&
YOUR DIMENSION

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Summary & Recommendations

Ukraine has inherited a Soviet-era system of orphanages and other institutions for children and adults with disabilities. Estimates vary widely, but it is likely that there are at least 82,000 children living in some form of institution (including orphanages, boarding schools, or social care homes for persons with disabilities). Despite the decline in Ukraine's population, there is an increasing rate of institutionalization throughout the country. For children with disabilities, placement in an orphanage can be a gateway to lifetime institutionalization. While some excellent community-based programs exist to help children with disabilities, these programs are not large enough to meet the enormous needs of children with disabilities in the country. In addition, Ukraine has a large number of adults with disabilities who remain institutionalized for life in psychiatric facilities, nursing homes, and other facilities.

Cut off from families and community, children are especially vulnerable to violence, exploitation, and a range of other serious human rights violations. International experience has shown that institutional placement at any age leads to increased disability. This is particularly true for young children, who may experience psychological damage from being raised without a family. From childhood through adolescence, institutional placement can lead to developmental delays and increased disability. Even in adulthood, isolation from society results in loss of social functioning. Apart from the tremendous human cost of such segregation, Ukraine's national investment in institutions funnels precious resources away from essential community-based care. The vast majority of children placed in orphanages have a living family member. But families who wish to keep their children with disabilities at home are often forced to place a child in an institution because of a lack of community support.

Many children placed in orphanages in Ukraine do not have disabilities at the time they are placed in orphanages. Since any child may become disabled as a result of institutional placement, this report examines the concerns of all children in institutions – whether or not they have a disability at the time of placement. In Ukraine, children may be placed in orphanages because of health problems, substance abuse, or disability on the part of parents. Children are also placed in institutions because authorities determine that parents are abusive or inadequate – or because authorities determine that they have “abandoned” their children. While children must be removed from truly abusive homes, many parents simply lack the financial resources, healthcare, or disability services they need to keep their children.

The new UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by Ukraine, recognizes that all persons with disabilities have a right to live as part of society. The CRPD makes clear that it is the obligation of all States Parties to create community-based services and support systems to make community integration possible. The obligations of governments to implement article 19 of the CRPD have been summarized by the Council of Europe's Commissioner for Human Rights in an excellent report on “The Right of People with Disabilities to Live Independently and Be Included in the Community. Perhaps the most important implication of the CRPD – for Ukrainian policy and for international donors – is that it establishes that “[t]he right to live in the community applies to all people with disabilities. No matter how intensive the support needs, everyone, without exception, has the right and deserves to be included and provided with opportunities to participate in community life.

Article 32 of the CRPD also creates obligations for international donors to advance the principles of the convention. International assistance to support further segregation of people with disabilities in any way – including the construction or refurbishing of new institutions – runs contrary to these international principles. On the contrary, international donors can play a very important role in supporting the development of new community services. There are important lessons to be learned from international best practice in service system reform that can and should be included in international development efforts.

Recommendations to government of Ukraine

To fulfill its obligations under international law, Ukraine must take immediate steps to plan for the reform of its disability service system to bring about full community integration of children and adults with disabilities. Ukraine can learn from extensive lessons learned from international experience in developing plans for strategic reform.

Drawing on these sources, DRI recommends:

- 01 Support to families of children with disabilities** to preserve the family, prevent new placements, and allow full inclusion in community life; expand and replicate successful community-based models of care for children with disabilities and their families;
- 02 Expand foster care (or substitute family programs)** so all children can grow up with a family in the community; this should include emergency foster care for children who are moved quickly out of abusive situations;
- 03 Establish a moratorium on new placements of children** - DRI has called for a moratorium on the placement of children in institutions as strategy toward the elimination of all institutions for children. While UNICEF has followed this approach in some contexts, the UN Guidelines on Alternative Care have only called for a moratorium on admission of children ages 0-3. The Council of Europe's Commissioner of Human Rights has taken a stronger stand, recommending a no new admissions policy for people with disabilities of all ages. DRI recommends an immediate moratorium on admission of young children and plans for the creation of community supports so that the moratorium can be extended to all persons with disabilities;
- 04 Provide appropriate education and ensure full inclusion** of children with disabilities at all levels of mainstream schools;
- 05 Create community-based supported, independent living programs for adults**, including group homes for up to 4 adults with disabilities, on a nation-wide basis; special attention is needed to support the community transition of children graduating from orphanages;
- 06 Plan inclusive reform to achieve full community integration of children and adults with disabilities** - a national plan for integration should be drafted, identifying sources of funding and establishing target dates; such a plan can be used to seek international support for reform. The creation of such a plan should be inclusive and should involve participation by people with disabilities, family members, and groups that represent them.

07 Immediate steps needed - The planning process should not be used to delay immediate steps to address life-threatening abuses, lack of treatment, and inhumane conditions that exist in institutions; while rebuilding and refurbishing institutions should be avoided, international law requires immediate action to protect against inhuman and degrading treatment or torture. In addition, a broad array of low-cost steps can be taken immediately to break down barriers that segregate children with disabilities from society.

08 Create an independent human rights oversight and enforcement mechanism to monitor and protect the rights of children and adults with disabilities in institutions and in community programs. As outlined in CRPD art. 16, age and gender-specific protections and prevention program are needed to prevent abuse and protect these especially vulnerable populations.

DRI's reports from other countries provide detailed strategic recommendations that can be adapted to the situation in Ukraine. These included detailed recommendations for integration in the absence of funding for reform. These reports are posted on DRI's website at www.DRIadvocacy.org.

Recommendations to international funders

International assistance is urgently needed to help Ukraine respond to the urgent concerns of children who are segregated from society and detained in the country's orphanages. International donors have a history of rebuilding crumbling institutions in Ukraine and other countries. Instead of repeating this mistake, foreign assistance programs should help children avoid institutions by remaining with their families. Aid programs should support the right of people with disabilities to be fully included in the community.

Set aside funding for Ukraine to address the immediate and urgent human rights concerns of children and all people with disabilities detained in the country's institutions. Given the valuable lessons learned from the international disability rights movement, US and European donors should provide technical assistance to governments in planning reform and supporting local disability advocacy organizations addressing these issues.

Ban the use of aid which perpetuates segregation through the construction or support of orphanages, psychiatric facilities, or other institutions for persons with disabilities. The EU has adopted a guidance on the use of structural adjustment funds for EU member states that serves as a model for other international donors. This guidance prohibits the use of funds for segregated institutions. The US Agency for International Development (USAID) has a valuable disability policy prohibiting discrimination against people with disabilities. Yet this policy does not explicitly prohibit the use of US government funding to build or rebuild segregated institutions for people with disabilities, orphanages, psychiatric hospitals, or other facilities. Explicit language about institutions in the USAID policy would be helpful.

Establish a pro-active role in assisting with the transition from institutional to community-based care and commit resources to advance this process in Ukraine as a model for what international donors should be doing around the world. The EU has recognized that pro-active measures are needed to address the problem of segregation in institutions. While community-based care may be less expensive than custodial care in institutions, there are extra costs involved in making the transition to community-based care. In 2014, the European Union committed a fixed percentage of its total foreign aid to the protection of vulnerable social groups, and explicitly recognized the need for these funds to contribute to the elimination of institutions and the establishment of alternative services in the community. Its 2010-2012 action plan for disability specifically identified deinstitutionalization as a priority area for action.

|| **Ensure inclusion of children and adults with disabilities** from the first stages of assistance onwards in Ukraine and other countries.

Lessons learned – the importance of inclusion in crisis assistance

In times of international crisis, the concerns of people with disabilities are often overlooked. Yet this is the time when some of the largest and most far-reaching international assistance packages are designed and implemented. Such assistance will have major implications in a country for years to come. While times of political and economic crisis may seem like the worst time to think about people with disabilities – these are exactly the times when such consideration is most important. Lessons from the Republic of Georgia are valuable for Ukraine. Following Georgia's war with Russia, the United States provided a large 1 billion dollar aid package to Georgia. Funding from the United States provided valuable support for Georgia to create an ambitious deinstitutionalization program and almost all orphanages in the country were closed. A large system of community supports, including foster care and group homes, was established. Despite these extremely important accomplishments, the concerns of children and adults with disabilities in institutions were overlooked. Adequate supports to enable transition to community-based care were not established. Instead of closing institutions for children and adults with disabilities, several of these facilities were reinforced and expanded. DRI's report on Georgia documents the dangers of this approach. See *Left Behind: The Exclusion of Children and Adults with Disabilities from Reform and Rights Protection in the Republic of Georgia (2013)*.

Model USAID program in Georgia - The US Agency for International Development has now funded a new program in Georgia that demonstrates how support for advocacy by people with disabilities, along with allies in the human rights field, can be used to promote full community integration. The USAID program also provides technical assistance to the government of Georgia on the creation of community-based care programs for all children with disabilities. In the coming years, this USAID-funded program may become a model for how international support can be used to support the full community integration of all children with disabilities.

Structure of Services in Ukraine

According to UNICEF, at least 82,000 children are segregated from society in Ukraine’s orphanages and boarding schools as of 2012. Other activists have reported as many as 200,000 children in the country’s orphanages.

These numbers conflict with the Ukrainian government’s official statistics, which claim there are 28,619 children in Ukraine’s residential institutions as of 2013. Based on the UNICEF numbers, there is an increased rate of institutionalization in recent years. While the overall number of children in institutions appears to be declining, this has been accompanied by a swift overall population decline— resulting in a larger proportion of all Ukrainian children placed in institutions.

Ukraine’s Increase in the Institutionalization of Children

	2000	2012	Percent change
Ukraine Population*	49,175,848	45,593,300	7.3 % Decrease
Total # of children in residential institutions^	99,100	81,800	17.5% Decrease
Rate of children in residential institutions (per 100,000)^	921	1023	11.1% Increase

*Source: World Bank World Development Indicators

^Source: UNICEF TransMonEE 2014, only public institutions

The vast majority of children in Ukraine’s orphanages are not true orphans— approximately 90-98% have at least one living parent. UNICEF reports that poverty and a lack of supports for vulnerable families remain the primary reasons for Ukraine’s epidemic of child abandonment. Stigma and discrimination increases the risk for children with disabilities.

A. Organization of residential institutions

One of the challenges to understanding – and reforming – orphanage policy in Ukraine is the division of institutional structures into different ministries. The institutional service system for children in Ukraine is divided among three ministries: Health, Education and Social Policy. The Ministry of Health operates “baby houses” for children from age 0 to 4. Baby houses are the entry point for most children in Ukraine’s institutional system and include children with a full range of conditions and abilities—ranging from children with no disabilities to those considered to have severe disabilities or complex medical issues.

At age 4, if a child shows signs of a disability, he/she will be evaluated by a multi-disciplinary panel of professionals called the Medical Pedagogical Committee. This committee almost single-handedly determines a child's future by evaluating the child's education potential—determining if a child is “educable,” or “non-educable.” The panel also considers whether a child would benefit from institutionalization, and if so, in what kind of institution. In practice, children without parental care are always referred to an institution due to the complete lack of alternatives in the community.

A child determined by the panel to have educational potential will be referred to Ministry of Education orphanages (known as “specialized boarding schools”). Children whom the committee deems “non-educable” are referred to institutions operated by the Ministry of Social Policy.

Activists in Ukraine report to DRI that the process of evaluation takes approximately 10 minutes. Institution directors have reported to DRI that the evaluation process involves arbitrary methods of intelligence testing, such as requesting that the child build a pyramid out of blocks or divide items by colors. Each child is then given a classification from 0-4:

0. No disability

(Ministry of Education boarding school-- if no parental care)

1 & 2. Mild intellectual disability

(Ministry of Education specialized boarding school)

3. Moderate intellectual disability

(“Uneducable” Ministry of Social Policy Orphanage)

4. Severe intellectual disability and/or a physical determination of being “bedridden.”

(“Uneducable” Ministry of Social Policy Orphanage)

Medical Pedagogical Committee officials report to DRI that children who have physical disabilities that render them “immobile” are automatically assigned a level 4 “non-educable” status, regardless of the child's intellectual capacity.

Historically, institutions in Ukraine for children with disabilities under the Ministry of Social Policy and the Ministry of Education have been designed to segregate people with disabilities from the larger society.

It's no secret that during the USSR there was a taboo and a stigma against people with disabilities. That's why these institutions are usually located in isolated and remote places and are closed off from everyone else.

– Director, Vilshany Orphanage for children with disabilities

The Ministry of Social Policy operates 53 orphanages for children across the country for children considered un-educable, while the Ministry of Education operates 46 specialized boarding schools.

Ukraine's sole reliance on an institutional care system for children with disabilities deprived of parental care means that initial placement in an institution for these children usually results in life-long detention, according to directors of institutions visited by DRI.

When people are admitted, they stay the rest of their lives.

–Director, Novobilychi institution for men with disabilities

The Ministry of Social Policy operates 323 institutions (“psycho-neurological internats”) for adults with disabilities. Additionally, several Social Policy orphanages have recently opened “youth wards” for young adults age 18-35. The directors of several of these orphanages report to DRI that they are afraid to transfer their residents to the adult psycho-neurological internats, and have opened the youth wards to keep the young adults in their care.

B. Causes of institutionalization

In Ukraine, it is much easier to enter the institutional system than to leave it. There are several pathways for entry. For children with visible or obvious impairments at birth, advocates report that it is common for doctors to persuade mothers to give up their children to an orphanage, suggesting that parents should “focus on their healthy children,” or “try again” when children are born with a disability.

Parents who attempt to raise their child with a disability at home face a myriad of obstacles, often feeling they have no choice but to abandon their child in an institution when the realities of raising a child without supports becomes overwhelming or financially impossible. These parents receive almost no public support other than a disability pension which parents report to DRI is woefully inadequate to support the needs of a child with a disability.

Other children are referred to institutions once they reach school age and are evaluated by the Medical Pedagogical Committee. It is DRI’s observation that children are classified by the committee to be “moderately to severely disabled” if their needs are greater than existing parental resources, educational systems, or community services can provide.

Ukrainian government officials recognize that institutions improperly segregate children and adults from society and persist because of the lack of community-based services and supports for families.

Internats are outdated now. It is no longer about protecting children. It is simply about keeping children. ...Setting up community rehabilitation programs would solve a lot of problems.

– Deputy Director of the Center for Child Services, L’viv Oblast.

According to activists and institution directors interviewed by DRI, only a limited number of services to help children at risk of institutionalization exist in Ukraine, and poor families are unlikely to be able to take advantage of them.

The Coalition for People with Intellectual Disabilities (CIPD), Ukraine’s largest umbrella organization of family members of persons with intellectual disabilities, reports that the Ukrainian government pays the costs for only 288 children out of 17,000 children served by daycare centers throughout the country. The waiting list of poor and vulnerable families for these services is long, reports CIPD, and the availability of services in rural areas is seriously inadequate.

The challenges facing families of children with disabilities were painfully made clear in one case DRI witnessed in the Bukovo Orphanage for girls with disabilities in southwest Ukraine. DRI advocates visiting the Bukovo institution happened across a woman grasping a young girl and sobbing. She told DRI she had come to give her child up to the institution because she was single, and could not work and care for her child at the same time. She said she wanted to keep her child but had no

other choice but to leave the child in the institution. There were no available community services, such as day care, which would allow her raise her child at home. The mother said that doctors told her the child would be better off in the institution than with her mother.

Families such as hers feel they have no choice but to abandon their children to an institution. Families often cite advancing parental age, financial hardship, lack of training in caring for a child with a disability and physical accessibility challenges as reasons for admitting their children to institutions.

C. Lack of services and rehabilitation in institutions

Children deemed “non-educable” and placed in an orphanage under the Ministry of Social Policy face pervasive discrimination. While children considered to be educable receive special education services and limited vocational training, those in non-educable institutions receive almost no services. Several Social Policy institution directors told DRI that the children in their care had no hope of ever rejoining the community and therefore the orphanages do not attempt to prepare children for independent living.

In every Social Policy orphanage visited by DRI, advocates observed children rocking back and forth, hitting themselves or biting their own fingers. These self-injurious behaviors are often the result of being placed in an environment that is lacking in human contact and stimulation. In several institutions, DRI advocates observed rooms where children of all ages were confined to cribs for the vast majority of the day— with minimal staff interaction.

DRI observed that children in specialized boarding schools under the Ministry of Education receive a basic education and limited vocational training— DRI observed programs teaching sewing, carpentry, crafts and assembling paper boxes.

If children in specialized boarding schools fall behind in their school work, they can be re-assessed and re-labeled as non-educable. DRI investigators interviewed a young woman in one Social Policy orphanage in central Ukraine who explained that she was transferred out of a specialized boarding school after she had difficulty memorizing a poem.

Model Programs in Ukraine

While there is a general lack of community-based support systems in Ukraine to preserve families and keep children out of institutions, there are some isolated models of excellent community care created by non-governmental organizations. One such program is Dzherelo in L'viv. This program was created at the initiative of family members, providing high quality, comprehensive services and education to children and young people with a broad range of intellectual and physical disabilities. The program helps more than 300 children and young adults with disabilities live with their families. The program provides daycare services to 150 children and young adults who participate in daily programs, early intervention therapies and education. Every day, vans from the institution provide transportation to children who participate in the education center and the school. Dzherelo provides a powerful model of what can be achieved in terms of community integration for children with all levels of disability in Ukraine. It is important to note that the services provided by Dzherelo would be even more effective if the broader service and educational system were fully integrated and supportive. Instead of providing a stand-alone school and community center, disability services should ultimately be integrated into mainstream schools and community programs serving all other children. There are also other valuable models of services helping children from orphanages that greatly assist in promoting community integration for adolescents and young adults graduating from orphanages. One such program is Universal

For children with certain levels of disability, it is all but guaranteed that upon reaching the age of 18 (or 35 where youth wards have been established) they will be eventually transferred to a psycho-neurological institution for adults with disabilities.

Regardless of whether a child is placed in a Ministry of Education or Ministry of Social Policy institution, activists report to DRI that there are no services to assist in transition to adulthood for children aging out of orphanages. In a few cases, residents may have parents or relatives who will take them in. In most cases, however, young adults are simply transferred to adult institutions where they will spend the rest of their lives.

Aid for Children (UAC) based in Odessa. This program provides an array of support to help them gain the job skills they will need to transition toward independent life. For children with disabilities, such a program can help avoid the trap of life-time institutionalization. As with Dzherelo, however, UAC would be much more effective if an array of community-based services were available to support individuals with disabilities. Without supported housing in the community for people with disabilities, for example, many people who would be capable of living in the community still have no choice but to return to adult institutions. A program like UAC provides invaluable low-cost services that could and should be expanded and replicated throughout the country at a time when many adolescents and young adults are in need of its support.

Directors of orphanages echoed these concerns:

They have nowhere to go after they turn 18. The only place they could go is another psycho-neurological internat for adults.

– Director, Myrogoshcha Orphanage for boys with disabilities

Even for those whose families took them back when they turned 18, eighty percent of them will go back to an institution at some point.

–Director, Bila Tserkva Orphanage for children with disabilities

DRI found that many residents of adult psycho-neurological institutions were graduates from specialized boarding schools who did not receive support after leaving the school and were soon re-institutionalized.

D. Perpetuation of segregated services by governmental and international donors

Ukraine's current system of institutional care is based on common perceptions that children and adults with disabilities are undesirable or dangerous. And given the lack of resources and community services, authorities told DRI that there is, in practice, no choice but to place many children with disabilities in institutions. Yet policy choices made today and in recent years perpetuate the system of segregation. The government of Ukraine and international donors continue to invest considerable amounts of money to preserve and in some cases expand institutional care. Every institution visited by DRI in Ukraine had undergone recent renovations— often with the assistance of international donors. While these investments may have dramatically improved physical conditions, opportunities for rehabilitation and inclusion in society remain nearly nonexistent for children and adults with disabilities in Ukraine's institutions.

Several financial disincentives for systems reform exist in Ukraine's current financing structure for institutions. First, all institutions for persons with disabilities in Ukraine receive 75% of each resident's disability pension. The use of this significant pooled fund is restricted, and is primarily used for physical renovation of facilities. The European Union Ad Hoc Expert Committee on Transition from Institutional to Community Based Care found in 2009 that investments in the physical infrastructure of institutions make it more difficult to transition to community alternatives, as officials are hesitant to close newly-funded facilities.

International donors play a large role in the reconstruction of Ukraine's institutions—although their role is often hidden. Cumbersome banking regulations make it difficult for state-run institutions to open foreign currency bank accounts or receive direct financial donations. As a result, most international donors who intend to support an institution will give to a locally-registered Ukrainian charity which will then provide in-kind services for the institutions, such as construction or equipment donation. DRI has documented several instances of this financial work-around.

E. Plans for reform

In recent years, the Ukrainian government has often stated its support of reform efforts to close institutions and promote community integration of children with disabilities. The National Action Plan of 2012 committed to supporting families and advancing the right of all persons to live in the community. In 2014, the government of Ukraine and the World Bank supported the planning stages of a deinstitutionalization pilot program in two oblasts of Ukraine. Such plans have not yet been implemented. Implementation may have slowed, or even reversed, in light of frequent changes in government. Political and economic turmoil in recent years has certainly distracted government leaders from implementation of ambitious reform plans.

Ukraine took a very important step when it ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). Article 19 of the CRPD guarantees the right to live in the community with equal access to services and supports. Article 23 of the CRPD prohibits the separation of a child from its parents because of the disability of the child or its parents. The CRPD established an important legal commitment on the part of Ukraine to plan for community integration of all children.

There are a number of important model programs serving children with disabilities in the community. Some programs for supporting families and preventing institutionalization have received government support. Several baby homes under the Ministry of Health have begun establishing early intervention drop-in centers to provide therapies and services for parents of vulnerable children. Valuable as they are, these family support programs only serve a fraction of the population in need. Funding is needed to replicate and expand these programs on a national level.

Ukraine has not yet demonstrated a full commitment to address the country's most serious human rights violations facing children and adults with disabilities. If current plans were fully implemented, there may be the closure of a few institutions. Serious reform will require acknowledgement of the extent of the problem, coordinated efforts between all ministries, and budget allocations that back up promises. While the Ukrainian government bears the ultimate responsibility to protect the human rights of children and adults with disabilities, international donors can play a critical role in encouraging and supporting the transition from institutional to community-based care.

Role of International Funders

The concerns Ukraine faces are emblematic of a larger problem of segregation throughout the world that must be better addressed by the human rights and international development movement. Worldwide, there are 10 million children in institutions. Scientific evidence demonstrates that raising children in institutions is dangerous and generates more disability. In addition, children raised in institutions are especially vulnerable to exploitation, violence and abuse. Instead of working to promote community integration, the international development community has often perpetuated the problem. Disability Rights International (DRI) has documented numerous instances around the world where international aid to developing countries has overlooked or actively excluded persons with disabilities from reform programs. DRI's recommendations are based on our international findings over twenty years and are supported by international law and extensive scientific research.

International consensus against segregation of children: Given the overwhelming evidence about the danger of institutions for children, UNICEF's 2013 "State of the World's Children" report calls for governments to "end institutionalization. The UN General Assembly has called on governments to "plan for the progressive elimination of institutions for children. The new UN Convention on the Rights of Persons with Disabilities (CRPD) recognizes that all children with disabilities have a right to live in the community and families should receive the support they need to keep their children.

A. Take pro-active steps to decrease institutional populations worldwide

Despite international consensus about the dangers of institutions, **the worldwide population of orphanages continues to rise, mainly in developing countries.** Governments should adopt a pro-active approach ensuring that dedicated social programs are funded that contribute to the process of eliminating segregated institutional care for persons with disabilities and creating the community-based services necessary to allow for community integration.

Commit resources targeted to assisting the transition from institutional to community-based care

It is not sufficient for international aid programs to support only the creation of positive community programs which support families and prevent abandonment—**targeted aid must also be provided to address the initial transition costs in closing institutions and moving their residents to community-based care in family-type settings.** The European Expert Group on Transition from Institutional to Community-Based Care (EU Expert Group), commissioned by the European Union in 2009, underlined the importance of planning for the initial investment necessary to close institutions and create alternative community services in their place, stating that: **"These costs have to be built into the budgets accompanying deinstitutionalization strategies."**

In response to this problem, the European Commission committed a fixed percentage of its total foreign aid to the protection of vulnerable social groups, with a specific focus on transition from institutional to community-based care for persons with disabilities. Other international development organizations are beginning to change as well. Several international and faith-based charitable

organizations are shifting their approach from investing in orphanages to investing in families, which require less money to support a child than an institution does. Most international donor countries, including the United States and many EU member states, have not adopted such a policy.

The EU Expert Group stresses that while creating community-based services, reform programs must concurrently close institutions completely; when there are empty beds available in an institution during a partial deinstitutionalization program, there is an inclination for these services to absorb new residents over time.

The very existence of institutions encourages families to place their children into care, and draws funding away from services that could support children to thrive within families and communities.

– Save the Children

Ban the use of international aid in constructing or supporting segregated institutions for persons with disabilities – consistent with international human rights law

International human rights law establishes the right of children to grow up with a family – as well as the right of persons with disabilities to be fully included in all aspects of society. Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) recognizes the “... **right of all persons with disabilities to live in the community, with choices equal to others**... Article 32 mandates that international development programs promote the objectives of the convention. International funding for orphanages and other institutions directly contravenes human rights principles.

International development agencies and private charities can and must be a part of the solution. **Unfortunately, many well-intentioned but misguided donors continue to fund the construction, renovation, furnishing and staffing of orphanages around the world.**

It is important to recognize the dangers of well-meaning efforts to fix up institutions. International donors provide hundreds of millions of dollars across the world in renovating buildings or donating supplies in the hope that they can help vulnerable children in these abusive institutions. In reality, investments in the physical infrastructure of institutions can make it more difficult for a country to transition to a system of community-based services. The EU Expert Group warns that “[c]ostly improvements in the physical conditions of existing institutions, which are often proposed as a response to findings of substandard care, are also problematic because they fail to change the institutional culture and make it more difficult to close these institutions in the long term.

International experience and extensive studies have shown that, even in clean and well-staffed orphanages, children do not get the consistent care that a parent, extended family member, or even a substitute (foster) family can provide in a home. Custodial settings, regardless of how well-managed they are, may cause lasting psychological and physical damage— an infant loses one month of development for every three months it is institutionalized.

In 2013, DRI documented the use of US government funding to build and renovate two new segregated institutions for persons with disabilities in the Republic of Georgia. The US Senate Committee on Appropriations found this use of aid to be inconsistent with US policy.

...[US foreign aid to Georgia] resulted in the improper segregation of children and adults with disabilities during a period in which the Government of Georgia adopted a policy of deinstitutionalization for children. The committee directs USAID to rigorously implement its Disability Policy, which calls for community integration and full participation in society of people with disabilities, and ensure that USAID staff is properly trained.

–US Senate Committee on Appropriations Report to accompany the 2012 Foreign Appropriations Bill (2012)

DRI has documented dozens of additional examples where international funders have contributed to the perpetuation of segregated services, including recent examples in Haiti, Ukraine and Serbia.

The lessons learned from Georgia and elsewhere in the world should be used by international development agencies to develop models and establish guidelines to ensure that international aid does not perpetuate the segregation of children and adults with disabilities, but instead promotes their human right to live a full life in the community.

B. Ensure that reform programs do not discriminate against persons with disabilities

There is a temptation when developing deinstitutionalization programs to focus on the “easier” cases first, and to return to children and adults with more complex disabilities later on. DRI’s experience has shown that it is unlikely that discriminatory reform programs will ever come back to integrate those left behind into the community, a decision which is often rationalized by depletion of funds or flagging political will for reform.

In UNICEF’s 2013 State of the World’s Children report, the agency warns that where countries have sought to close institutions and place children in loving families in the community, children with disabilities are among the last to benefit.

Serbia, for example, began wholesale reforms in 2001. Deinstitutionalization was given priority...Progress ensued, but close examination revealed that children without disabilities had been released from institutions at a much faster rate than children with disabilities... This revelation served to demonstrate the importance of ensuring that reforms are designed and implemented so no children are excluded from progress.

- UNICEF 2013 State of the World’s Children Report

The EU Expert Group warns that less-disabled residents in institutions are often key caregivers for those residents with more severe disabilities. A partial deinstitutionalization program leaves those with more complex disabilities with less support and subject to more neglect, abuse and marginalization than ever before. **“These risks must be avoided,”** the expert group asserts, **“by including people with severe disabilities and complex needs from the beginning fully in any deinstitutionalisation effort.”**

A 2013 report by Disability Rights International, **Left Behind**, found that deinstitutionalization reforms in the Republic of Georgia largely excluded children and adults with disabilities. This exclusion has permitted life-threatening abuse, neglect and segregation to continue in Georgia's orphanages and other institutions. DRI's report demonstrates that it is both discriminatory and dangerous to leave out children and adults with disabilities from these reform programs.

Georgia has become one of the first ex-Soviet republics to abolish state orphanages in favour of foster care. But disabled children continue to be marginalised and face the prospect of life-long isolation from society.

– BBC World News coverage of DRI's Left Behind report

The case studies of Serbia and Georgia provide a key lesson for other countries undergoing deinstitutionalization: **children and adults with disabilities should be included from the beginning of the reform process. The creation of supports which allow all persons to live in a family setting in the community is essential. This is true regardless of the perceived severity of their disability.**

Conclusion

Ukraine faces enormous challenges in protecting the rights of 82,000 children residing in its orphanages, as well as many more adults living in adult care facilities. Under international law, including the newly ratified UN Convention on the Rights of Persons with Disabilities (CPRD), all children and adults with disabilities have a right to live in the community with choices equal to others. To make that possible, Ukraine must create a full range of community-based services and support systems to help families of children with disabilities keep their children. Ukraine should also create a range of substitute family programs and other supports for children who have no family to support them, and it must ensure that inclusive education is available in schools. By creating these services, Ukraine can establish a moratorium on any new placement of children in institutions, as recommended by UNICEF.

While UNICEF has recommended a moratorium on the institutional placement of children ages 0-3, DRI recommends working toward the end of placement of all children or adolescents in institutions. Research demonstrates that all children need to grow up with a family and being raised in a group setting can lead to increased disability.

International models for reform and best practices for full community integration are available to guide Ukraine's efforts (see www.DRIadvocacy.org for examples from neighboring countries). Even in a situation of economic crisis, there are immediate steps that can be taken to promote community integration with few resources available. Ultimately, support for families in the community is both more humane and less expensive than maintaining the country's system of orphanages and institutions. Any investments that can be made in the creation of community services will help avoid the creation of new disabilities among children.

Excellent Ukrainian models exist and should be expanded throughout the country. These programs demonstrate how children and adults with disabilities can be integrated into the community within the Ukrainian context.

International assistance can play an enormous role in helping Ukraine through this time of transition. The period of transition to a community-based system can be costly, and outside assistance can help Ukraine save limited resources in the long-run by moving to a less expensive and more humane service system.

International donors are under legal obligations to support community integration rather than segregated services. Article 32 of the UN Convention on the Rights of Persons with Disabilities states that international donors should support the human rights principles outlined in the convention. The core provision of the CPRD, under article 19, is that people with disabilities should live as part of society. DRI recommends that all international donors follow the model established by the EU banning the use of foreign assistance to rebuild or refurbish institutions. Funds should be used, instead, to support community services and citizen advocacy for reform.