

Left Behind

The Exclusion of Children and Adults with Disabilities from Reform and Rights Protection in the Republic of Georgia

**A report by
DISABILITY RIGHTS INTERNATIONAL**

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Disability Rights International (DRI) is an international advocacy organization dedicated to the human rights and full participation in society of people with disabilities. DRI documents abuses and promotes international awareness and oversight of the rights of children and adults with disabilities. DRI trains and supports disability rights and human rights activists worldwide to promote rights enforcement and service-system reform.

DRI is based in Washington, DC with regional offices in Mexico, Serbia and Ukraine. DRI has investigated human rights conditions and collaborated with activists in more than two dozen countries of the Americas, Asia, Europe and the Middle East. DRI has authored reports on Mexico (2010 and 2000), the United States (2010), Vietnam (2009, published by UNICEF), Serbia (2007), Argentina (2007), Romania (2006), Turkey (2005), Peru (2004), US Foreign Policy (2003, published by the US National Council on Disability), Kosovo (2002), Russia (1999, published by UNICEF), Hungary (1997), and Uruguay (1995). These reports have brought unprecedented international attention to the human rights of people with disabilities.

Disability Rights International and staff are the recipients of the Charles Bronfman Prize (2013), the Disability Rights Legal Center's Charles D. Siegel President's Award (2013), the Henry Viscardi Achievement Award (2013), On Our Own of Maryland's Distinguished Service Award (2013), the University of Chicago Public Service Award (2012), the American Psychiatric Association Human Rights Award (2009), the Washington Psychiatric Society's Senator Paul and Mrs. Sheila Wellstone Mental Health Visionary Award (2009), the American Association of People with Disabilities Henry B. Betts Award (2008), and the Thomas J. Dodd Prize in International Justice and Human Rights (2007).

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Preface: Goals and Methods of this Report

One billion people with disabilities around the world are disproportionately represented among the world's poor, and are widely subject to stigma and discrimination.¹ Over twenty years, Disability Rights International (DRI) has documented the most extreme abuses against people with disabilities that take place where people are segregated from society: in orphanages, psychiatric facilities, nursing homes, and “social care” facilities (see our reports at www.DRIadvocacy.org).

The recent adoption and widespread ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) brings needed attention to important human rights protections of a population long overlooked by the human rights community. Article 19 of the CRPD establishes that *all* persons with disabilities have a right to live in the community. Although 138 countries have ratified the CRPD², most countries still segregate children and adults with disabilities. According to UNICEF, there are *at least* 8 million children in institutions around the world.³ The actual number may be much larger, as DRI has found children detained off the public record in many countries. There is no accounting for the vast number of children who die in institutions without ever being counted or noticed – or for children who grow up and languish in adult institutions for a lifetime.

This report documents policies and practices of the Republic of Georgia to examine the protection of rights of the country's most vulnerable population: children with disabilities who are detained in institutions. While we examine rights abuses within institutions, such as life-threatening practices, inhuman and degrading treatment, and torture, our experience has shown that the protection of rights ultimately depends on the enforcement of CRPD article 19. Until all children have the opportunity to live in the community with the love and protection of a family, their rights cannot be fully enforced.

DRI's broader strategic goal is to bring an end to the segregation of people with disabilities worldwide as required by CRPD article 19. This report is part of our ***Worldwide Campaign to End Institutionalization of Children***. Through this campaign, we are demonstrating the dangers of placing *any* child in an institution – a practice that creates disability, kills children at an alarming rate, and leads to life-time segregation for millions of people with disabilities.⁴ Children are abandoned to institutions due to poverty, disability, or being part of a devalued minority.⁵ We are partnering with activists across the globe to fight for the world's most marginalized people.

DRI's ***Worldwide Campaign to End Institutionalization of Children*** is also intended to help donors and international development agencies develop programs that comply with the CRPD and effectively promote the right to community integration. It is our hope that this report will assist in the international effort to protect and serve people with disabilities in Georgia. The CRPD includes an innovative provision, article 32, requiring international donors to promote the “purpose and objectives” of the convention and to ensure that development programs are “inclusive of and accessible to persons with disabilities.” While governments bear the ultimate responsibility for the protection of human rights, donors can and must also be held accountable to the principles of the CRPD.

This report is the product of extensive fact-finding efforts, in collaboration with a broad array of local government and non-governmental organizations in Georgia, as well as legal, medical, and disability experts from abroad. From July 2010 through September 2013, DRI conducted 6 fact-finding visits to the Republic of Georgia. DRI examined conditions in 10 residential institutions including all state-run baby houses and orphanages for children with disabilities, four social care homes for adults with disabilities and a boarding school for children with disabilities. This report does not examine Georgia's psychiatric hospitals.

DRI engaged the volunteer expertise of a high level group of experts, including: James Conroy, Ph.D., of the Center for Outcome Analysis; Lawrence C. Kaplan, MD, ScM, Division Chief of Developmental and Behavioral Pediatrics at the Baystate Children's Hospital; Robert M. Levy, JD, Adjunct Professor of Law at Columbia University Law School; and Karen Green McGowan, RN, President-Elect of the Developmental Disabilities Nurses Association.

This report is not intended to place blame on any individuals, policy-makers, or institution staff. We recognize that both governmental authorities and international advisors have intended to do what is best for children and adults with disabilities. Many members of institutional staff we encountered work under the most difficult of circumstances and could not continue to work except out of their professional dedication and care for the individuals they serve. DRI would like to thank the many public officials, professionals and staff who contributed their time and insight to our work.

In every institution we visited, we attempted to be as thorough as we could in understanding the human rights situation of people living in the facility—in many cases, returning to the institution several times. We asked to visit all parts of the institutions. We interviewed institutional authorities, staff and residents. During each site visit, DRI brought a video camera to record observations. We took photographs in each institution. It is our experience that photo and video documentation is tremendously helpful in corroborating our observations and helping the public to understand the reality of life in an institution. We are sensitive to the concerns of individuals depicted in the photographs, for whom placement in an institution may constitute a massive violation of their privacy and their ability to make choices about their lives. We generally find that people within institutions are amenable or eager to have their photographs taken.

DRI visited the following institutions:

- Tbilisi Infant Home (5 visits)
- Makhinjauri Infant Home (1 visit)
- Kodjori Orphanage for Children with Disabilities (3 visits)
- Senaki Orphanage for Children with Disabilities (2 visits)
- Tbilisi Boarding School #200 for Children with Disabilities (1 visit)
- Martkopi Social Care Home for Adults with Disabilities (2 visits)
- Dzevri Social Care Home for Adults with Disabilities (1 visit)
- Temi Home for Adults with Disabilities (1 visit)
- Qedeli Home for Adults with Disabilities (1 visit)
- Gldani Psychiatric Hospital (2 visits)

There is no doubt that there are valuable programs — as well as serious abuses — that we were not able to include in our report. In recent years, numerous model programs have been established to provide support to people with disabilities in the community, particularly family support and early intervention programs designed to prevent institutionalization. It is our hope that this report will support the extension of these programs to include all institutionalized persons with disabilities.

This report issues recommendations to the Government of Georgia and to development agencies based on international standards consistent with the UN CRPD to ensure that children and adults with disabilities are afforded their human right to live full and meaningful lives, in a family, in the community.

In addition to our investigation, Disability Rights International (DRI) has worked with local activists and government officials in the Republic of Georgia since 2010 to actively protect the human rights and promote the full community integration of children and adults with disabilities in the country. **As a result of our advocacy and collaboration with local partners, some of the most egregious human rights abuses facing people with disabilities that we observed in Georgia have already been addressed – in advance of this release of this report:**

- **Children’s lives have been saved by reducing the arbitrary and discriminatory denial of medical care to children with disabilities** - As a result of DRI’s sustained advocacy in cooperation with local organization Children of Georgia and the Georgia Public Defender’s Office, children with disabilities in Tbilisi Infant’s House who were being discriminatorily denied medical care were given life-saving treatments. As this report describes, however, the denial of appropriate care remains a challenge and urgent action is still needed to protect children with disabilities.
- **DRI contributed expert medical and legal support to the Georgia Public Defender’s Office** in 2012 to investigate and publish a powerful and well-documented report on torture and ill-treatment within Georgia’s state-run institutions for persons with disabilities.⁶
- **Plans to create small new institutions have been modified to create group homes** - In 2011, DRI learned of plans being developed by a major international donor to create 14-bed facilities for children with disabilities.⁷ Following a 2012 training by DRI of Georgian activists and government officials, the donor reversed its plans and the government agreed to no more than 6 residents for any future community-based residential services for children with disabilities. This “less is more” approach has been dubbed by some local activists as “the DRI model.” We should note, however, that DRI is in favor of the most integrated settings and support even smaller homes or family placements as the best model.
- **The US Congress has condemned US government practices of rebuilding institutions** - After DRI presented its documentation of USAID and Department of Defense funding to build and renovate segregated institutions for persons with disabilities in Georgia, the US Senate Committee on Appropriations condemned the use of USAID funds which “**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 further directed the US Agency on International Development to develop and implement a plan for the community integration of children and adults with disabilities who are in institutional settings. While USAID has funded a number of valuable disability projects, including family support programs and foster care, the US government has not, to our knowledge, taken action to integrate persons into the community who live in institutions rebuilt with US government funds.

This report was originally written in English. While we have made every effort to provide an accurate translation, there are inevitably differences in technical meaning or nuance. If there is any question about a discrepancy between the two versions, please refer to the English original.

Acknowledgements

Disability Rights International (DRI) is indebted to the many individuals and organizations who volunteered their time and energy to provide insights on the human rights situation of persons with disabilities in the Republic of Georgia.

EveryChild of Georgia, The Georgia Public Defender’s Office, Children of Georgia, First Step of Georgia, UNICEF and the US Agency for International Development were particularly generous with their time.

DRI is appreciative to have learned from the lived experience of Georgia’s disabled person organizations (DPOs). Advocates we met from the Partnership for Equal Rights, the Georgia Coalition for Independent Living, and An Accessible Environment for Everyone were truly inspiring.

We would like to thank the Ministry of Labor, Health and Social Affairs for allowing us access to institutions for this investigation. We would like to thank Giorgi Kakachia in particular for his blunt and honest assessment of Georgia’s challenges, and his obvious compassion for children and adults with disabilities in institutions.

We would like to thank Bruce Curtis, World Institute on Disability, for inviting us to Georgia and introducing us to disability activists in the country.

On every trip, we had the fantastic experience of being driven by Zviad Pirtskhalava.

None of DRI’s work is possible without the support of Adrienne Jones, our Director of Finance and Administration, and her assistant S. Sinclair. We are additionally grateful for the work of Julia Wolhandler, our Development Associate, in reviewing and editing the citations of this report.

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Executive Summary

Left Behind: *The Exclusion of Children and Adults with Disabilities from Reform and Rights Protection in the Republic of Georgia* is the product of a 3-year investigation by Disability Rights International (DRI) into the orphanages, adult social care homes and other institutions that house children and adults with disabilities in the Republic of Georgia.

This report documents violations of the human rights of persons with disabilities in the Republic of Georgia under international human rights treaties ratified by Georgia, including the United Nations (UN) Convention on the Rights of the Child⁸, the European Convention on Human Rights⁹, and the UN Convention against Torture¹⁰, as well as the UN Convention on the Rights of Persons with Disabilities,¹¹ which Georgia has signed.

The report documents the exclusion of children and adults with disabilities from domestic reforms and international development agendas. Over the past decade, the Government of Georgia has undertaken an ambitious child care reform process. As a result, the majority of its state-run institutions for children *without* disabilities have been closed and replaced with community services which enable vulnerable families to keep their children at home. The positive results of these efforts are extensive and credit should be given to the government and its partners for these achievements. UNICEF has played an important and valuable leadership role in planning these reforms. **DRI's investigation found, however, that institutionalized children with disabilities were largely excluded from this reform process. These children continue to be marginalized and abused.** Without services for adults with disabilities, these children face the prospect of life-long segregation from society.

A parallel system of orphanages exists under the authority of the Georgian Orthodox Church. While the government is shutting down state-run orphanages, it continues to fund the establishment of new orphanages run by the church. Because these facilities are completely unregulated, they create particularly serious risks to human rights. The exact numbers of children in these facilities are off the public record.

The exclusion of many children and adults with and without disabilities from reforms has permitted life-threatening abuse, neglect and segregation to continue in Georgia's orphanages and other institutions. Even while the Republic of Georgia was closing state-run institutions for children without disabilities, the United States government and other international organizations provided funding for the building or renovation of new institutions for persons with disabilities—perpetuating segregated care for Georgia's most vulnerable population. These actions have not

advanced the principles of human rights promoted by the UN Convention on the Rights of Persons with Disabilities.

Within Georgia's residential institutions, children with disabilities are subjected to physical and emotional neglect and abuse, and many children are denied life-saving medical treatment simply because they have a disability. In one orphanage, DRI documented a 30% death rate for children with disabilities over an 18-month period in 2009-2010. Those who survive to adulthood are warehoused indefinitely.

In institutions DRI visited in Georgia, investigators witnessed children and adults who spend their lives in inactivity, some rocking back and forth, biting their hands and gouging their eyes. Psychological studies have shown that self-abuse is often created by the mind-numbing boredom and emotional neglect of placement in an institution.¹²

A. Children and Adults with Disabilities are Left Behind

While Georgia has engaged in a valuable reform project to close orphanages, children with disabilities have been largely excluded. The primary finding of this report is that the Government of Georgia has undertaken a reform process in a manner that discriminates against children and adults with disabilities detained in institutions.

Georgia's child care and deinstitutionalization reforms entered its most active phase in 2009. That year, the Georgian government signed the UN Convention on the Rights of Persons with Disabilities, committing itself to the community integration of persons with disabilities. A year earlier in 2008, the US government committed \$1 billion in aid to Georgia, setting aside \$50 million to improve Georgia's social services.¹³ This was a moment of opportunity for institutionalized children with disabilities in Georgia to be integrated into the community.

Authorities at UNICEF, Georgia's main strategic partner in planning child care reforms, explained to DRI that they fully intended to support the community integration of children with disabilities into society. They reported to DRI, however, that they **made a decision to prioritize the community integration of children without disabilities**.¹⁴ According to UNICEF, this would allow them to return to children with disabilities later.

For most children with disabilities in Georgia's institutions, "later" has never come—and many have died waiting. In the interim, funding for reform has been greatly reduced and the opportunity to help children with disabilities is diminished. Political will to complete deinstitutionalization has faded. This report demonstrates the danger of excluding children with disabilities from all stages of reform.

In 2009, UNICEF hired an independent consultant, Oxford Policy Management, to review the first stages of its child care reform strategy. The consultants warned UNICEF that ***“the needs of people with disabilities are thought to represent a big gap in service provision...”***¹⁵

Whatever approach may have been intended by international advisors to help the children with disabilities who remain behind in institutions, the Government of Georgia has not fully accepted that all children with disabilities, as a matter of basic human rights, should be integrated into the community:

The strategy is that physically healthy children will not stay in large-scale child care institutions, but be adopted and raised in family-based care—according to the international experience, it is the best option for them. As for children with disabilities, it is reasonable and fairly normal to be brought up in and stay in a child care institution. — Georgia Minister of Labor, Health and Social Affairs (November 2013)¹⁶

DRI’s investigation has found that nearly 5 years later, children and adults with disabilities remain largely excluded from Georgia’s reforms. Children with disabilities who are considered by the government as too disabled to benefit from the community services created by the reforms, remain in state-run institutions today.¹⁷

UNICEF and USAID report that the institutional population in Georgia’s state-run orphanages has decreased by more than 90% since 2005¹⁸— leaving less than 150 children in state-run institutions.

This number, however, does not include children living in church-run institutions. It does not include the children who live in Georgia’s six residential boarding schools for children with disabilities. Nor does it account for the many children who have been permanently transferred to adult institutions over the course of a decade. **As the government was closing state-run orphanages, children were being transferred to these other forms of segregated environments.**

The government is playing a shell game with these children. —Representative of the Georgia Public Defender’s Office (2013)¹⁹

A spokeswoman for the Georgian Orthodox Church refused to give DRI the number of children under their care during a September 2013 interview—claiming that “a few children” live in informal housing in monasteries across the country.²⁰ The Director of the Georgian government’s Department of Programs for Social Protection and UNICEF have reported to DRI that **they do not know how many children live in Georgia’s church-run institutions**, and that they are completely unregulated. One Georgian children’s activist reported to DRI in 2013 that there could be as many as 1,200 children in orphanages run by the Georgian Orthodox Church, while a US Agency for International Development (USAID) representative estimated as many as 1,500.²¹ If these estimates

are correct, there are approximately 1,650 children with and without disabilities still languishing in Georgia's orphanages and institutions.ⁱ The actual number could be larger.

The children in Georgia's church-run institutions are completely excluded from deinstitutionalization reforms. According to Oxford Policy Management, without any data from these institutions, **"...it is impossible even to say whether the total number of children in residential care in the country is going up or down, let alone be able to assess their welfare."**²²

The government's lack of information concerning the number or location of children in church-run institutions creates a danger that children could be abused or trafficked without the government's knowledge.

USAID and the Public Defender's Office have reported on the transfer of children from state-run institutions to unregulated church-run orphanages:

Sometimes social workers look to the church to find a placement for a child...I think it is a violation of freedom – USAID representative (2013)²³

There was a case of one child who changed 6 or 7 institutions. He started in state-run, he went to church, he went to private, back to church, back to private, then I found him back in a state institution, and now—I don't know where he is. Kids are thrown out all the time from foster care and small group homes because they don't have enough resources, so they have to put them somewhere...but officially, they will not tell you this – Representative of the Georgia Public Defender's Office (2013)²⁴

In one state-run institution, DRI interviewed and documented several parents who have had their children taken away from them.²⁵ According to the director of this institution, children were placed by government authorities in unregulated church-run orphanages.²⁶

The church needs a license to provide 24-hour residential care and they don't have such a license. So we have just one possibility: we could go to court. But it's very difficult to go to court against the church. –Director of Department of Programs for Social Protection, Ministry of Labor, Health and Social Affairs (2013)²⁷

The Director of the Georgian government's Department of Programs for Social Protection reported to DRI that the Georgian Orthodox Church will sometimes seek out vulnerable families and

ⁱ UNICEF's estimate as of Sept. 2013 is that 150 children with disabilities remain in state-run orphanages. The government does not know how many children live in church-run orphanages. As described below, local activists have reported to DRI that as many as 1,500 children live in Georgia's orphanages run by the Georgian Orthodox Church.

encourage them to hand their children over to the church.²⁸ It is unknown how many children in private or church-run institutions have disabilities.

While state-run institutions for children without disabilities are being closed, the Georgian Orthodox Church is building new institutions partially financed by the government, with no regulation or oversight.²⁹ As of September 2013, these children are still excluded from reform efforts.³⁰

Given the lack of oversight and monitoring in church-run institutions, there is a risk that children could be subject to human trafficking.ⁱⁱ The director of the Georgian government's Department of Programs for Social Protection reports to DRI that according to law, the transfer of children from state-run to church-run institutions should be regulated by the state, but in reality it is not.³¹ According to a Georgian child rights activist, these transfers are performed completely off the record, with no paperwork.³²

DRI's concern for the safety of children in unregulated orphanages is heightened by the fact that human trafficking has been publicly identified as a problem in the Republic of Georgia. In 2013, Georgia was downgraded to a "Tier 2" country by the US Department of State's Office to Monitor and Combat Trafficking in Persons, finding that Georgia no longer met minimum standards necessary to protect persons from sex trafficking, forced labor, or other kinds of modern slavery.³³

Women and girls from Georgia are subjected to sex trafficking within the country, as well as in Turkey, the United Arab Emirates, and, to a lesser extent, Egypt, Greece, Russia, Germany, and Austria. –US State Department 2013 Trafficking in Persons Report³⁴

The complete lack of monitoring of church-run institutions in the current context of the country's human trafficking record presents dangers to children who are kept in segregated, unregulated and closed-off institutions.

ⁱⁱ DRI has not documented instances of human trafficking and is not suggesting that the Georgian Orthodox Church is committing trafficking by operating unregulated orphanages. The risk of human trafficking is created wherever there is no oversight and it is impossible to monitor or identify the location of children by family members or government authorities. It is especially likely for criminal activity to occur in a closed environment in which independent human rights monitoring does not take place. The United Nations defines human trafficking as: "...the recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include, at a minimum, the exploitation of the prostitution of others or other forms of sexual exploitation, forced labour or services, slavery or practices similar to slavery, servitude or the removal of organs."

B. Inadequate and Discriminatory Community Services

According to UNICEF, the community services created by the reform thus far are insufficient for children who are perceived to have “complex or severe disabilities.” While children with minimal disabilities have been served, in reality any children with significant disabilities cannot be served by the existing community services. UNICEF reports that the chances for foster care placement for children with severe disabilities, or older children who have been institutionalized most of their life, is “slim to none.”³⁵

They’re not going to get into foster care, even with intensive support—a lot of kids in these institutions. –Chief of Child Protection, UNICEF-Georgia (2012)³⁶

In the most severe cases we have no option for them. The future for them is to stay in institutions – Director, Tbilisi Infant House (2011)³⁷

Even children with perceived mild disabilities face considerable barriers to leaving institutions. Foster care services are hampered by financial disincentives for potential foster families willing to care for children with disabilities.³⁸

Children with disabilities have been completely excluded from all 45 group homes created in the community to enable deinstitutionalization, according to reports from Georgian government and UNICEF officials.³⁹ Twenty-five of these homes were built with USAID funds, none of which house any children with disabilities, despite the US agency promising in a press release that the initiative would “emphasize the inclusion of children with disabilities.”⁴⁰

We need a certain amount of small group homes for children with disabilities. We don’t have any yet. And honestly, we can’t find a location in the state budget right now for this. –Deputy Minister of the Ministry of Labor, Health and Social Affairs⁴¹ (2012)

In addition to noting the general lack of services for children with disabilities, the 2009 Oxford Policy Management evaluation commissioned by UNICEF stressed the absence of any transitional plan to support children with disabilities aging out of orphanages or community alternatives.⁴² ***“Any good progress made in supporting the development of children up to the age of 18 may be under threat if they are then required to fend for themselves suddenly and without support,”*** the report warns.⁴³

More than 2 years later in November 2011, local advocates reported to DRI that the transition to adulthood remained completely off the agenda for children with disabilities:

They have no choice but to move to the adult institutions after 18 because they have no education, no professional or social skills to take care of themselves and be competitive in the modern society. –Director of the Georgia Coalition for Independent Living⁴⁴ (2011)

A few private initiatives have been created to house adults with disabilities, including two rural farming communities and two group homes. However, according to the director of the Georgian government's Department of Programs for Social Protection, these services are either filled to capacity or have insufficient resources to serve as an alternative to institutionalization for many adults with disabilities.

When children with disabilities turn 18, there are only three possibilities: They can go to the adult institutions in Martkopi, Dzveri or Dusheti. –Director of the Department of Programs for Social Protection, Ministry of Labor, Health and Social Affairs (2013)⁴⁵

The exclusion of a transition plan to adulthood for children with disabilities has begun to show its consequences: DRI has documented dozens of young adults with disabilities in Georgia's adult institutions who were minors at the beginning of the reform process. Now, as adults, they will not benefit from any future child care reforms.

C. Abuses in Georgia's Institutions

Persons with mental disabilities are a particularly vulnerable population in any society, especially those who are shut away and forgotten in segregated institutions. The human rights concerns of institutionalized populations have been documented by such authorities as the former UN Special Rapporteur on the Right to Health, Paul Hunt, who has identified institutional placement as a threat to the right to health.⁴⁶ The UN Special Rapporteur on Torture, Juan Méndez, has made clear that due to the "fear and anxiety produced by indefinite detention," placement in an institution can violate the UN Convention against Torture.⁴⁷

From July 2010 to September 2013, DRI documented a broad array of human rights violations against children and adults with disabilities detained in residential institutions in the Republic of Georgia. DRI observed and assessed institutionalized children within Georgia's state-run orphanages. In the Tbilisi Infant Home, staff report that infants with disabilities are denied life-saving medical care simply because of doctors' perceptions that the children will not have a good quality of life. As a result, staff report that they can sometimes do little more than wait for children

to die in their cribs. In an 18-month period in 2009-2010, local organization Children of Georgia documented a 30% death rate among children with disabilities in the Tbilisi Infant House⁴⁸.

Following DRI's advocacy, in collaboration with local organizations such as Children of Georgia, staff at the Tbilisi Infant Home reported to DRI in 2013 that most children are now receiving care and that mortality rates have dropped sharply. However, during a September 2013 visit to the infant home DRI observed multiple children who were still being denied medical treatment.

Children with spina bifida and hydrocephalus in Georgia's orphanages are the most likely to be refused medical treatment, according to Children of Georgia.⁴⁹ **In a single 4-month period between visits by DRI to the orphanage in 2012, 50% of the children with hydrocephalus in the Infant Home passed away (5 of 10 children).**⁵⁰

DRI's investigation revealed that children who are denied life-saving treatment at the beginning of their lives are also refused pain management at the end. None of the children examined by DRI's pediatric expert who were suffering moderate to severe pain at the Tbilisi Infant's Home were receiving pain medication.⁵¹

Pain and discomfort comprises a significant part of these children's lives. –Dr. Lawrence Kaplan, Director of Baystate Behavioral-Pediatric Hospital, Massachusetts, USA⁵²

According to the UN Special Rapporteur on Torture, the denial of pain medication to children in severe chronic pain may rise to the level of torture under the UN Convention against Torture.⁵³

In September 2013, DRI investigators witnessed a 2-year old child lying in a crib with untreated hydrocephalus. His head had swelled to the size of a basketball, rendering him completely immobile. No pain medication was prescribed for the child. Staff reported that the only method for managing this child's pain was to give him sleeping pills.⁵⁴

In the Senaki orphanage for older children with disabilities, DRI documented several malnourished children who, according to staff, were bedridden and spent most of the day confined to their cribs.

In one case, DRI found an emaciated 7-year old girl named Mariam in a dark back room of the institution in the middle of the day—alone and screaming. The girl was covered in bedsores and had atrophied limbs. She died one month after DRI's visit.

Those who survive to adulthood are warehoused indefinitely in large-scale institutions—some built with funding from the US government.

Georgian law on legal capacity is not consistent with the UN Convention on the Rights of Persons with Disabilities and contributes to the denial of rights.⁵⁵ Adult residents of institutions are routinely stripped of their legal capacity and put under state guardianship—a process which denies the person of any control of his or her financial, legal and personal life.

Even adults who retain their legal personhood are often at the mercy of the institution in which they live to exercise their rights. DRI has documented three couples living in institutions who have been forcefully separated from newborn children with no judicial review.

Rehabilitation programs are nearly non-existent.⁵⁶ Residents in one institution reported to DRI investigators that the only activities they have to do all day is knit or listen to music.⁵⁷ According to the directors of two adult institutions, residents are often forced to do unpaid jobs as a form of “work therapy.”⁵⁸ In some instances, the Georgia Public Defender’s Office has reported that staff take residents home to work on their farms or do household chores.⁵⁹

D. New Investments in Segregated Institutions by International Donors

States Parties to the present 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... --United Nations Convention on the Rights of Persons with Disabilities (Article 19)

Adults with disabilities are warehoused for a lifetime in Georgia’s adult institutions. **Despite adoption of a national Disability Action Plan in 2010 to promote inclusion of persons with disabilities in society, the Georgian government has since increased the number of long-term institutions for adults with disabilities—using US government funding.**

The Georgian government has used nearly \$1 million in international aid from the United States government to open two new, long-term institutions for adults. While undoubtedly well-intentioned, this international development aid has resulted in the perpetuation of institutional care in a country with a stated commitment to deinstitutionalization.

Costly improvements in the physical conditions of existing institutions, which are often proposed as a response to finding 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. - European Commission Ad-Hoc Expert Group on the Transition from Institutional to Community-Based Care⁶⁰

The US government financed the reconstruction of the Martkopi institution, a new institution for 68 adults with disabilities located in a remote area 40km outside Tbilisi. The US European Command donated \$500,000 for the main rebuilding project, and USAID donated \$100,000 for furniture and equipment.⁶¹ Children who have aged out of Georgia’s orphanages, and who did not benefit from

the deinstitutionalization of children's services, have been sent to Martkopi, where they will live indefinitely.⁶²

The US government has characterized the facility as promoting "family style" or "apartment style" living.⁶³ DRI investigators found this characterization to be wholly inaccurate.

The facility consists of 3 floors that sleep approximately 23 men and women on each floor. Most rooms have 4 beds, and all bathrooms, the day room, and the dining room are communal. The staffing of the institution, which consists of 13 caretakers for 68 residents during the day—*and only one caretaker per floor at night*—makes any meaningful rehabilitation or habilitation impossible.⁶⁴ Most residents in wheelchairs are restricted to the third floor—where they are fed in their rooms. According to a 2013 report by the Georgia Public Defender's Office, since staff have turned off the elevator to prevent residents from using it, the residents in wheelchairs cannot eat in the first-floor dining room or access the second-floor day room, without being carried down stairs by staff. DRI interviewed several residents who were forcefully separated from their children or parents when they were moved to the Martkopi institution. **The facility at Martkopi is most accurately described as a segregated large-scale institution that was renovated specifically to warehouse persons with disabilities.**

I was brought up without a mother, and without a mother's love, and I don't want my child to grow up without a mother—Mother in the US-funded Martkopi adult institution whose 10-month old child was taken away from her (2012)⁶⁵

She can independently take care of her child...there is no reason to take her child away from her—Director, Martkopi institution (2012)

The US government also spent \$300,000 on the construction of the new long-term Temi institution for 30 adults with disabilities in the rural village of Gremi.⁶⁶ *"You can see the deprivation of people,"* a student volunteer told DRI in Temi, regarding the residents with disabilities. *"It's challenging because they never get supported....and we have to work with the caretakers who have no professional training."*⁶⁷

In addition to funding the Martkopi and Temi institutions, the US government has also invested funds to improve the physical infrastructure of both the Tbilisi Infant Home and the Senaki orphanage for children with disabilities, where DRI has documented extensive neglect and abuse.ⁱⁱⁱ In 2008, UNICEF reports that the UN agency spent "hundreds of thousands of euros" to rebuild two wings of the Senaki orphanage.⁶⁸

ⁱⁱⁱ USAID financed a playground and landscaping at the Tbilisi Infant's House, and the US State Department financed a computer room and gym at the Senaki Institution for children with disabilities.

Summary of Recommendations

Legal recognition of the rights of persons with disabilities is gaining ground around the world. Since the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD), governments have begun reforming laws and social service systems to protect the basic rights of people with disabilities. The CRPD's article 19 now recognizes the right of "all persons with disabilities to live in the community, with choices equal to others."⁶⁹ To implement this right, governments must take immediate action to reform social services to provide the supports necessary for community integration. Under the new UN "Guidelines for the Alternative Care of Children," governments must begin to plan for the "elimination" of institutions for children.⁷⁰

In 2009, the Republic of Georgia signed the CRPD and committed itself to the treaty's principle of inclusion. While taking valuable steps to integrate non-disabled children into society, **Georgia chose to leave the most vulnerable people behind—children and adults with disabilities.** Institutionalized infants with complex disabilities, older children with disabilities who have spent entire lives in institutions, and adults with disabilities have been essentially written off by the Republic of Georgia—violating the prohibition against discrimination under article 14 of the European Convention on Human Rights.

International development organizations which fund and implement aid programs must comply with article 32 of the CRPD which mandates that "international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities."

By leaving out institutionalized children with disabilities from reform plans, international agencies' assistance to Georgia has discriminated against persons with disabilities. Georgia and international donor organizations have failed to live up to the obligations of CRPD articles 19 and 32.

In 2013, the Republic of Georgia is again at a crossroads. If Georgia chooses to address these gaps in an otherwise ambitious and aggressive reform effort, it has the potential to become the region's first country to fully integrate children with disabilities into society.

If Georgia fails to take immediate action to include all persons with disabilities in its deinstitutionalization reforms, the potential for true change will be lost—replaced by cosmetic reforms that leave the true stakeholders continuing to suffer in abusive institutions, more invisible and silenced than ever before.

A. Ensure Persons with Disabilities' Right to Live in the Community

Article 19 of the CRPD requires governments to take immediate steps toward the community integration of children and adults with disabilities. Reform programs that exclude persons with disabilities are discriminatory and violate this right.

Georgia's experience with deinstitutionalization provides a key lesson for other countries undergoing deinstitutionalization as they implement article 19 of the CRPD: **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.**^{iv}

Despite UNICEF's declaration that Georgia's three state-run orphanages for children with disabilities would be closed by the end of 2012,⁷¹ this goal remains unachieved. Services in the community remain inadequate to support the deinstitutionalization of persons with disabilities, and the funding and political will that existed at the beginning of the reform process are now gone.

Adults with disabilities are warehoused indefinitely in new institutions built with international development funds. This violates the spirit of USAID's disability policy, and this policy should be amended and clarified to make clear that such funding violates US law.

In many countries, individuals with disabilities have been 'warehoused' in abysmal conditions with total disrespect for their rights. Those rights must be respected.—
Disability Policy, US Agency for International Development⁷²

In institutions supported by international development funds in the Republic of Georgia, DRI investigators witnessed infants dying slow painful deaths because of the intentional withholding of medical care; children who are subjected to the neglect and lack of stimulation that leads to self-abuse; and children whose disabilities were so worsened by lack of appropriate one-on-one care that they had become permanently bed-ridden.

Key Recommendations

- **The Georgian government** should (A) commit the financial resources necessary to deinstitutionalize children and adults with disabilities who remain in state-run institutions, and to create community-based alternatives with appropriate services and safeguards; and (B) create the community supports necessary to plan for the elimination of all institutions for children, including private and church-run facilities;
- **UNICEF** should develop a global statement of best practices mandating that country offices do not discriminate against children with disabilities in planning for deinstitutionalization

^{iv} Successful disability reforms have demonstrated that it is feasible and immensely beneficial to bring people with the most severe disabilities into inclusive, small, family-like settings. For example, such as has been accomplished in the United States at Pennsylvania's Pennhurst Institution, Oklahoma's Hissom Memorial Center, and the Robert Wood Johnson Foundation's national self-determination initiatives.

and service system reform as documented in Georgia. Instead of coming last, children with disabilities should be part of every aspect of reforms;

- **The United States** should take immediate action to ensure that future investments in segregated care do not occur—either in Georgia or elsewhere in the world. The USAID Disability Policy should be updated to reflect such a prohibition. The US Department of Defense and the US Department of State should adopt similar comprehensive disability policies in regard to international aid programs;
- **The United States** contributed to the current segregated system, and has a responsibility to undo the effects of its misguided efforts that have left adults with disabilities segregated from society. These adults face the prospect of remaining segregated for a life-time in US-funded institutions. The US should commit to providing the funding necessary to deinstitutionalize immediately the persons with disabilities detained in Georgia’s US-funded institutions and to develop appropriate community services to allow them to live full, meaningful lives in the community.

B. Ensure Access to Healthcare

Children with disabilities routinely die in Georgia’s orphanages due to the denial of life-saving surgeries which are available and affordable in the Republic of Georgia. Article 24 of the UN Convention on the Rights of the Child states that nations must provide the highest attainable services and facilities to all children and must “strive to ensure that no child is deprived of his or her right of access to such health care services.”⁷³

Article 25 of the CRPD mandates that States “[p]revent discriminatory denial of health care or health services...on the basis of disability.” And further, that States provide “services designed to minimize and prevent further disabilities, including among children...”⁷⁴

Furthermore, the denial of pain medication to children in severe chronic pain in the Tbilisi Infant Home may rise to the level of torture under the UN Convention against Torture. In February 2013, the UN Special Rapporteur on Torture, Juan Méndez, released a report detailing the types of abuses in healthcare settings which could rise to the level of torture or ill-treatment under international law. Méndez concluded that when authorities deny pain treatment which “...condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment.”⁷⁵

Such a determination would require the criminal prosecution of responsible authorities, in accordance with article 7 of the Convention against Torture.

Key Recommendations

- **The Georgian government** should establish a monitoring system to ensure that children with hydrocephalus and spina bifida receive immediate medical treatment, as well as appropriate follow-up care;
- **The Georgian government** should ensure the availability and accessibility of pain medications to children suffering painful conditions in the Tbilisi Infant Home;
- **The Georgian government** should prepare a country-wide system of community-based health centers for providing healthcare and support for children and adults with disabilities. The Tbilisi Infant Home should be closed—or transformed into a non-residential center for expertise and training.

C. Protect Children from Trafficking

In the Republic of Georgia, the lack of oversight, regulation, or monitoring of church orphanages puts *all* children – especially children with disabilities – in great danger. According to a UNICEF representative, orphanages run by the Georgian Orthodox Church are “completely unregulated.”⁷⁶ The representative explained that because the church is “very powerful,” it has become a sensitive political issue.

The director of the Georgian government’s Department of Programs for Social Protection confirmed to DRI that the church-run institutions in Georgia were unlicensed to house children, but that it would be “very difficult,” to challenge the church.

Recent DRI investigations in Guatemala and Mexico have found that trafficking is allowed to flourish behind the closed doors of institutions—with no oversight, regulations or regular monitoring. And various organizations around the world have demonstrated that children are all too often trafficked from orphanages into prostitution rings, as exposed in Russia, China, Cambodia, Portugal, India and more.⁷⁷

Key Recommendations

- **The Georgian government** should establish independent safeguards and oversight mechanisms within private and church-run institutions to protect against trafficking, exploitation, violence and abuse;

- **The Georgian government** should create a registry of children and adults in all institutions. A system for tracking admissions, discharges, deaths, and transfers of persons between institutions or to other placements should be created, so that they cannot disappear from society. Information about the total number and characteristics of persons receiving services should be published and made public.

I. Introduction: Political and Social Context of Reforms

The Republic of Georgia has been described by historians as a country that has existed throughout history on the edge of empires, continually overshadowed on the world stage by its more illustrious neighbors—Russia to the north, historical Persia to the south-east, and Turkey to the west.⁷⁸

Recent history, however, has brought Georgia into the international spotlight. In the years following the break-up of the Soviet Union in 1991, Georgia existed in a state of near-collapse marked by corruption, poverty and bloody periods of civil war.⁷⁹ First Step of Georgia, a service provider for children with disabilities in Georgia, described the collapse of organizational structures during this time as chaos, when “many of the basic human needs that we simply take for granted – food, utilities, healthcare, education, social services – were at best sporadic and at worst, non-existent for periods of time.”⁸⁰

It was during this time that the first stages of child care reform began. Following Georgia’s 1994 ratification of the UN Convention on the Rights of the Child, pilot programs for prevention of child abandonment launched in 1999, recruiting the country’s first social workers and providing cash assistance to families with children at risk of institutionalization. A national action plan for child care reform was drafted in 2002, but was never enacted and later abolished.⁸¹

Social discontent climaxed in 2003. Outraged over dubious election results, protestors took to the streets en masse sparking the peaceful “Rose Revolution” symbolized by the red roses offered by protestors to deployed military forces. On November 23rd, Communist-era President Eduard Shevardnadze peacefully resigned.⁸² According to the BBC, not a single person was injured during the revolution. Opposition leader Mikhail Saakashvili and his United National Movement party were subsequently elected to power.⁸³

The election of Saakashvili marked a turning point in the nation’s economic history. Georgia’s economic growth rate quickly became one of the highest in the region, with gross domestic product rising from \$4 billion in 2003 to \$10 billion in 2007.⁸⁴

This economic upturn spurred the second stage of reforms for children, which focused on dismantling Soviet-era governmental structures and establishing a government commission on Child Protection and Deinstitutionalization.

However, violence in Georgia’s breakaway provinces of South Ossetia and Abkhazia continued to escalate. In early August 2008, firefights between the Georgian military and Russia-backed South Ossetian forces eventually led to the invasion of Russian forces into Georgia, displacing more than 20,000 Georgians and disrupting the Georgian economy. On August 12, a cease-fire was signed and advancing Russian troops halted en route to Georgia’s capital city of Tbilisi.⁸⁵

With then-U.S. Senator Joseph Biden calling the Russian invasion of Georgia, “one of the most significant events to occur in Europe since the end of Communism,” the US pledged \$1 billion dollars in assistance to stabilize Georgia’s economy, improve infrastructure and provide

humanitarian assistance. Georgia became one of the world's largest per capita recipients of US economic assistance.⁸⁶

Georgia's child care reform entered its most active phase following this substantive influx of foreign aid in 2008, of which nearly \$50 million was earmarked for health and social infrastructure projects.⁸⁷ The government's Child Action Plan for 2008-2011 was adopted and large-scale institutions began to close in favor of re-integration with biological families, adoption, foster care and small group homes in the community.

By the time implementation of the Government's Child Action Plan for 2008-2011 was in full swing in 2009, the Georgian government budget allocations for social welfare stood at an all-time high of 25% of total state expenditures, up from 11% in 2003.⁸⁸ In July 2009, Georgia signed the UN Convention on the Rights of Persons with Disabilities, committing to the community integration of persons with disabilities. And approximately \$50 million of US aid stood ready to improve Georgia's social services.⁸⁹ If there was ever a moment of opportunity for institutionalized children with disabilities in Georgia, this was it.

II. Observations

Over the course of a three-year investigation from July 2010 to September 2013, Disability Rights International (DRI) documented the human rights situation for the Republic of Georgia's most vulnerable population— persons with disabilities detained in institutions including orphanages and adult social care homes.

Despite the country's ambitious child care reform plan, children and adults with disabilities in institutions have been largely excluded from the country's reforms. Children with disabilities remain at high risk for life-threatening medical neglect in Georgia's orphanages; older children in orphanages are not eligible to take advantage of existing community services; and adults with disabilities are warehoused indefinitely—many in institutions built with foreign assistance funds.

A. Denial of Medical Care for Children with Disabilities

DRI documented a broad range of medical neglect in the Republic of Georgia's orphanages, including the discriminatory denial of life-saving surgeries, dangerous medical practices and denial of pain medication.

❖ The Tbilisi Infant Home

The Tbilisi Infant Home in the center of Georgia's capital city houses, at any given time, approximately 40-60 children with disabilities from age 0 to 6. In recent years, DRI has documented a mortality rate for children with disabilities at the orphanage as high as 50%^{90v}. About 20 of the children with disabilities are labeled by the institution as severe and kept separated from the rest of the children in two dimly lit rooms lined with rows of cribs. Over 5 visits to the orphanage, DRI observed that most of the children with disabilities were kept in cribs even in the middle of the day. The children were often completely silent – awake, but not crying – a characteristic common of babies in institutions who have given up on crying as a means of receiving care or attention. Toys and stuffed animals are nailed to the wall, above cribs, out of reach. DRI investigators noticed drawn curtains even on bright, sunny days.

Between the two buildings that made up the orphanage was a playground, funded by the US Agency for International Development (USAID). During all of DRI's visits to the orphanage, investigators never saw any children outside.

^v DRI documented a 50% mortality rate of children with hydrocephalus over a 4-month period in 2012 and local NGO Children of Georgia documented a 30% death rate of all children with disabilities over an 18-month period in 2009-2010.

Many children in the institution are not true orphans, but are given up to the orphanage for reasons of poverty, social stigma or disability. Indeed, UNICEF reports that 90% of children in Georgia’s orphanages have at least one living parent.⁹¹

Many doctors pressure parents to give a child with a disability up to the orphanage at birth, according to the Tbilisi Infant Home director, telling them the future for their child is hopeless. The local organization Children of Georgia reported to DRI that many parents of children with complex medical conditions are faced with a difficult decision: They must choose between keeping their child at home without sufficient insurance to cover medical costs, or abandon their child to the orphanage in order to receive full coverage.^{vi}

Mortality of children with spina bifida and hydrocephalus

In the Tbilisi Infant Home, children with spina bifida and hydrocephalus are among the most likely to die preventable deaths, according to Children of Georgia.⁹² In a 5-year period from 2008 to 2012, 58% percent of all children with spina bifida or hydrocephalus admitted to the Tbilisi Infant’s Home died, according to Children of Georgia⁹³, due to the denial of surgical intervention to treat the condition at birth or upon diagnosis.^{vii}

Hydrocephalus is an abnormal buildup of cerebral spinal fluid in the skull. When left untreated, hydrocephalus is fatal in most cases.⁹⁴ However, when appropriate treatment is provided, the mortality rate of children who die from hydrocephalus is between 0 to 3 percent.⁹⁵ It is most commonly treated by inserting a tube, called a “shunt,” to drain away the excess fluid and relieve the pressure on the brain.⁹⁶ This procedure is regularly denied to children in the infant home despite being affordable^{viii} and available in the Republic of Georgia.⁹⁷

In a single 4-month period between visits by DRI to the orphanage in 2012, 50% of the children with hydrocephalus in the Infant Home passed away.

On a 2011 visit, DRI investigators observed a particularly haunting scene. A child with hydrocephalus lay still in his crib in a dark corner of the orphanage. The child was only six months old but the built-up fluid had ballooned his head to nearly three times the normal size. His head was covered in open wounds— the expanding skull stretching his skin so tight that the pressure from his blankets and pillow would rip open his skin. Staff informed DRI that the child would die anytime. Indeed, when DRI visited again four months later, the child had died, and a new admission with untreated hydrocephalus had taken his place.

^{vi} In 2012 Georgia created universal health insurance for all children. However, advocates report that this coverage does not pay for diagnostic tests, which are sometimes cost-prohibitive for the parents. If parents give up a child to an institution, the diagnostic tests are fully covered.

^{vii} Spina bifida is a spinal malformation which obstructs the normal flow of spinal cerebral fluid and often leads to the development of hydrocephalus, a build-up of fluid in the skull. In many cases, hydrocephalus can be prevented by performing surgery on the spina bifida condition at birth, ideally within the first 24 hours after birth. In cases where hydrocephalus does develop, a shunt is most beneficial when placed immediately upon diagnosis.

^{viii} Estimated to be a total 3,000 GEL, or \$1,800 USD

Upon reviewing medical records of current residents with untreated hydrocephalus in June 2012, DRI's pediatric expert, Dr. Lawrence Kaplan,^{ix} observed that all the children would have benefited from the insertion of a shunt at the time of original diagnosis, and that the near-death condition of the children was not due to the severity of their illness, but rather to a decision to not treat their condition at an earlier stage.⁹⁸

The assessment further revealed that the majority of children in the orphanage labeled as "terminally ill" would likely survive if provided with immediate medical treatment.

...those with hydrocephalus are in this reviewer's opinion being abused and neglected.

-Dr. Lawrence Kaplan, Director of Baystate Behavioral-Pediatric Hospital, Massachusetts, USA

Discrimination on basis of disability

The denial of medical care on the basis of disability is a form of discrimination. Approximately a third of children with hydrocephalus will develop some degree of an intellectual disability.⁹⁹ The probability and severity of this risk increases the longer a child goes untreated.¹⁰⁰ Tbilisi Infant Home staff reported to DRI that neurologists who determine the suitability of a child for receiving a shunt base their decision on the child's prospects to develop what they consider to be a good quality of life.¹⁰¹ Staff reported to DRI that the children in the orphanage would not receive treatment because they were deemed by the doctors to be "hopeless," and to "have no future."¹⁰²

The first huge mistake is in maternity wards. Doctors say to a mother that it is hopeless and the child will die. – Director, Tbilisi Infant's House (2011)¹⁰³

...it appears very likely that the expectation of those who cared for the children prior to their admission to the Tbilisi Infant Home was that they were being placed there to die. –

Dr. Lawrence Kaplan, DRI pediatric expert

Infant home staff have reported to DRI that hospitals will sometimes turn away children with disabilities without examining them. The Director of Neurology at Tbilisi's Iashvili Children's Hospital echoed this concern:

I don't want to name the hospitals and clinics...but there were cases when people from the

^{ix} Director of the Baystate Developmental-Behavioral Pediatric Hospital in Massachusetts, USA.

infant house took children to hospitals and they refused to treat the children. –Director of Neurology, Iashvili Children’s Hospital (2012)¹⁰⁴

During a visit to the Tbilisi Infant’s Home by DRI in 2012, a one-year-old boy with untreated hydrocephalus had just returned to the orphanage after being admitted to the Iashvili Children’s Hospital for vomiting and respiratory distress. Despite a request for a consultation from the hospital’s neurology department regarding the child’s hydrocephalus, the child was returned to the orphanage with no indication as to the result of the neurologist’s examination, or even to whether an examination had taken place at all.¹⁰⁵

Medical professionals in Georgia cite the high risk of complications and infection after placing a shunt as justification for refusing treatment.¹⁰⁶ In countries where treatment is provided, complications are not uncommon; thirty to forty percent of shunts placed in pediatric patients will fail within 1 year, with infection as a common cause.¹⁰⁷

When hydrocephalus is treated and managed, however, the prognosis is good. The majority of children who receive shunts and appropriate follow-up care reach adulthood. In the US, a study found that more than half graduate from mainstream education.¹⁰⁸

Denial of pain medication

Children who are denied life-saving treatment at the beginning of their lives are also refused pain management at the end. DRI’s medical expert Dr. Lawrence Kaplan conducted an in-depth medical assessment of 20 of the children with disabilities at the Tbilisi Infant Home. His assessment found that 10 of the children suffered from moderate to very severe chronic pain^x. None of these children received any pain medication.

DRI observed many children who appeared to be near-death, lying motionless in cribs and covered in bed sores.

Pain and discomfort comprises a significant part of these children’s lives. -Dr. Lawrence Kaplan, Director of Baystate Behavioral-Pediatric Hospital, Massachusetts, USA

The two children with the most severe chronic pain were among those who were refused treatment for hydrocephalus. DRI observed one of these children, a 1-year-old girl, crying out in pain and vomiting during a brief medical examination by orphanage caretakers.¹⁰⁹

^x On the Wong-Baker pain scale, four children were assessed at a #4 (moderate pain), four children at #6 (severe pain), and two children at #8 (very severe pain).

http://www.chpnyc.org/patients/bi_home/pdfs/wong_baker_faces_pain_rating_scale_0-10.pdf

Dangerous medical practices and lack of habilitative services

Nearly all the children with disabilities assessed by DRI in the Tbilisi Infant Home^{xi} have cerebral palsy and need assistance in order to learn how to stand, walk, or use a wheelchair.¹¹⁰

The orphanage lacks physical therapists, occupational therapists, communication therapists, and nutritional and dietary consultants. Except for wheelchairs, the orphanage has no basic equipment necessary for children with disabilities, including adaptive seating and orthotic devices.¹¹¹

There was a striking absence of habilitative resources which would be requisite for the health and well-being of the range of needs these children have. – Lawrence Kaplan MD, ScM.

Without physical therapy or sufficient movement and interaction by caretakers, the children assessed by DRI experts in the orphanage are at risk for developing conditions such as joint contractures, hip dislocation, scoliosis, bed sores and chronic pain.^{xii} DRI observed several children who would be at risk of becoming permanently bed-ridden without immediate intervention.

Protracted inactivity of remaining in a crib can be dangerous for any child in terms of their physical development, as well as their psychological health.¹¹² It is detrimental for children to lie on their backs in a crib for prolonged periods of time. When this happens, their heads flatten and their bones don't grow properly because gravity does not pull on them at the proper angle. As such, many children who grow up in cribs remain small.¹¹³ Children with abnormal movement or children with limited movement only degenerate in cribs without consistent therapy. According to developmental disabilities nurse Karen Green McGowan, these children need consistent care, so that on a neurological level their brains will develop healthy movement patterns and on a physical level, they will develop the muscle tone and bone for actual movement.

To maximize growth and development, experts recommend that children have a care plan that consists of "feeding, sleeping, physical therapy, play, other ways to foster growth and development, medications, psychosocial needs, family needs, and pain assessment/management."¹¹⁴ This level of care is a level that most institutions cannot provide. Rather, it is the level of care that parents or other consistent care-givers naturally provide their children 24 hours a day.

^{xi} Of 20 children with disabilities assessed by DRI expert during June 2012 visit

^{xii} A contracture is a permanent shortening of a muscle or joint; scoliosis is condition where the spine becomes curved; bed sores are injuries to skin and underlying tissues caused by prolonged pressure on the skin

Just getting out of bed and being held and moved around can be life-saving.

– Karen Green McGowan, RN, CDDN, DRI Expert, President-Elect of the Development Disabilities Nurses Association.

It is generally common for children with complex physical disabilities, and particularly cerebral palsy, to have trouble eating or swallowing. This can lead to “pulmonary aspiration,” where food or saliva enters the lungs, often resulting in pneumonia or death from asphyxiation.¹¹⁵ In the Tbilisi Infant Home, infants spend the majority of the day and night on their backs in cribs, making swallowing an even more challenging task. In an 18-month period in 2009-2010, 15 children in the orphanage died from pneumonia, according to Children of Georgia.¹¹⁶

DRI’s medical experts observed that the Tbilisi Infant Home lacks infection control procedures, including appropriate hand washing and decontamination procedures. DRI observed one child with a highly contagious infection, which in the absence of appropriate precautions, presented serious risks for every child in the orphanage.¹¹⁷ In the same 18-month period, infection played a role in at least 10 deaths.¹¹⁸

The orphanage’s medical staff also reported the common usage of Depakote, an antiepileptic seizure medication, on children under 3 years of age. Studies have shown that this medication on children under 3 years of age presents a high risk of liver failure.¹¹⁹

Children who receive little stimulation and are emotionally deprived of a relationship can develop a medical condition known as failure to thrive, which can lead to permanent emotional, mental and physical developmental deficits.¹²⁰ Even children who receive adequate food in clean institutions may become disabled; some children become so emotionally neglected that they will not eat – and they may become malnourished and die.¹²¹ The staffing levels at the infant home cannot provide the consistent care and emotional support that a mother or father can provide. The director informed DRI during a 2012 visit that the staff consists of 3 caregivers assigned for every group of 10-13 children. DRI observed, however, that in practice there are often only 2 caregivers present at any given time. Each caregiver works a 24-hour shift every three days.¹²²

Nine of the children assessed by DRI’s pediatric expert in the Tbilisi Infant Home showed evidence of failure to thrive.¹²³

Developing an early emotional connection to a caregiver is also critical for an infant’s well-being. Absence of attachment to a consistent caregiver...can have significant negative effects on brain development and cognitive functioning.¹²⁴ – World Health Organization

The children that I saw in the Tbilisi Infant Home were simply not getting enough nurturing, as in mothering, and that is more important than movement in terms of keeping children alive. ...We have learned from long, hard experience that babies and

young children who grow up without nurturing often die. – Karen Green McGowan, RN, CDDN, DRI Expert, President-Elect of the Development Disabilities Nurses Association.

Barriers to medical care

The local organization Children of Georgia cites additional barriers to receiving appropriate medical care for spina bifida and hydrocephalus in Georgia. Insurance in Georgia will not cover diagnostic tests such as an MRI, according to Children of Georgia. The organization reports that despite the presence of visual symptoms in many children, Georgia's insurance will not pay for the necessary surgeries until the diagnostic tests have been performed.¹²⁵

As a result, parents in Georgia are faced with a daunting decision. They can delay treatment to save the money necessary for diagnostics and thereby risk increased disability and chance of death for their child; or they can give the child up to the Tbilisi Infant's Home, where the child will be covered by insurance for all procedures, including diagnostics, according to Children of Georgia.

Neither scenario ends well for the child. When a child is relinquished to the infant home in order to receive coverage, there are considerable waiting times for insurance companies to process paper work, often resulting in a delay between every step of the process (diagnostics, examination, and surgery), according to the director of the Tbilisi Infant's Home. The director reported to DRI that by the time the child is approved for surgery, the doctor will sometimes refuse treatment based on the child's chances for a perceived good quality of life.

As of September 2012, of the 36 children with spina bifida or hydrocephalus admitted to the infant home in the past five years, 21 had died and 14 were still in the orphanage. Only 1 child was ever reunited with his family.¹²⁶

Parents who do keep their child need time to save money for diagnostic treatments, leading to the child experiencing deterioration in health and increased disability. This deterioration can similarly result in denial of surgery and abandonment of the child to the orphanage.

❖ The Senaki Orphanage for Children with Disabilities

DRI documented medical neglect in the Senaki Orphanage for children with disabilities, a three-story building in the northwest region of the country housing 50 children age 7-18. The director of the Tbilisi Infant Home, as well as the Georgia Public Defender's Office, have expressed concern that there is no intensive care clinic near Senaki, and that the nearest hospital equipped to care for children with complex medical needs is more than an hour away.¹²⁷

DRI has documented several bed-ridden children with atrophied muscles in the Senaki institution for older children with disabilities age 7 to 18 who, according to the director of the institution, have spent their entire lives in cribs.

DRI investigators found a young girl named Mariam who was transferred from the Tbilisi Infant Home to the Senaki Institution for children with disabilities at age 6. One year after her transfer, in October 2011, DRI found 7-year old Mariam in a dark back room of the institution in the middle of the day—alone and screaming. The girl was covered in bedsores and had atrophied limbs—both avoidable and very dangerous products of lack of care in the institution.

Upon request by DRI,^{xiii} Senaki’s pediatrician provided DRI with an evaluation of Mariam’s condition in October 2011. In addition to her primary diagnosis of cerebral palsy, the medical evaluation revealed that she “has not had food for a number of days,” and had extensive bedsores^{xiv} from lying in bed for long periods of time. Mariam also had “multiple fractures of lower limbs, which are now healed with deformities of legs.”¹²⁸ DRI arranged for an independent pediatrician to travel to Senaki to give a second-opinion on Mariam’s condition and evaluate options for medical interventions. Authorities later informed DRI that Mariam died the day before DRI’s pediatrician was scheduled to arrive.¹²⁹

During a 2012 visit to Senaki, DRI’s pediatric expert observed Giorgi,^{xv} another severely malnourished and emaciated 8 year old boy with cerebral palsy lying in a crib. Staff reported that he was brought to the orphanage 4 months earlier by his mother because she was no longer able to support him at home. According to staff, he was already severely underweight at the time of admission, but his weight had dropped even further to 15 kgs (33 lbs) after placement in the institution.

Giorgi had bedsores on the side of his head from lying in bed for too long without being moved. He spends his days and nights in a crib that DRI observed was infested with bugs.¹³⁰

I suspect his bed has vomit in or around the frame and springs which is attracting the bugs— Lawrence Kaplan MD, ScM, FAAP.

Staff told DRI that being separated from Giorgi had caused the mother to become depressed, and that she called the orphanage every day.

On the same visit to the Senaki institution, DRI observed a staff member grasping the hands of a self-abusive teenager, who would hit himself if left unrestrained.

^{xiii} Medical evaluation received through International Medical Support Services who contacted the Senaki pediatrician at DRI’s request.

^{xiv} Bedsores are caused by prolonged pressure on the skin and can be avoided by ensuring that a person is able to leave a bed/crib and be repositioned on a regular basis. Untreated bedsores can lead to the development of sepsis, a life-threatening and rapidly progressing condition when bacteria enters the bloodstream through an open wound and causes organ failure.

^{xv} Pseudonym

Self-abuse is created and exacerbated among children who receive no love and attention...Psychological experts agree that they crave some form of stimulus, so they would rather feel pain than feel nothing. – Karen Green McGowan, RN, CDDN, DRI Expert, President-Elect of the Development Disabilities Nurses Association.

Staff affirmed to DRI that they employed no other therapies for addressing the child's self-abuse except for holding his hands. The staff assured DRI that one of the two staff members in the ward would hold his hands at all times. Upon later returning unannounced to the same room, DRI observed another teenage patient holding the child's hands while the staff members were elsewhere. Another resident provided DRI with a photograph that shows the self-abusive teenager with his hands tied together with what appeared to be rope.

B. Segregation and Abuse of Children and Adults with Disabilities

❖ Community Services Discriminate Against Children with Disabilities in Institutions

Local organizations, with the assistance of UNICEF and international donors, have made important steps forward in promoting foster care, small group homes and day care centers to promote deinstitutionalization of children in Georgia.

Children with disabilities, however, have been largely excluded from deinstitutionalization reforms.

While some children with mild disabilities are benefiting from recently created foster care services for children with disabilities, UNICEF has told DRI that the foster care services were not designed or equipped for children with severe disabilities and that the chances of foster care placement for older children who have been institutionalized for most of their life are "slim to none."¹³¹

Children with disabilities who are not included in foster care reforms are also denied placement in community group homes. UNICEF reports that in recent years the government has supported the creation of 45 small group homes across the country for 8-10 children each. **None are inclusive of children with disabilities, according to the Ministry of Labor, Health and Social Affairs (MoLHSA).**¹³²

Officials from MoLHSA informed DRI that these homes were designed for children without disabilities.¹³³ Any possible future placements of children with disabilities in these group homes will be complicated by the fact that most of the homes are physically inaccessible.

The US Agency for International Development (USAID) funded the construction or renovation of 25 of the 45 group homes.¹³⁴ Despite a 2010 USAID press release announcing that the small group home initiative would “emphasize the inclusion of children with disabilities,”¹³⁵ USAID-financed small group homes in Georgia all exclude persons with disabilities,¹³⁶ and most are physically inaccessible.¹³⁷

We need a certain amount of small group homes for children with disabilities. We don't have any yet. And honestly, we can't find a location in the state budget right now for this.

–Deputy Minister of the Ministry of Health, Labor and Social Affairs (2012)¹³⁸

Small group homes in Georgia are, according to UNICEF, “the last resort for children who cannot be with their families or for whom a foster family is not possible.”¹³⁹ **For Georgia's children with disabilities in orphanages who are prevented from taking advantage of any of the existing community services, lifelong institutionalization remains the only option.**

As of September 2013, according to NGO EveryChild of Georgia, there are approximately 100 children with disabilities in specialized foster care.¹⁴⁰ However, a 2012 Needs Assessment of alternative community services conducted by EveryChild and Children of Georgia (“Needs Assessment report”) showed that the structure of the foster care service system contributes to the exclusion of children with disabilities through several financial disincentives.¹⁴¹

Families fostering children with disabilities receive a 25% increased stipend,^{xvi} but are not eligible for this increased stipend until the child obtains official disability status. Unfortunately, a child cannot get such a determination until the age of 3. This delay leaves children under three continuing to languish in orphanages, according to the Needs Assessment report.¹⁴² A large body of empirical data has shown that children under three are most at risk of long-term impairment from institutionalization.¹⁴³

Additionally, according to the Needs Assessment report, foster parents of children with disabilities are not provided with adaptable equipment such as wheelchairs and are not reimbursed for medical or habilitation expenses related to the child's disability.¹⁴⁴

A positive practice has been the creation of eighteen day care programs^{xvii} serving children with disabilities living with their families. These day care services are critical supports for these families, providing daytime care and education for children; parental support and empowerment; and early intervention therapies for children with disabilities.¹⁴⁵ The Needs Assessment report found, however, that the current capacity of Georgia's day care centers can neither meet the demand for quantity of services, nor meet the demand for regional availability of services.¹⁴⁶

^{xvi} Foster families usually receive 450 Lari (\$272 USD) per month. Those fostering a child with a disability receive 600 Lari (\$360 USD) per month, according to MoHLSA.

^{xvii} As of April 2011, according to the Needs Assessment Report. These centers provide services to children with disabilities living at home, helping prevent institutionalization—but do not serve children who are already in institutions.

The government provides vouchers to families of children with disabilities to pay for day care services. However, First Step of Georgia, an organization in Tbilisi which runs a day care center for children with disabilities, informed DRI that current funding from the government is not sufficient to cover the actual cost of their services and they have to rely on ever-decreasing international donations to cover the gap.¹⁴⁷ The Needs Assessment report found that many day care centers across the country are experiencing financial difficulty.¹⁴⁸

While these services are valuable for children fortunate enough to be residing with parents, day care services do not serve or benefit children with disabilities who are already in institutions.

❖ **Abandonment of Adults with Disabilities**

Any good progress made in supporting the development of children up to the age of 18 may be under threat if they are then required to fend for themselves suddenly and without support—2009 independent Oxford Policy Management evaluation of UNICEF reform strategy¹⁴⁹

In the Republic of Georgia there are three large-scale state-run institutions for adults with disabilities, in addition to two privately-run institutions in rural villages which are funded in part by the government. There are also two 10-person privately-run group homes for adults with disabilities which receive government funding.¹⁵⁰ **During DRI's visits to several of these institutions, investigators observed extensive neglect, an absence of appropriate rehabilitative therapy, and a complete disregard for private and family life—including parents being forcefully separated from their children.**

In December 2009, the Georgian government approved the 2010-2012 National Disability Action Plan. A main objective of the plan included deinstitutionalization of large residential homes and the creation of community-based alternatives.¹⁵¹ **During this period, however, the government instead increased the number of adult institutions in the country**—using approximately \$1 million from U.S. foreign assistance to build/renovate two new long-term institutions for adults with disabilities which are isolated and segregated from the community.^{xviii152}

Indeed, during a February 2010 visit to Georgia by the European Committee for the Prevention of Torture, **investigators noted that there were no existing programs for deinstitutionalization of adults with disabilities.**¹⁵³ In November 2011, the director of Georgia's Coalition on Independent Living reported to DRI that the situation remained stagnant, stating, "We've been waiting for the [National Coordinating] Council [of the action plan] to meet for about 3 years now...Due to the fact that this Council has never met, the disability action plan is not implemented effectively...."¹⁵⁴ As of

^{xviii} The state-run Martkopi institution for adults with disabilities, and the privately-run Temi Special Needs Home for adults with disabilities.

September 2013, no plans exist for the community integration of adults in institutions, according to the MoLSHA.¹⁵⁵

The vast majority of deinstitutionalization reforms are only accessible to children under 18, establishing an arbitrary division in reform beneficiaries.^{xix} In 2012, DRI documented dozens of young adults in their teens and twenties who were transferred away from orphanages to adult institutions where they will stay indefinitely.¹⁵⁶

Activists and government officials agree that there is a significant gap in services to assist in the transition from adolescence to adulthood for children with disabilities.¹⁵⁷ A government official in charge of overseeing state-run institutions informed DRI that if children under state care are deemed to not have skills for independent living when they turn 18, they will be sent to adult institutions.¹⁵⁸

...no one from state or non-state sector is talking about what happens to these children when they turn 18. They are deprived of one of the most important rights: freedom of choice. They have no choice but move to the adult institutions after 18 because they have no education, no professional or social skills to take care of themselves and be competitive in the modern society. –Giorgi Dzeladze, director of the Georgia Coalition for Independent Living (2011)¹⁵⁹

I don't like when 60 or 70 people live together in residential care. It is impossible to develop their personal skills and provide therapy in such kind of places. If we developed small community based services, that would be a better solution. –Director of Social Protection for the Ministry of Labor, Health and Social Affairs (2013)¹⁶⁰

The service of psycho-social rehabilitation was restricted in absolutely all [of Georgia's] institutions. In fact, none of the persons with disabilities is given the opportunity to develop his/her functional abilities and skills of independent living. –2012 Report on the State of Human Rights in Institutions for Persons with Disabilities, Georgia Public Defender's Office¹⁶¹

Investigators from the Council of Europe Committee to Prevent Torture (CPT) noted after a 2010 visit to the Dzevri institution for adults with disabilities that some residents have lived for there for nearly 50 years. The CPT requested information from the government on plans for deinstitutionalization of this population, and additionally requested information about an additional

adult institution it had heard was under construction.¹⁶² The government did not to respond to either of these requests in its official 2011 response.¹⁶³

In September 2012, the Government of Georgia opened the new Martkopi institution for adults with disabilities. Many residents, DRI documented, were young adults who grew up in orphanages and who were excluded from deinstitutionalization efforts when they were minors. The Martkopi institution was built and furnished with United States funding from the Department of Defense and US Agency for International Development.¹⁶⁴

In February of 2013, Georgia's Public Defender's Office released a report on the state of human rights in the country's institutions for persons with disabilities.^{xx} The report documented numerous instances of violence reported by institution residents. In the Dzevri institution for instance, according to the report, residents reported being hit, slapped, and beat with broomsticks when they did not do work ordered by the staff, such as cleaning toilets and cleaning soiled clothing. Other residents reported being beaten for not getting out of bed, and one resident told investigators that one staff member would hit residents who soiled their underwear. The Public Defender Office's report found similar instances of violence in 7 other institutions for children and adults with disabilities throughout the country.¹⁶⁵

in September 2013, the director of the Georgian government's Department of Programs for Social Protection expressed to DRI a desire to downsize the adult institutions, noting that there are many local organizations who are willing to provide community services for adults with disabilities, but reported that there was no money in the state budget to help establish these services.

However, directors of these institutions have stated to DRI their belief that most of the adults in institutions are not capable of full integration in the community, and that the large institutions will remain open for those who they perceive to have the most severe disabilities.¹⁶⁶ International experience has shown that people with even the most severe disabilities can be integrated into the community.^{xxi}

The Martkopi Institution for Adults with Disabilities

The Martkopi Institution for adults with disabilities is a newly reconstructed long-term residential institution, the renovation of which was financed by the United States government. The institution houses 68 adults with intellectual and physical disabilities and is located 40km outside of Georgia's capital city of Tbilisi. The majority of residents are young adults who have grown up in orphanages and transferred to Martkopi as adults. Because they are no longer minors, they will not benefit from

^{xx} Two DRI representatives participated in the investigative team for this report in 2012.

^{xxi} Successful disability reforms have demonstrated that it is feasible and immensely beneficial to bring people with the most severe disabilities into inclusive, small, family-like settings. For example, such as has been accomplished in the United States at Pennsylvania's Pennhurst Institution, Oklahoma's Hissom Memorial Center, and the Robert Wood Johnson Foundation's national self-determination initiatives.

child care reforms. No plans for community integration of adults with disabilities exists—and according to the director of Martkopi, the residents will stay in the institution indefinitely¹⁶⁷.

The construction and furnishing of the Martkopi institution was financed with US foreign aid. The US European Command under the Department of Defense funded \$500,000 for the main reconstruction project, while USAID donated \$100,000 for furniture and equipment.¹⁶⁸ According to USAID, the institution was designed to give residents “as many independent living opportunities as possible.”¹⁶⁹ Based on our observations, DRI finds that the facility is most accurately described as a segregated large-scale institution that was renovated specifically to warehouse persons with disabilities.

The Martkopi facility consists of three floors that sleep approximately 23 men and women per floor, with bedrooms arranged off the hall in a dormitory style. During DRI’s first visit to the institution in February 2012 before it was opened, the director noted that despite the presence of 4 beds in most rooms, that there would actually be only two residents per room. On DRI’s return trip after the institution had opened, DRI documented an average of 4 residents per room, and observed residents who slept on two extra mattresses arranged at the end of one hallway. All bathrooms are communal—as is the single dining room and day room. Residents do not have access to a kitchen. Two floors do contain a small kitchenette with a fridge and hotplate, but DRI did not observe any residents using these facilities.

Those perceived to have the most severe disabilities are kept on the third floor of the institution, including most of the residents in wheelchairs. During a November 2012 visit to the institution, during which DRI was accompanied by the US Ambassador to Georgia, the director informed DRI and the Ambassador that the elevator was broken—and as a result, the residents in wheelchairs living on the third floor could not leave the top floor without assistance— severely limiting their mobility. However, a report by the Georgia Public Defender’s Office (PDO) report released in February 2013, revealed that staff at Martkopi purposefully keep the elevator shut off to keep residents from using it and would only turn the elevator on for emergencies.

The lack of a functioning elevator means that residents with mobility impairments cannot reach the dining room on the first floor for meals without being carried down the stairs, or reach the day-room located on the second floor. Nor can they go outside without assistance. The director reported to DRI that those kept on the third floor, including those in wheelchairs, are fed in their rooms and do not often interact with the other residents.

DRI observed staff spoon-feeding the residents on the third floor with chopped-up meals served in bowls. DRI did not observe any effort to teach the residents independent eating skills.

DRI observed many residents rocking back and forth—a form of self-stimulation often evident in institutionalized persons who are not receiving sufficient attention and rehabilitation. One of these children sat on a mattress in the hallway, rocking back and forth, and tearing small pieces of cotton off the mattress and eating them. When DRI brought this to the attention of staff, the problem was acknowledged but nothing was done to either stop the behavior or address the underlying issue.

During a single shift, there are only thirteen caretakers for all 68 residents.¹⁷⁰ **According to the PDO, during the night shift, there are only three caretakers for the entire institution** and they are often unable to cope with aggressive behavior, resulting in violence against staff and other residents until a psychiatrist arrives to intervene by, in at least some cases, injecting a sedative.¹⁷¹

For those residents who are not assisted to eat in the dining hall and are forced to eat meals in their rooms, the PDO reports that care-givers have to create a “safety-corridor” to hand food to these residents to protect them from aggressive residents who will try to attack them and grab their food.¹⁷² A disturbance on one floor, staff reports, means that care-takers have to leave residents on one floor unattended to assist on other floors.

In case of injury, according to the PDO report, it takes up to an hour for an ambulance to arrive to the relatively isolated institution.¹⁷³

Residents reported to DRI that the only activities people do all day in the institution are knit, sing or listen to music.¹⁷⁴ The director informed DRI that six persons are involved in craft-making, and 30 residents do unpaid cleaning and other housekeeping chores as a form of “work therapy.” Thirty-three of the residents are deprived of their legal capacity and are not able to go outside without supervision, according to the director.

Because residents can become aggressive, there is a staff person during the day who was described to DRI as a “strongman” to restrain residents when they become upset. Staff will sometimes send a resident to the psychiatric hospital for up to 21 days when he or she is aggressive, or refuses to take medication.¹⁷⁵

USAID, which spent \$100,000 refurbishing this institution, described in a letter to DRI the goal of the institution as providing “family-type apartments” for persons with disabilities. In reality, because law prohibits children from living in the institution with their parents, Martkopi is only home to broken families. DRI has documented three couples living in the institution who have been forcefully separated from their children.

DRI interviewed the mother and father of a 10-month-old boy in November 2012. The parents had grown up in various orphanages and upon birth, the child was taken away and placed in the Tbilisi Infant Home. Both parents are desperate to find a way to be with their child—but because they have no support to live in the community, they told DRI, they cannot leave Martkopi. The child is not permitted to live with them in the institution.

I was brought up without a mother, and without a mother’s love, and I don’t want my child to grow up without a mother—Mother in Martkopi whose child has been taken away (2012)

She can independently take care of her child...there is no reason to take her child away from her—Director, Martkopi institution (2012)

The father has secured a cleaning job outside the institution to save money, and the mother has filed legal complaints to protest the revocation of her parental rights. The PDO reports that the mother applied for legal aid from the government and was denied.¹⁷⁶

The Director of Social Protection under the MoLHSA told DRI after our interview with the parents that he would make it a personal mission to re-unite the family. The US Ambassador to Georgia, who accompanied DRI, promised that he would put pressure on the government to find a solution.

In late 2012, the child was placed in foster care with another family. As of September 2013, the family is still separated.¹⁷⁷

The director of Martkopi informed DRI that one person in the institution was placed there only because of her mother's failing health. According to the director, the young adult could have remained at home if the family was provided support.¹⁷⁸

The PDO reports that two other couples have children who are being kept in an orphanage run by the Georgian Orthodox Church. Both couples, the PDO reports, are rarely able to visit their children and are only able to do so with the help of the Martkopi director. Both couples reported to the PDO that it had been several months since they had last seen their children.¹⁷⁹

Another resident had grown up in various orphanages, but was aware that he had a living mother, somewhere. He told DRI that he had several desires: to leave the institution, to obtain a job and an apartment, and to find his mother.

The director informed DRI that she was aware that at least one female resident was subjected to sterilization before arriving at Martkopi.¹⁸⁰

The Temi Special Needs Home for Adults with Disabilities

In the small village of Gremi, 120km east of Tbilisi, the US Department of Defense spent \$300,000 in 2009 on the construction of a new residential institution located inside the Temi Community.¹⁸¹ The Temi Community is a privately run self-sustaining rural commune for socially vulnerable persons, including the poor, orphans, the elderly, and according to its website, "anybody who wishes to join the inclusive community."¹⁸² According to its director, the community previously, but no longer, accepted drug addicts and criminals.

At the ribbon cutting of the new institution for persons with disabilities inside the commune, the Former U.S. Ambassador to Georgia John Bass stated, "The construction of the new wing of the Temi Special Needs Home embodies our continued commitment to improving the lives of one of the most vulnerable groups in any society, children and those with special needs."¹⁸³

There are 100 persons living in the Temi Community, including 50 persons with physical or mental disabilities. The 30 young adult residents (18-30 years old) who are perceived to have severe disabilities live separately from the rest of the commune in the new institution. The institution is built in a similar dormitory style to that of Martkopi, with 4-5 beds per room.¹⁸⁴

Touring the institution, DRI investigators noticed that most of the building was empty. The majority of residents were contained in a single day room. DRI observed that most residents sat quietly, doing nothing or rocking back and forth, many staring into space. A few were extremely excited, and rushed to greet DRI investigators. Caretakers quickly scolded and hurried those residents away.

DRI investigators interviewed a German student who had volunteered in the Temi community for 8 months. According to the student, many of the residents of the institution not permitted to leave the building because of the perceived severity of their disability. A caretaker in the institution confirmed to DRI that approximately 15 residents do not go outside, but are occasionally taken on trips to a church or to the nearby village.

“You can see the deprivation of people,” the student told DRI, regarding the residents labeled as having severe disabilities. ***“It’s challenging because they never get supported....and we have to work with the caretakers who have no professional training.”***¹⁸⁵

The director is aware of the shortcoming of the institutional staffing, reporting to DRI that there is no occupational or physical therapy available, and that the institution can only care for the basic physical needs of their residents with moderate to severe disabilities.¹⁸⁶

❖ Denial of Legal Personhood and Access to Justice

In Georgia’s institutions, adults with disabilities are denied the ability to make any meaningful decisions about their lives by being routinely stripped of their legal capacity and placed in guardianship of the state. Legal capacity deprivation in Georgia entails a near total denial of rights to make any legal decisions about life, including the right to manage finances; to marry and have a family and a private life; to own and inherit property; and to decide on medical care. For persons in institutions, even the most basic decisions about everyday life are restricted. Residents of institutions reported to DRI that they are not allowed to choose when to get up and out of bed, when to eat, or what to do with their day.

According to a report released by the Mental Disability Advocacy Center (MDAC) in 2007, there are approximately 23,000 adults under full guardianship in Georgia.¹⁸⁷ MDAC reports that full guardianship is the only mechanism established under Georgia’s 1997 Civil Code for persons who require assistance in making decisions—there are no mechanisms that allow for partial guardianship based on a functional assessment of a person’s abilities. Under full guardianship, the guardian has complete autonomy to control all aspects of a person’s financial, legal and personal life, and is not required to consult with the person under guardianship, according to MDAC.

For children with disabilities under state care transitioning into adulthood, the process of legal deprivation begins immediately, and is outside of their control. The director of Georgia’s State Care Agency informed DRI that when a child under state care turns 18, he/she is evaluated by social workers and the resulting assessment is sent to a “special board” under the authority of Georgia’s Social Services Agency. The board then decides if the young adult can go to alternative community

services, such as a small group home, or if the child needs long-term institutionalization. It should be noted, however, that the director's explanation of the process to DRI was largely theoretical, as no community-based services for adults with mental disabilities currently exist in Georgia apart from two 10-person group homes, which are already filled to capacity. If a young adult is deemed in need of long-term institutionalization, then the person's legal capacity is automatically deprived with no court involvement, according to the director.¹⁸⁸

In the Martkopi institution for adults with disabilities, DRI documented three couples who have had their children separated from them, and their parental rights have been removed without any judicial review, according to the director of the institution.¹⁸⁹ The director informed DRI that Georgian law mandates that if a parent and child are living in separate institutions, parental status will be automatically revoked.¹⁹⁰

Most residents of institutions cannot afford to hire legal help due to disability pensions being their sole income. The Georgia Public Defender's Office (PDO) has reported that the State Care Agency is responsible for assisting institutionalized persons in execution of their legal rights when necessary and within the agency's competence. The PDO has reported multiple instances where adult residents of institutions for persons with disabilities have been turned down for legal representation by the State Care Agency, including a mother who was seeking to retain her parental rights to her child who was forcefully removed from her without judicial review, simply because she lived in an institution.¹⁹¹

In regard to adults with disabilities who live in the community with full legal capacity, the World Health Organization reports that the only prerequisite in Georgia to begin the process of legal deprivation is for a relative of that person or the hospital administration (if the person is hospitalized) to write a formal request to the courts to declare the person legally incapacitated.¹⁹²

Advocates from the organization Partnership for Equal Rights reported to DRI that it is not uncommon for relatives to request legal deprivation of a relative with a mental disability in order to obtain control of real estate or other financial assets.¹⁹³

DRI interviewed a long-term, or "chronic" patient, Alex,^{xxii} at the Gldani Psychiatric Hospital, a hospital with residential wards for a total of 230 short-term and long-term residents. Alex informed DRI that his uncle applied for guardianship shortly after he entered the hospital seven years ago, and then immediately sold Alex's apartment. Now, he told DRI, he would like to leave the institution but is not allowed to simply because he has nowhere to stay.

We cannot help it if the guardians decide to keep all their money. – Partnership for Equal Rights activist¹⁹⁴

After a deprivation of legal capacity has been requested by relatives or the hospital administration, according to MDAC, the person concerned will be examined by a board consisting of at least three

^{xxii} pseudonym

doctors and a psychologist to assess their capacity to move, communicate, have self-control, and look after himself/herself. MDAC reports that it is not mandatory for the person to be present at the meeting, as Georgian laws provide exceptions for vaguely defined situations when a person is considered “long distance,” or has obstacles in reaching the place of assessment. The person can appeal a decision only within 30 days. MDAC reports that appeal process can be complicated if authorities fail to inform the person of the decision.¹⁹⁵

❖ **Insufficient Oversight and Monitoring**

...there is no legal basis for being able to demand minimum standards for non-state child care facilities, or to monitor their operation. No law specifies fully which child welfare services must be licensed and regulated... The need for licensing and regulating non-state entities, including those of the church, must be emphasized. – Assessment of the Child Welfare Reform Process in Georgia, Oxford Policy Management (2011)¹⁹⁶

The Georgia Public Defender’s Office (PDO) is charged with conducting human rights oversight of places of detention, including institutions for persons with disabilities. In recent years, the PDO has published several powerful and comprehensive monitoring reports on state-run institutions for persons with disabilities. The PDO has not, however, ever conducted monitoring of church-run institutions.

A local children’s rights advocate and a USAID representative reported to DRI in 2013 that they estimate that there could be as many as 1,500 children in residential orphanages run by the Georgian Orthodox Church. It is impossible to know for sure, however, as there has been no independent monitoring or oversight of church-run institutions.

Following its 2010 visit to the Dzevri institutions for adults with disabilities, the European Committee for the Prevention of Torture reported that residents at the institution were not allowed to use contraception—a decision reached due to pressure from the Georgian Orthodox Church.¹⁹⁷ As a result, the Director for Social Protection of the MoLHSA reported to DRI, “12-15” children a year, for several years, were born and placed in a nearby church-run orphanage.¹⁹⁸ The MoLSHA official claims that this practice has now stopped.

According to the director of the Martkopi institution for adults with disabilities, four children of residents of Martkopi have been moved to these church-run orphanages.¹⁹⁹

The government is playing a shell game with these children. —Representative of the Georgia Public Defender’s Office (2013)²⁰⁰

It's trafficking. The real word is trafficking. According to law, children being transferred to church institutions are supposed to be regulated by the state, but they're not. There's no paperwork. Nothing. –Georgian Child Rights Advocate (2013)²⁰¹

It is very political and sensitive. The church is very powerful... We don't even know the exact number of institutions or kids. It is unregulated. –UNICEF-Georgia representative (2013)²⁰²

Children in church-run orphanages have not been included in child-care reforms²⁰³—nor have UNICEF counted them in their tally of institutionalized children in Georgia, which generally refers to children in state-run orphanages.

The absence of information on the number of children in residential institutions run by the church and other private organizations, and on their living conditions, is a serious constraint on the ability of the government to understand what progress is being made nationally on improving the welfare of the child... Without basic information on these other service providers it is impossible to say whether the total number of children in residential care in the country is going up or down. –Assessment of UNICEF's Child Welfare Reform Process in Georgia, Oxford Policy Management.²⁰⁴ (2011)

In the privately-run Temi institution in the village of Gremi, the director reports that the privately-run institution receives between 17,000-18,000 Georgian Lari per month (\$10,000-\$11,000 USD) from the government as a stipend for caring for the 30 young adults in its institution. The director reported to DRI that due to a lack of staff, there is no financial bookkeeping at the institution.²⁰⁵

EveryChild and Children of Georgia's 2012 Needs Assessment reported that monitoring visits to foster families by social workers are inadequate for children with disabilities. The report states that because monitoring visits are required to be announced ahead of time—resulting in monitors not always observing the every-day scenario for the child. A previous experience of conducting unannounced visits to foster families by EveryChild in 2011 found that conditions are often worse if a social worker does not previously announce the visit, including the home's temperature and cleanliness, and the child's hygiene and clothing.²⁰⁶

The organizations also report that the Individual Development Plans which are developed by social workers for child with disabilities in foster care are superficial and address only a child's basic needs, presenting a challenge in both provision of proper care giving and development, as well as effective monitoring of the plan.²⁰⁷

The children who have been most invisible to Georgia's monitoring and oversight bodies, have also been overlooked in Georgia's reform process. Children in church-run and privately-run institutions have not been included in deinstitutionalization reforms—nor has UNICEF counted them in their

quarterly updates on the population of institutionalized children in Georgia, which refer only to children in state-run orphanages.

For children with disabilities to count, they must be counted – at birth, at school and in life. We contribute to their exclusion by failing to gather enough data to inform our decisions. When we fail to count these children, we are failing to help them count for all they should in their societies. —Executive Director of UNICEF²⁰⁸

III. Human Rights Obligations and Strategic Recommendations

The following is a summary of DRI’s findings and analysis of the Republic of Georgia’s obligations to reform under international human rights treaties. DRI has documented violations of human rights under international treaties which Georgia has ratified or acceded to, including the UN [Convention on the Rights of the Child](#) (CRC), the European Convention on Human Rights (ECHR) and the UN [Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment](#) (CAT).

By signing the UN Convention on the Rights of Persons with Disabilities (CRPD), the government of Georgia has committed itself to refrain from acts that defeat the object and purpose of the treaty. The protection against discrimination is one of eight principles underlying the convention, but it has been described as the unifying principle behind the CRPD.²⁰⁹ The broad denial of rights on the basis of disability is core to the definition of discrimination as defined in the CRPD:

“Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.²¹⁰ – Article 2, UN Convention on the Rights of Persons with Disabilities

This report provides evidence of the fact that segregation from society on the basis of disability also entails the denial of a broad deprivation of a person’s ability to exercise all other rights – the right to life (art. 10), right to health (art. 25), right to habilitation and rehabilitation (art. 26), and the right to live in the community with choices equal to

others (art. 19). Georgia's social service systems consistently subject adults and children with disabilities to discrimination by providing them with care in a manner that leads to their segregation from society.

Georgia's segregation of children and adults with disabilities in long-term residential institutions runs counter to the general principles of the CRPD, including: Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; Non-discrimination; Full and effective participation and inclusion in society; and Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.

DRI also includes strategic recommendations consistent with the CRPD and international best practices in order to assist the Republic of Georgia in developing appropriate policies and programs to bring about service system reform and rights enforcement.

A. Right to Health

DRI documented dangerous medical practices and a complete lack of habilitative services in Georgia's orphanages, putting the lives of children at risk, in violation of article 2 of the ECHR, protecting the right to life. At the Tbilisi Infant Home, children with disabilities routinely die because of the denial of life-saving surgeries which are available and affordable in the Republic of Georgia. Article 24 of the CRC states that nations must provide the highest attainable services and facilities to all children and must "strive to ensure that no child is deprived of his or her right of access to such health care services."²¹¹

Article 25 of the CRPD mandates that States "[p]revent discriminatory denial of health care or health services...on the basis of disability." And further, that States provide "services designed to minimize and prevent further disabilities, including among children..."²¹²

The denial of pain medication to children in severe chronic pain in the Tbilisi Infant Home may rise to the level of torture under the UN Convention against Torture. In February 2013, the UN Special Rapporteur on Torture, Juan Méndez, released a report on abuses in healthcare settings that could rise to the level of torture or ill-treatment under international law. Méndez states that when authorities deny pain treatment which, "...condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment."²¹³

Such a determination would require the criminal prosecution of responsible authorities, in accordance with article 7 of the Convention against Torture.

Strategic Recommendations:

1. **The Government of Georgia should create a system of community-based services** across the country for providing healthcare and support for children and adults with disabilities. These services should provide a community resource for families of children and adults with disabilities to access, when needed. Babies and children should be supported to live in families. The Tbilisi Infant Home should be closed—or transformed into a non-residential center for expertise and training.
2. **Children with hydrocephalus should receive immediate and appropriate care** – A monitoring system should be established to guarantee the quality of prognoses of children born with spina bifida and hydrocephalus and to guarantee the provision of appropriate medical intervention within the medically appropriate time frame—typically within 24 hours of birth. Delays in care related to insurance coverage should be eliminated. Georgia’s pre-natal folic acid program to prevent the development of hydrocephalus should be reviewed and strengthened.
3. **Denial of medical care on the basis of disability should be recognized and addressed**– The government of Georgia should establish a system of oversight for to ensure that doctors responsible for turning persons with disabilities away from hospitals or denying them medical care based on a perceived “quality of life,” are held accountable.
4. **Palliative care should be established for children in severe pain** – As recommended by the Special Rapporteur on Torture, the government should assure the availability and accessibility of essential medicines, including opioid analgesics, as part of their minimum obligations under the right to health.

B. Right to Community Integration

International human rights law recognizes a right to community integration for all persons with disabilities. Article 19 of the CRPD recognizes “the equal right of all persons with disabilities to live in the community, with choices equal to others,” and that persons with disabilities should 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.” The CRC mandates that special services must be made available which make it possible for children with disabilities to live in the community.

The government of Georgia, with assistance from local and international organizations, has implemented several important programs to promote community integration of children and to preserve biological families, including: the development of foster care; family-like small group homes as alternatives to large-scale institutions; day care services; early intervention services; mother and infant shelters; and direct material and financial support to vulnerable families. DRI notes that further development of recent child care reforms to be inclusive of all children with

disabilities, as well as the expansion of these services to adults, has enormous potential to completely integrate persons with disabilities in Georgia into the community.

At present, however, a large number of children and adults with disabilities remain institutionalized because of a lack of appropriate community services.

DRI's investigation has documented several populations that are most likely to be denied community integration. These vulnerable populations include infants with severe disabilities and complex medical conditions; children with moderate to severe disabilities who are denied placement in small group homes and for whom existing foster care services are not sufficient; older children who have become "institutionalized" by spending the majority of their life in an orphanage; and adults with disabilities in long-term social care homes and psychiatric hospitals. The Council of Europe Disability Action Plan for 2006-2015 reiterates the obligation for nations to transition away from institutional care, while placing particular stress on the need for specialized services for persons in need of a high level of support, "without departing from a model of community-based services."²¹⁴

The Georgia Public Defenders office reports that the majority of long-term residents in Georgia's psychiatric hospitals have been declared by doctors to be ready for discharge, but are forcefully detained for entire lifetimes due to the lack of community supports. According to the UN Special Rapporteur on Torture, Juan Mendez, "Inappropriate or unnecessary non-consensual institutionalization of individuals may amount to torture or ill-treatment as use of force beyond that which is strictly necessary."²¹⁵

Strategic Recommendations:

1. **The Georgian government should integrate children and adults with disabilities into the community.** Authorities should create a community-based service system to allow people with disabilities to live in the community with choices equal to others. Georgia should also deinstitutionalize children detained in orphanages run by the Georgian Orthodox Church.

As Georgia creates new community services, it should not make the mistake of simply moving from larger to smaller institutions, or new homes within the grounds of existing institutions. Research has shown that, even when they are cleaner and newer, smaller institutions do not confer the benefits of the most integrated and inclusive environments.²¹⁶ In addition to being consistent with the requirements of CRPD articles 19 and 12, social services in a more inclusive environment that reflect choices by participants have been shown to provide better outcomes for persons with disabilities.²¹⁷

2. **New placements of children in institutions should be brought to an end** – As a strategy for bringing about the full realization of the right to protect all people with disabilities from improper segregation from society under article 19, we recommend ending all new placements of children with disabilities in institutions.

The dangers posed by institutionalization of children is well researched and documented, especially for children 0-3 years old. For infants, death is a likely outcome in the Republic of Georgia. If a child does survive an institution, they are likely to have a variety of serious medical problems, speech and language delays attachment disorder, autistic like symptoms, brain and physical growth deficiencies, sensory difficulties, behavioral and social problems. Children growing up in orphanages face a higher risk of abuse and violence than children who reside with families.

Georgia should adopt legislation that will end any new placements of children with disabilities by a specific, publicly declared target date, by which time safe and humane, family-based support should be available for all children with disabilities.

3. **Alternatives services in the community should be enhanced and expanded to serve all children with disabilities** — The capacity of specialized foster care programs should be enhanced to be safe and appropriate for children with moderate to severe disabilities. Child-related variable costs such as medical care not covered by insurance, adaptable equipment and wheelchairs, day care services, early intervention and other necessary supports should be covered by the state budget, separate from foster carer salary.

Georgia's 45 small group home in the community should be inclusive of children with disabilities. A plan should be developed in coordination with civil society organizations and persons with disabilities and their families, to plan for the integration of persons with disabilities into these homes. Additional, fully accessible homes of no more than 6 persons should be created as necessary to deinstitutionalize all children with disabilities as soon as possible.

Special preparatory programs for children with and without disabilities aging out of foster care or small group homes should be developed, focusing on independent living skills, vocational training and job placement programs, as well as social and recreational opportunities. Temporary housing programs should be established for children aging out of childcare services to assist in the transition to adulthood and independent living.

The critical role that day care centers play in supporting families and enabling deinstitutionalization should be recognized by the government. The government should fully support enough of the operational costs of day care centers to ensure a consistent minimum-care standard, available to all families with children with disabilities throughout Georgia.

4. **Alternatives services in the community should be created for adults with disabilities** — Georgia has expanded its segregated system of care for adults with disabilities in recent years, building two new large-scale institutions for adults since 2009. Georgia should immediately plan for the deinstitutionalization of all adults with disabilities by parallel system of services similar to those developed for children. Reforms should include supports to allow for the discharge of long-term residents in psychiatric hospitals — doctors report

that the majority of long-term patients in Georgia’s psychiatric hospitals are ready for discharge, but have no place else to live and no means for securing employment.

Community services for adults can include:

- a. In-Home supports, such as habilitation training specialists, adaptive equipment and medical supplies and services;
- b. Adult foster care, with appropriate supports to care for adults with a range of disability severity.
- c. Adult Companion Programs, where an adult with disabilities shares a home with a companion who is not a service recipient. The companion provides support and transportation services and includes the service recipient in leisure and social activities.
- d. Small group homes for no more than 6 residents in a home-like setting. Group homes should provide services tailored to the individuals, meeting all support needs but allowing flexibility for independent choice-making.

C. Right to Legal Personhood

Article 12 of the CRPD recognizes that persons with disabilities should “enjoy legal capacity on an equal basis with others in all aspects of life,” and that states should “provide access by persons with disabilities to the support they may require in exercising their legal capacity.” In Georgia, full guardianship is the only mechanism available for people who may need only need assistance in making decisions about certain parts of their lives.

In Georgia, persons with disabilities are routinely stripped of their right to make decisions about any aspect of their life—including the right to choose where to live, the right to manage finances, to marry, and to enter into legal contracts.

It is not enough to strive to implement legal capacity reforms within residential institutions. It must be recognized that a key component of article 12 includes the right to decide where to live and to have the agency to exercise that right. Indeed, The UN High Commissioner on Human Rights has confirmed this link between CRPD article 12 and 19, stating that community integration must be legally recognized and enforceable through meaningful choices.²¹⁸ Further, “[t]he key element of any intervention aimed at giving effect to the right to independent living and community inclusion is the *explicit legal recognition* of the right of persons with disabilities to determine where and with whom to live. This recognition should also openly reflect the unlawfulness of arrangements for residential care made against the wishes of a person with disabilities.”²¹⁹

DRI additionally documented several instances where adults with disabilities had their parental rights revoked and children given away to far away orphanages or foster families, without any court involvement.

Article 23 of the UN CRPD states “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. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.”

DRI documented one case of a woman with a disability who was sterilized. Article 23 of the CRPD states: “Persons with disabilities, including children, retain their fertility on an equal basis with others.”

Strategic Recommendations:

- 1. Establish alternatives to full guardianship**— Legal capacity laws should be reformed to reflect supported-decision making models consistent with international standards. Supported decision-making programs should be established, in order to protect the right of people with disabilities to exercise legal capacity and protect against arbitrary detention and to maximize the potential for individuals with disabilities to make meaningful choices. Supported-decision making models, in accordance with CRPD principles, are based on the principle that the person concerned retains all legal capacity and is appointed a support person or support network to assist the person in making decisions. The person concerned should be able to consent to the person(s) who make up his/her support network. Full guardianship should be abolished.
- 2. Integrate persons with disabilities into the community**— Since DRI’s inception in 1993, DRI has interviewed thousands of individuals detained in institutions, as well as staff and government authorities around the world. Our findings show overwhelmingly that persons with disabilities in residential institutions are almost always, *de facto*, stripped of legal capacity. Even in instances where they have limited legal rights, people segregated from society without outside support cannot challenge the authority of institutions and are not able to make meaningful choices about their lives. The fact of living in the institution is of far greater importance than the existence of laws that may or may not conform with the letter of CRPD article 12. ***Until people with disabilities are integrated into the community – and given meaningful options about actual choices to make – any meaningful implementation of article 12 is impossible.***

The very existence of institutions, and the lack of community-based support services (such as housing, physical and mental health care, social services, income support, integrated education, etc.) also has a detrimental impact on the larger number of people with disabilities who live in the community. In the absence of such community-based support,

people with disabilities live precarious lives. As a practical matter, when meaningful or dignified choices are unavailable, it matters little what the law says about legal rights to exercise such choice. There is also a much broader, less visible, and more insidious problem faced by people with disabilities. Every individual with a disability who challenges established authorities – be they governments, health care providers, social services agencies, or members of their own families – is faced with the risk of being relegated to the institution. This creates a powerful chilling effect on the exercise of meaningful choice or the exercise of legal rights. People with intellectual and psychosocial disabilities are at particularly high risk for such coercion and abuse. Until a range of community-based support systems are created, as required by CRPD article 19, a country cannot be said to be comply with CRPD article 12.

- 3. Abolish state regulations that forcibly separate families without judicial review—** Georgia’s regulations mandating the loss of parental rights if both the child and the parents are in an institution, should be revoked. Further, temporary family shelters should be created to allow for reunification on institutionalized parents with their children. Mother-and-baby shelters are not sufficient—as they may force mothers to choose between their child and their spouse. Consistent with CRPD standards, no child should be separated from his/her parents, based on the disability of either.

D. Human Rights Oversight

Article 16 of the CRPD requires governments to create independent oversight mechanisms to protect against exploitation, violence and abuses. These oversight mechanisms are important to protect children and adults in community-based services and foster care as well as in institutions. Safeguards and oversight mechanisms should be established to protect the rights of children and adults detained in institutions or receiving support from community programs.

Privately-run and church-run institutions are not subject to human rights monitoring in Georgia. Local advocacy group Children of Georgia and EveryChild report that monitoring of alternative community services in Georgia is inadequate.

As required by CRPD article 16(2), oversight mechanisms should be age, gender, and disability sensitive.

Strategic Recommendations

- 1. A registry of children in institutions and in alternative services should be created—** Such a registry should include children in church or privately-run institutions. Also, a system for tracking admissions, discharges, and transfers of children and adults at and between institutions or from institutions to other placements should be

created, so that they cannot disappear from society; information about the total number and characteristics of persons receiving services should be published (this will also greatly assist in planning for improved services and reform).

- 2. Monitoring and oversight systems should operate independently of the social service system.**
- 3. Grievance and complaint procedures should be established—** Such procedures should be accessible to people receiving services or to their personal representatives that may be appointed by such individuals. The system must ensure a fair and impartial investigation into complaints in a manner that protects against reprisals. One model is to create an independent ombudsman with responsibility for managing the grievance/complaint function; access to legal or non-legal advocates should be available when other means of resolving complaints prove unsuccessful.
- 4. Develop a process for independent, professional and thorough investigations of abuse—** An efficient system should be created to allow for thorough investigations and monitoring of all reports of physical and sexual abuse, as well as for monitoring and following up on serious injuries, including injuries of unknown origin, illness, and all deaths.
- 5. All information about rights, grievance procedures, and advocacy services should be accessible and appropriate for people with physical, sensory, or mental disabilities.**
- 6. Independent oversight bodies should be empowered to conduct regular, unannounced visits to facilities and programs.**
- 7. Specialized age and gender specific programs should be established—** these programs should be sensitive to the particular concerns of children and women with disabilities; services should be “trauma-informed” and sensitive to the needs of survivors of abuse.
- 8. Reports of findings of oversight bodies should be made public.**
- 9. People with disabilities and their representative organizations should receive training and funding to participate in independent monitoring programs—** To ensure stakeholder inclusion, programs should especially reach out to people with specific kinds of disabilities served by particular programs.
- 10. The mandate of Georgia’s Public Defender’s Office should be expanded to include human rights monitoring of privately-run and church-run institutions.**

IV. Recommendations to International Donors

Article 32 of the CPRD requires that states take “appropriate and effective measures” to ensure that international funding supports the purpose and objectives of the Convention, including the right to “living independently and being included in the community” (article 19).

The US government spent nearly \$1 million to construct new long-term institutions for adults in the Republic of Georgia, including the Martkopi institution, a facility for 75 adults with disabilities located in a remote area 40km outside Tbilisi; and the Temi Community Institution for 30 adults with disabilities in the rural village of Gremi. The US European Command donated \$800,000 for the main construction projects, and USAID donated \$100,000 for furniture and equipment.

Additionally, from 2010-2012, The US Agency for International Development (USAID) financed the construction of 45 small group homes in the community to help enable deinstitutionalization of Georgia’s orphanages. Despite promising in a press release that the small group home initiative would “emphasize the inclusion of children with disabilities,” USAID-financed small group homes in Georgia all exclude persons with disabilities, and most are physically inaccessible.

The USAID disability policy recognizes: “In many countries, individuals with disabilities have been ‘warehoused’ in abysmal conditions with total disrespect for their rights. Those rights must be respected.” During a three-year period, in which USAID disbursed approximately \$500 million in assistance, the United States government played a role in refurbishing and supporting Georgia’s orphanages and adult institutions.

DRI documented dozens of young adults who aged out of Georgia’s orphanages, and have been sent to long-term institutions built by the United States. This use of international development funding in a nation with a stated interest to end institutionalization, represents a significant misuse of United States policy and funding.

The United States recognizes the rights for its own citizens with disabilities to live as part of society, and should ensure that US assistance programs deliver no less to this most vulnerable population in other countries. For a smaller investment than the United States made in funding segregated institutions in the Republic of Georgia, this situation can be corrected, and the lives of people with disabilities can be spared. Most important, the lessons learned from Georgia can be used to develop models and establish guidelines to ensure that, in the future, the United States government can respond more appropriately.

Strategic Recommendations:

1. **New investments in infrastructure or building of institutions should be avoided** – If institutions are unsafe, then immediate, life-saving measures are essential. Major capital investments in new infrastructure, however, cannot be justified. Instead, governments

should provide the support necessary for transfer of individuals to safe environments in the community. Major new building programs on the grounds of institutions that keep people segregated from society are not consistent with CRPD article 19.

International experience has demonstrated the dangers of continuing to invest in institutions. As described by Save the Children: “[t]he 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.”²²⁰

2. **Create a plan and build capacity for the community integration of Martkopi and Temi Community Institution residents** – The 68 individuals detained in Martkopi and the 30 in the Temi Community Institution were most directly affected by US government programs. US government authorities should work closely with the government of Georgia to devise a plan for the community integration of this population. The institutions should be immediately declared “short term facilities intended only to keep people safe and healthy until community homes are made ready for them.” This would also serve as a model for beneficiaries who age out of the services established by the childcare reforms.
3. **Creation of human rights safeguards within development agendas** – As a general rule, the United States should not fund programs for people with disabilities without ensuring that basic rights and services will be protected within them. In the United States, federal law requires that human rights oversight mechanisms exist to monitor and protect rights for all people detained in institutions. Article 16 of the UN Convention on the Rights of Persons with Disabilities similarly requires all governments to create oversight and enforcement mechanisms to protect against violence, exploitation and abuse (including age and gender specific mechanisms) for people with disabilities in institutions and community programs.
4. **Children and adults with severe disabilities must be included in model programs**— Without the inclusion of persons with severe disabilities, model programs will not accurately reflect the real challenges and full range of services needed to create effective community integration for the current population in Georgia’s institutions. Model programs that start with non-disabled children may be misleading, because they may result in an underestimate of the cost of community integration. Programs demonstrating that children and adults with severe disabilities can be integrated into the community are most useful to the development of new policies and a new political consensus for reform because they prove that children with less severe or no disabilities can be similarly integrated.
5. **Creation of policy guidance for international donors** – The USAID Disability Policy calls for community integration and full participation in society of people with disabilities, but it does not provide guidance to USAID missions on the proper response to children and adults detained in institutions. USAID should update its disability policy to reflect the right to deinstitutionalization and the responsibility of international aid in pursuing its realization.

The Department of Defense and US State Department do not have disability policies, and should begin the process of establishing guidelines to protect the human rights of persons with disabilities in their international programs.

A. Global Implications

DRI's findings in Georgia provide lessons to international development agencies and reformers on a global level. Implementation of the CRPD articles 19 and 23 require international donors to shift away from supporting institutions to helping governments create the community based support systems necessary to keep children with disabilities with their families. For children who are segregated from society in institutions, immediate support is needed to create the community-based services necessary to allow for community integration. In its annual "State of the World's Children Report," UNICEF took a strong stand against orphanages in recommending that governments around the world "end institutionalization."²²¹ UNICEF and other international development agencies deserve credit for supporting the reform of service systems necessary to close down institutions. But the lessons of Georgia are clear: it is both discriminatory and dangerous to leave out children with disabilities from these reform programs. It is neither legal or practical to deinstitutionalized the non-disabled first and come back for children with disabilities later. As this report shows, later may never come. Funding and political support for reforms may be fleeting, and children with disabilities can easily be left behind once the needs of non-disabled children from institutions are met.

A global effort that addresses the problem of segregation and protects the right to community living for both disabled and non-disabled children is urgently needed. According to UNICEF, there are *at least* 8 million children in institutions around the world.²²² International development agencies and private charities should be part of the solution. Unfortunately, in much of the world, they perpetuate the problem of segregation for children with and without disabilities. International aid agencies, churches and governments 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.²²³

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.²²⁴ The EU Expert Group on Transition from Institutional to Community Based Care 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."²²⁵

It is important to recognize the dangers of well-meaning efforts to fix up institutions. 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.²²⁶ 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.²²⁷

While many governments have long had policies against raising children in congregate care, there have also been holdouts throughout the world. Some sources have observed that the world population of orphanage continues to rise, mainly in developing countries.²²⁸ Yet international development organizations are beginning to change.²²⁹ Several international and faith-based charitable organizations are shifting their approach from investing in orphanages to investing in families²³⁰, which require less money to support a child than an institution does.²³¹ But many well-intentioned but misguided donors continue to fund the construction, renovation, furnishing and staffing of orphanages around the world.²³² The evidence is vast and overwhelming: institutions are dangerous.²³³

After DRI documented the use of US government funding to build and renovate segregated institutions for persons with disabilities in Georgia, the US Senate Committee on Appropriations expressed concern that:

...[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. The Committee further directs USAID to work with Georgian officials, service providers, and disabled people's organizations to develop and implement a plan for the community integration of children and adults with disabilities who are in institutional settings. –US Senate Committee on Appropriations Report to accompany the 2012 Foreign Appropriations Bill (2012)²³⁴

It has been US government policy for over a century not to raise children in congregate settings.²³⁵ The Americans with Disabilities Act recognizes that it is a form of discrimination to segregate people with disabilities from society who are capable of living in the community.²³⁶ The United States should ensure that US assistance programs deliver no less to this most vulnerable population in other countries.

Article 32 of the UN Convention on the Rights of Persons with Disabilities mandates that international development programs are inclusive of persons with disabilities and promote the objectives of the convention,²³⁷ including article 19 which recognizes the “***...equal right of all persons with disabilities to live in the community, with choices equal to others...***”²³⁸

The lessons learned from Georgia should be used by international development agencies worldwide 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.

V. Appendix A: Clinical Evaluation by Dr. Lawrence Kaplan

**Clinical Evaluation of Children with Complex Special Health Care Needs
Residing in the Tbilisi Infant House, the Senaki Institution for Children with Disabilities,
And the Makhinauri Infant House in the Republic of Georgia
June 25—29, 2012**

Report submitted to Disability Rights International
Washington, DC, USA

August 24, 2012

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Executive Summary

During the period of June 25 to June 29, 2012, as a member of a three person team from Disability Rights International (DRI), I participated in a series of site visits to four facilities that care for children and adults with disabilities in the Republic of Georgia. This consultation was at the request of the Public Defender of Georgia, office of the Ombudsman in an effort to better understand the state of health and well being of persons ages birth to late adulthood whose collective lifespan is represented by each of these State run institutions.

The facilities included the Tbilisi Infant House (TIH) in Tbilisi, the Dzeri Institutions for adults with disabilities in Kutasi, the Senaki Institution for Children with Disabilities, Senaki, and the Makhinauri Infant House in Batumi. This report focuses on findings and recommendations concerning the Tbilisi Infant House, Senaki, and Makhinauri.

Particular focus was directed to 20 children residing in the Tbilisi Infant House, among who were seven (7) children with *congenital and acquired hydrocephalus* whose health and well-being was of particular concern to staff of both the Office of Ombudsman and leadership from Disability Rights International. For these children I personally oversaw the systematic chart review and direct clinical examination each child, working closely with physician staff affiliated with TIH.

Methodology ranged from comprehensive clinical evaluation, to selected consultative assessment of children for whom our hosts had special concern or who during the site visits individual, appeared to have significant acute and chronic health and developmental needs.

At the Tbilisi Infant House clinical acuity ranged from stable chronic health status to situations of advanced morbidity and life-threatening illness. Seven (7) children with a history of or direct clinical evidence of hydrocephalus were identified and examined. Two of these children were medically unstable, one near death, and the majority of others had advanced untreated hydrocephalus for which I found evidence of significant complications directly related to earlier decisions to not initially treat their hydrocephalus.

The majority of all 20 children at TIH had cerebral palsy including those with hydrocephalus, two had possible recognizable malformation syndromes, and one was medically healthy but developmentally delayed and possibly deaf.

Care plans reflected an uncertain combination of decisions that had been made by referring institutions or providers prior to children's entry at TIH, and not changed, or interventions typically carried out in similar facilities which unlike TIH are equivalent to skilled nursing facilities or specialty care hospitals. Despite evidence of caring and compassionate staff there was a striking absence of habilitative resources which would be requisite for the health and well being of the range of needs these children have.

At Senaki and Makhinauri Infant House, medically complex children in residence were older than those in TIH but still reflected the range of disabilities seen at TIH with the exception of children with hydrocephalus in which no children with hydrocephalus and or spina bifida were seen suggesting that this group of children is unique to TIH or do not survive their stay at TIH.

Two children at Sanaki were of special concern, one of whom was a 10 year old child with cerebral palsy whom this consultant felt had protein-calorie malnutrition and a body habitus more underdeveloped than what would be explained by his neurologic disease. This child raised concerns regarding how food is prepared and administered to the more fragile children at Sanaki.

Finally, I conclude that there are *three critical topics and themes* that require further priority attention by the Office of the Public Defender and the Ministry of Health. These include:

1. The defined vs. the perceived role of the Tbilisi Infant House in the continuum of care for children and adults with disabilities in the Republic of Georgia needs to be reconciled immediately. The question must be asked if this facility is being utilized by some, including some medical specialists as a hospice care facility as opposed to a skilled care facility that prepares children for foster care or adoption or for further outplacement. Is this in practice, what is occurring for children with particular diagnoses, and does the facility management and staff realize and understand this? In case, resources, staffing, training, and communication with nearby health care facilities is significantly lacking to serve the function of a long term care.

2. In order to change or possibly close the Tbilisi Infant House a National system of community based and family centered early intervention system and clinical resource centers/clinics must be created that provides continuity of care and support to children living in their communities.

3. There must be a renewed commitment to the deinstitutionalization of residential facilities throughout the Republic of Georgia and a shift to a model that helps families share in the care of their children and young adults with disabilities instead of encouraging them to abandon family centered care. This must include a rethinking of the form and function of facilities currently used as residences such as TIH to potentially become community based outpatient clinics for persons with disabilities.

Introduction

As the pediatrician guest/member of the June, 2012 contingent from Disability Rights International hosted by the Office of the Ombudsman, to visit the Republic of Georgia, I was grateful to be charged with the task of providing DRI and the Ombudsman with a *new kind of knowledge base* concerning children with disabilities who currently live in any one of three institutional facilities. Rather than observe groups in their resident surroundings, and base conclusions on informed impressions, my task was to review in as much detail possible, the individual medical and developmental histories of a targeted group of children, to oversee direct clinical examination of these children, and to formulate a clinical database which can serve to inform discussions regarding how best to serve persons with disabilities and special needs in the Republic of Georgia.

The methodology to do this was piloted in January, 1992 at a State-run facility for children with disabilities in Kingston Jamaica under the auspices of Americares and the Pan American Health Organization (PAHO). That methodology and lessons learned from the experience has been refined for the purpose of this project. Using background and training in Neurology, Genetics, and Child Development, and nearly 30 years overseeing academic medical center clinics for the evaluation and care of children with special needs, my charge was to learn as much as possible about each of the 20 children in residence at the Tbilisi Infant House, in Tbilisi, Georgia presently considered the most medically fragile children in this facility, and to prepare a database respectful of individual's confidentiality which can be referred to for further consideration and discussion.

In addition, Disability Rights International in collaboration with the Public Defender of Georgia and the Office of the Ombudsman has grown especially concerned about the fate of a particular group of children living at TIH who appear to have a higher rate of neonatal, infant, and toddler deaths than other residents, the reason for which has been unclear. Broadly defined this is a group of 11 children 6 of whom have died in the past year, who have congenital or acquired hydrocephalus with or without spina bifida.

Because there appears to also be an association suggested between their deaths, and an emerging theme that few if any were ever treated for their hydrocephalus, rather than review reports or rely only on interview data, these clinical assessments were intended to provide a more detailed insight into both history and current clinical status, possibly providing valuable information that might impact questions of best practice in the care of persons with disabilities, and possibly issues of human rights of disabled persons.

The intensive work in this project was devoted over two days to children based in the infant hall of Tbilisi Infant House, but modifications of the approach were employed also at the following other facilities throughout Georgia:

- Dzeri Institutions for adults with disabilities in Kutasi,
- Senaki Institution for Children with Disabilities, Senaki, and
- Makhinhauri Infant House in Batumi.

This report focuses on findings and recommendations concerning principally, the Tbilisi Infant House, and secondarily, Senaki, and Makhinhauri, but not Dzeri. It should be noted, however that these facilities currently represent an established continuum of care in Georgia for the country's most fragile disabled persons. As such, children typically begin their life journey not necessarily at home with a family but in the Tbilisi Infant House, "graduate" at approximately six years of age to Senaki or Senaki, and very typically, as they grow into adulthood, spend the rest of their lives at Dzeri or other similar institutions for adults throughout Georgia.

Descriptions of each of these facilities, their staffing, and programs will be discussed elsewhere in this report.

I wish to thank Ms. Ana Arganashvili and the NPM Monitoring team as well as Eric Mathews, and the senior leadership team from Disability Rights International for this opportunity to assist DRI and the Government of Georgia in this important effort. I am grateful to have been a part of the team and to work on behalf of persons with disabilities in the Republic of Georgia.

Methodology employed at TIH

As a guest of the Government of Georgia, but not as a licensed practicing physician in this host country, I elected to approach this project through collaboration with physicians who are assigned to the regular medical staff of TIH. I wish to express my gratitude to each of them who helped turn this consultation into a team effort with elements of informal continuing education added to the process.

Ms. Ana Arganashvili, the representative from the Ombudsman hosting the team served for two days (June 25-26, 2012) as medical translator.

20 children were identified for this review. The TIH records were collected for review prior to examining the child. The chart review was in the form of a structured interview based on the **Disability Assessment Tool (DAT)** (©, 2012, Lawrence C. Kaplan) which included key demographic information, past medical, surgical, and hospital history, and where possible a disability-focused review of systems. (Appendix I).

A unique identifier number was assigned to each child evaluated in the sequence 001-020. For purposes of this summary report, the gender of each child was added after the unique identifier number. Ms. Arganashvili prepared a separate copy of the demographics page of the Disability Assessment Tool containing the full name of each child, to be kept in confidence in the Office of the Ombudsman.

The DAT was completed as fully as possible for each child through group review of the TIH records. This was conducted in part as a question and answer exercise similar to the format used in hospital teaching rounds in order to seek information which may not necessarily be immediately evident.

After the history was documented, the child was examined by one of the TIH physicians and observed by myself. Components of the physical examination included a general pediatric examination, obtaining of weight, height, and head circumference, a cardiovascular screening examination, extremity examination, and complete neurologic exam. In some cases, the child's circumstance limited the extent to which components of the physical examination could be completed, and in some cases vital signs including head circumference were not obtained.

The physical examination was conducted in the same collaborative fashion used in reviewing the history, and often I would request the examining physician to perform a specific physical examination activity as we discussed with translation findings in real time.

At the beginning of the examination and after its completion, I photographed each child evaluated and applied the same unique identifier to the photo log to enable me to match photographs with other documentation. Some photographs are missing in the final data display or the photographs were not obtained with flash. This was because some children were at risk or had seizures, and photic stimulation by a flash could cause seizures to occur. In other instances, it was felt that the child was under too much stress to undergo additional activities such as having a photograph performed.

During the examination, I voice recorded the findings of the physical examination into a hand-held digital voice recorder, and identified dictated entries by the unique identifier number used in the DAT. At the completion of the physical examination, I added some formulation notes to the dictation and discussed the child further with the medical staff participants.

Data assembly

In the text of this report (Results, see Appendix I) individual database pages were assembled from the following elements:

- Direct written transcription of the dictation for each child evaluated containing “step by step” details of the physical examination performed.
- Completion of a modified version of the KIDDaat ©, 2012 which was designed to determine complexity and severity of a wide range of disabilities. For this purpose, it provides a more detailed set of descriptors of the scope and degree of each child’s health and development (Appendix II)
- Completed responses to various “domains” which reflect diagnosis, diagnostic formulation, immediate interventions perceived and needed, ongoing chronic care recommendations, and other outcome variables.
- Narrative summary of the child’s salient points from the history and a summary of my formulations concerning each child.

A file therefore exists for each of the 20 children evaluated on June 25 and June 26, 2012 (Appendix III). In addition, individual photographs of each of the children seen (some exceptions as noted) are attached as JPEG files (Appendix IV)

Summary data referenced and discussed elsewhere in this report are all derived from these twenty child-specific databases.

In many cases, children will have been found to have dual diagnoses (two or more diagnoses including a primary diagnosis. For example, a child with advanced hydrocephalus can also have cerebral palsy as a direct result of compression and possibly damage to the motor cortex which then results in the clinical stigmata of cerebral palsy---spasticity, weakness, and hyper reflexia. In this case the increased intracranial pressure secondary to hydrocephalus can cause the child to also have cerebral palsy.

Methodology employed at Dzeri Institutions for adults with disabilities in Kutasi, Senaki Institution for Children with Disabilities, Senaki, and Makhinhauri Infant House in Batumi.

At these sites, the team toured the facility together and as a group observed each resident together. When there was a question raised about a particular child, or if I visually identified a sign or symptom of concern needing further evaluation, I photographed the child in question, then requested the unit Head Nurse or on duty physician to tell me more about the child.

Using the same unique identifier sequence, I then dictated a summary note and transcribed that information into a secure ledger that was given to the Ombudsman.

With one exception, this data is not included in this report, but it contributes to some of the conclusions made from this visit.

Results of evaluations conducted at the Tbilisi Infant House (TIH)

20 children were evaluated over two consecutive days. 18 resided in the main Tbilisi Infant House facility; two lived in the Mother and Infant Shelter (# 016, #017).

General Demographics

Table 1. Gender

Male	12
Female	8
Total	20

The average age of residents reflects the general policy for placement of children in TIH who are between the ages of birth to 6 years old. One child’s range was outside this range, the reason for which was not clear.

Table 2. Resident Age

Birth to 6 months	0
6 months to 1 year	3
1 to 2 years	7
2 to 3 years	5
3-4 years	1
4-5 years	1
5-6 years	2
6-7 years	0
7-8 years	1
Average age	32.5 months (2 years, 9 mo)
Age range	7 months to 8 years

Primary Diagnoses

Each child evaluated carried a series of identifying diagnoses ranging from one to six in number. For the purpose of this report, this primary diagnosis list was modified following our clinical evaluations to reflect new findings or revisions of existing diagnosis. Therefore it was possible for any one child to have a number of primary diagnoses consisting of various combinations of diagnoses with varying frequencies. While not necessarily correlated with complexity, we found that children who were clinically more complex or unstable also had combinations of primary diagnoses that occurred with higher frequencies in this facility. For example, a child with hydrocephalus with spastic quadriplegic cerebral palsy and seizures was typically more Medically complex than other children. This was not necessarily a “rule” since it might be the case that a child with less frequent hypertension and an infected ventriculoperitoneal shunt would be medical unstable and needing acute care. A summary of the primary diagnoses is presented in Table 3.

Table 3. Primary diagnoses in descending order of frequency

Hydrocephalus	7	Electrolyte disorder	1
Global developmental delay	7	Traumatic endotrach intubation	1
Spastic quadriplegic cerebral palsy	5	Chronic gagging and vomiting	1
Seizure disorder/epilepsy	5	Anophthalmia	1
Microcephaly	3	Cleft lip/cleft palate	1
Scoliosis	2	Small for gestational age	1
Hypotonia	2	Craniofacial malformation	1
Hypoxic-ischemic encephalopathy	2	Congenital heart disease	1
Porencephaly/porencephalic cysts	2	Hemiplegic cerebral palsy	1
Spina bifida	1	Malformation syndrome, nos	1
Paraplegic cerebral palsy	1	Developmental delay	2
Infected ventriculoperitoneal shunt synd.	1	Intracranial hemorrhage	1
Intellectual disability	1	Cortical blindness	1
Hypoplasia of the corpus callosum	1	Sensorineural hearing loss	1
Birth trauma	1	Hypertension	1
Loss of consciousness	1	Gastroesophageal reflux	1
History of sepsis	1	Cutis marmorata	1
Hypospadias	1	Nystagmus	1
Hypertonia	1	Facial nerve palsy	1
Neurologic decompensation	1	Posterior encephalocele	1
Nutritional insufficiency	1	Pulmonary insufficiency	1
Prematurity (< 25 weeks)	1		

The *five leading diagnoses* listed and highlighted in yellow as final diagnoses (“Center Diagnoses”) were:

- Hydrocephalus 7
- Global developmental delay 7
- Spastic quadriplegic cerebral palsy 5
- Seizure disorder/epilepsy 5
- Microcephaly 3

Etiologies reflected in the “Diagnostic Formulations”

At the completion of each child’s assessment, a determination was made as to the most likely **general cause** of the child’s disability derived from both available history and findings from the clinical examination. It should be noted that for the purposes of this evaluation, we assumed that multiple outcomes (e.g. cerebral palsy, seizures, and respiratory insufficiency) in any given individual can be diverse and seemingly unconnected, and yet may derive from a single causative process. These data from twenty children evaluated are presented in Table 4.

Table 4. Diagnostic Formulations

Formulation	Number of children who met this formulation. N=20
A congenital alteration of normal morphogenesis including possible genetic abnormalities	10
Pre or post natal disruption of otherwise normal health and development by illness, trauma, toxins, or by combined effects	12 (a)
Child’s condition represents the effect of harmful environmental factors on health and development	0

Two children were thought to possibly meet criteria in both statements A and B.

Functional Status

At the completion of each child’s evaluation, a number of specific observations were documented about the child with respect to the following variables:

- Development-Behavior
- Functional-adaptive
- The physical examination findings
- Assessment of comfort and pain (using the Wong-Baker Faces Pain Rating Scale)

This attempts to present a *basic* picture of what the child is able and unable to do, and whether he/she is experiencing pain or discomfort. Not having any abilities/capabilities identified means that those particular variables were not felt to be possible for the child at that day and time, and thus in the worst case scenario, a score would be *zero*. The more variables a child appears to be able to do, the higher the score.

Tables 5-6. summarize the Functional Status findings that were made for the group of 20 children evaluated. Please refer to each child’s individual Summary for more child-specific detail.

Table 5. Developmental-Behavioral functions

The number of children found to have 0 to 7 Developmental-Behavioral skills considered as being requisite to their health and well being.

0	1	2	3	4	5	6	7
10	0	2	2	0	0	1	4

These data indicate that 50% of the children examined were unable to do ALL of the following: seek joint attention, reciprocate socially, smile socially, and sit unassisted, stand unassisted, crawl, or walk.

Table 6. Functional-Adaptive functions

The number of children found to have 0 to 8 Functional-Adaptive skills Considered as being requisite to their health and well being

0	1	2	3	4	5	6	7	8
8	2	3	2	2	2	0	0	2

These data indicate that 38% of the children examined were unable to do ALL of the following: see, hear, communicate, have communicative intent, eat by mouth, self-feed, urinate in a toilet, defecate in a toilet.

Interventional Formulations

At the completion of each child’s evaluation, a number of specific recommendations for ongoing care were made using a structured set of common best practice interventions. Please see Appendix I for the worksheet used to assemble these recommendations.

The interventional recommendations were based on five separate domains. These included

- Immediate necessary health care intervention
- Surgical intervention
- Chronic healthcare maintenance

The intent was to list interventions we feel represent minimal considerations to assure improved or stable health for each child evaluated. The choices made in formulating these interventional recommendations were based on the assumption that optimal quality of life within any care facility depends on being able to assure that minimal resources exist to prevent further disability eliminate pain and discomfort, assure adequate nutrition can be delivered to each child, and corrective medical or surgical interventions are carried out.

Tables 7--10. summarize the structured recommendations that were made for the group of 20 children evaluated. Please refer to each child’s individual Summary for more child-specific detail.

Table 7. Health care interventions needed immediately

The number of children identified as needing a total of 0 to 14 immediate health care interventions

0	1	2	3	4	5	6	7	8	9	10	11	12	13	14
2	2	4	0	1	0	1	3	6	0	1	0	0	0	0

These data indicate a range of interventions that were considered critically important to carry out to address the health of the children evaluated. Among these included seizure management (2), nutritional intervention (2), and six children required, for example, eight (8) immediate interventions.

Table 8. Surgical interventions needed

The number of children identified as needing a total of 0 to 13 surgical interventions

0	1	2	3	4	5	6	7	8	9	10	11	12	13
6	7	3	1	1	0	0	0	0	0	0	0	0	0

These data indicate a range of surgical interventions were considered important for the children and that 6 out of 20 children needed no surgical assistance, 7 needed one intervention, and three needed two procedures.

Table 9. Chronic health care maintenance needed

The number of children identified as needing a total of 0 to 18 chronic health care interventions

0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1	1	0	0	0	0	5	0	2	3	0	3	3	1	1	0	0	0	0

These data indicate again a range of chronic care maintenance interventions were identified as needed for the children; for example only one child was felt to need no new chronic care supports, and five children needed six of the fourteen best practice services considered important for health and well-being.

Table 10. The degree to which the children evaluated experience pain and discomfort.

How many children were found to have pain or discomfort ranging from an intensity level of “0” to “10” on the Wong-Baker Pain Scale?

0	1	2	3	4	5	6	7	8	9	10
5	0	3	3	4	0	4	0	2	0	0

These data present an important observation that the various health and developmental challenges the examined children have are not without pain and discomfort and while 5 of the 20 children appear to be comfortable there is a wide enough distribution across the ten levels of pain and discomfort to suggest that attention to the question of pain must be a priority for this group of children. For example, 4 of 20 children have a moderate degree of chronic discomfort, and this could range from joint and hip pain to headache for increased intracranial pressure, to muscle spasm related to spasticity and cerebral palsy.

Children with hydrocephalus and neural tube defects

A specific charge to the Disability Rights International Team by the Office of the Ombudsman was to gain a better understanding of the status of children living in the Tbilisi Infant House between the months of February 2011 and June, 25, 2011. Concern was raised that there was a disproportionately higher number of children with congenital or acquired hydrocephalus,

(including those with hydrocephalus and other nervous system malformations) in residence at the facility.

Furthermore, the Office of the Ombudsman was investigating and continues to investigate reports of six (6) deaths of children from TIH with hydrocephalus all of which had occurred during that five month period. We were aware of a total of 11 children with hydrocephalus living at TIH since February, 2011. Six (6) of these originally identified children are now deceased. All five (5) survivors of this group of 11 children were evaluated by our team on June 25, and 26, 2012. One of these children was identified and evaluated at TIH following his return to the facility, and a 7th child whose earliest records reported as having “hydrocephalus,” did not have compelling evidence for active hydrocephalus at the time of these evaluations.

Thus, for the purpose of this discussion we identified a total of *seven (7) children* at TIH in residence at the time of our visit who met any of the following clinical criteria as having disorders involving hydrocephalus:

- ***Congenital hydrocephalus***---obstruction of cerebral spinal fluid flow between the lateral and third ventricles present at birth, and presumably due to a malformation of the central nervous system. This can therefore include children with spina bifida, one major component of which is congenital hydrocephalus in over 86% of cases.
- ***Acquired hydrocephalus***---obstruction of cerebral spinal fluid anywhere along the brain’s route of spinal fluid flow, secondary to an insult or injury to otherwise normal central nervous system. Examples can include intracranial hemorrhage with resultant scarring and obstruction to cerebrospinal fluid flow, and encephalitis/meningitis resulting in similar scarring due to bacterial and/or viral infection of the brain.
- **Mixed pattern hydrocephalus**---resulting from a combination of congenital influences on the developing brain associated with further injury to the brain itself.

Children meeting these criteria therefore comprised 33% of the entire group of children we were asked to evaluate.

Identified children included:

1. A 1 year 3 month old female (**#001**) with congenital hydrocephalus associated with L 4-5 spina bifida, paraplegia (cerebral palsy), status post placement of a ventriculoperitoneal shunt, possible active shunt infection (6/25/12).
2. A 2 year 3 month old male (**# 003**) with congenital hydrocephalus, intellectual disability (aka “mental retardation: and hypoplasia or underdevelopment of the midline corpus callosum.

3. An 8 month old male (# 012) who was a former 24 week premature infant, status post Grade IV intraventricular hemorrhage, multiple acquired porencephalic cysts, cortical blindness, sensorineural deafness, hypertension, and global developmental delay
4. A one year old female (#013) with hydrocephalus of unclear etiology, global developmental delay who had gall bladder disease as an infant, whose blood pressure is now stable.
5. A three year old female (# 014) who has only a history reported of hydrocephalus, neonatal asphyxia, and developmental delay of unclear etiology. This child is included in this group because her history is consistent with the diagnosis of hydrocephalus, although clinical examination and review of the TIH records does not substantiate this. She is included among those who have confirmable hydrocephalus.
6. A one year old male (# 019) with end stage or progressive hydrocephalus and neurologic decompensation.
7. A 7 month old male (# 020) who has a history of neonatal “hypoxic-ischemic”encephalopathy who now has multiple porencephalic cysts and hydrocephalus

Only *one child of these seven (# 001) had a ventriculo-peritoneal shunt in place*, which was being investigated for possible shunt infection.

The hydrocephalus in all of the children except (#014), for whom the diagnosis remains equivocal, presented as advanced macrocephaly with clinical evidence of advanced untreated increased intracranial pressure. This was evidenced by a full and bulging anterior fontanel, ophthalmoplegia, including the classic “sunset sign,” motor changes including spasticity and cerebral palsy, and depressed nervous system function including lethargy, visual and auditory impairment, and gastroesophageal reflux symptoms.

We could not find clear written orders regarding resuscitation, end of life care, or habitation plans for this group of children.

One, in my clinical opinion (#020) was in serious and near critical condition with physical changes seen only in children with hydrocephalus that had never been treated.

Another, (# 001) who had the single shunt of the group had clear evidence that repair of her lumbar level lesion had never been undertaken.

In sum, it appeared to this examiner, that these children’s disposition and care plans were undeveloped, disjointed, and in most cases non-existent. Given their state of health as documented in the Appendix for each of the six, it appears very likely that the expectation of one or more of those who cared for them prior to their admission to TIH was that they were being placed at TIH to die.

Summary of findings, conclusions, and recommendations regarding seven (7) children with hydrocephalus at The Tbilisi Infants House—These apply to all residents of this facility regardless of diagnosis or problem list.

- All children examined at TIH, with one exception, have significant and advanced hydrocephalus representing either complete failure to appropriately manage their care neurosurgically, or a deliberate decision to not treat them including palliative intervention for their comfort and including surgical insertion of a ventriculo peritoneal shunt.
- If the mission and purpose of the Tbilisi Infants House is to provide good and compassionate care for children of Georgia with disabilities including those we evaluated with hydrocephalus, minimal standards are not being met for these children including but not limited to:
 - Formal and accountable communication with the pediatric specialty community of Tbilisi to effectively manage their care both acute and chronic 24 hours a day, seven days a week.
 - Infection control measures including appropriate hand washing, decontamination routines and procedures, and policies concerning reverse precautions in particular
 - A thorough and complete revision of admission criteria which are based not on what is expected or demanded by referring parties but on what the facility expects and requires be put in place for a child before they are admitted.
 - Minimal habilitative resources on site to provide at a minimum:
 - Adaptive seating
 - Physiotherapy
 - Occupational therapy
 - Communication therapy and consultation
 - Nutrition and dietary consultation and intervention
 - Orthotic consultation
- Children with hydrocephalus currently receiving care at TIH are being managed by staff in a way that reflects hospice and end-of-life care as opposed to other types of care, and in and of itself, that care is substandard for a civilized society such as Georgia's to tolerate.
- All other children we evaluated are also receiving care closer to a respite care model than other models, and they are experiencing unacceptable complications and morbidities, but those with hydrocephalus are in this reviewer's opinion being abused and neglected.

- We have demonstrated that pain and discomfort comprises a significant part of these children’s lives. We do not accept the explanation that children with hydrocephalus do not feel pain. This is a disproven perception worldwide. This group of children are sick, in pain, and are suffering and the Dept. of Health, the neurosurgeons who remain responsible for their care, and the staff of TIH need to take immediate action to address this catastrophic state of affairs.
- Some of the children with hydrocephalus may no longer be candidates for surgery at this point given the extent of their conditions today. For one (#020) there are likely no palliative neurosurgical options available given the extent and complexity of his central nervous system anatomy. But all of these children need to be reviewed by experts in chronic and palliative care and revised care plans be put in place to assure that they are as comfortable and physiologically stable as they can be.
- It is not an international health care standard *to do nothing* for a child with severe central nervous system malformation or injury. Regardless of politics, economics or clinical resources, the standard must be first *to do no harm*, and second to apply the best available resources to help the child live to his/her fullest potential, even if that potential is extremely limited and even if others will discourage this approach.
- There appears to be a significant void between the expressed goals of the Dept. of Health for the care country-wide of persons with disabilities, and the practitioners who make the day to day decisions concerning children’s medical care.
- TIH is one component of a larger universe of direct services and resources to children and adults with disability. This examiner believes that a fundamental shift in the paradigm needs to take place to reflect the following concepts so that the future of TIH can be better conceptualized:
 - Transition from newborn care of children with congenital or acquired hydrocephalus needs a new system in Georgia of care management (case management) and early developmental intervention that is based in the communities where families of these children live.
 - The natural home with the support of a network of paid and volunteer providers should be the focus of attention, and not a system that immediately defaults to institutionalization.
 - There will be a need inevitably in the near future, for a few highly skilled nursing care programs located throughout Georgia, which have both respite and long-term residential options for a small specific subset of children with special needs (including those with hydrocephalus). These programs must also build a new

system of consultative medical care where families can go for medical advice and support. The concept of such “special needs” centers linked to an early intervention and case management capacity would serve Georgia very well.

- The Tbilisi Infants House needs to be redeployed as one of these special needs centers
- A formal curriculum in the medical and nursing schools of Georgia integrated with post graduate training programs is needed to teach current and future practitioners how to think about and serve children and adults with disabilities and special health care needs beyond just the focus of their own interest or career pathways. This should be a required and regular component of what doctors and nurses are expected to learn in Georgia. The goal of such a curriculum should ultimately be to increase sensitivity of future clinicians around issues of disability.
- Based on history and clinical examination, this examiner is concerned that past interventions and current care plans do not reflect a complete enough understanding of the natural history of children with this group of neuroanatomic abnormalities. In four of the seven children evaluated (to assure absolute confidentiality and respect to the parents of all of the children evaluated) this examiner believes *their quality of life could be improved, some significantly so were they to have ventriculoperitoneal shunts in place today, or if surgical intervention has been undertaken at an earlier stage in their course.*
- Finally, this examiner feels that formal dialogue is needed between the pediatric neurosurgeon community of greater Tbilisi and those providers who provide more regular care as well as those who work in and with facilities for children with disabilities.

Visit to Dzeri Institutions for adults with disabilities in Kutasi

An independently conducted tour and observation of residents at this facility took place on June 27, 2012. No direct clinical evaluations were undertaken but residents of interest were noted and photographed with permission of the Office of the Ombudsman. Observations and conclusions are as follows:

- The majority of residents have significant developmental or neurodevelopmental disabilities. Some have clinical stigmata of global developmental delay which includes motor, communication, and social-adaptive deficits.
- Two, including a recently admitted teenager had behaviors suggestive of and consistent with Autism Spectrum Disorder

- A range of behavioral and psychiatric conditions were observed including but not limited to anxiety, psychomotor retardation suggestive of depression or bipolar disease, speech and language disorders, mild to severe (but not profound) intellectual disability with co morbid behavioral disturbance, pica, self-stimulatory behavior, aggressiveness, oppositional defiant disorder, obsessive compulsive disorder, and mutism.
- Some residents with higher cognitive function and stronger communication skills function within this community as leaders, advocates, and in some cases, as bullies and/or manipulators of others' behavior.
- There appeared to be no residents at this facility with conditions akin to those observed at the Tbilisi Infant House. This raised the general question as to *where such children would in fact be when they reach adult age.*
- Living conditions, while not ideal, provided a residential base for this group of ambulatory adults with developmental disabilities. The extent of recreational, rehabilitative and habilitative resources was not fully explored and needs to be.
- Dzeri appears to be an adult psychiatric facility, but in this examiner's opinion, it is actually a residential facility for persons with a variety of needs, the majority of which are developmental or neurodevelopmental in nature.
- Health care for this population of children should be based on both pediatric and adult medical principles and practice since the age span of the residents includes adolescents, young adults, older adults, and the elderly. Clinical questions therefore are likely to cross a number of disciplines including internal medicine, general surgery, ophthalmology, audiology, and gerontology.
- Were Dzeri to close and discharge its residents to the community, a system of support, including developmental habilitation, therapy, care coordination, primary care must be in place to accommodate them.

Visit to Senaki Institution for Children with Disabilities, Senaki

On June 28, 2012 I accompanied the DRI and Office of Ombudsman teams on a visit to this rural residential facility for children and adolescents (ages 6 to 18 years). I participated in an informational interview with senior administrators of Senaki, and met with a physician on duty that day to learn about the medical care and monitoring routinely done at Sanaki, and to discuss one child in particular.

The methodology used at Tbilisi Infant House was not employed at Senaki. No direct clinical evaluations were undertaken per se but residents of interest were noted and photographed with

permission of the Office of the Ombudsman. The following represents observations that were noted and correlated with photographs:

- I saw one pre-adolescent male with Down syndrome
- I saw one possibly two males with clinical features and physical phenotype of the Fragile-X syndrome which would need to be ascertained by specific molecular testing
- I saw one child with possible Angelman syndrome a molecular deletion of the short arm of chromosome #15. If this is the case one of his parents may be at risk of passing on this genetic mutation to future offspring
- I saw two males under 10 years of age with what appears to be primary speech and language disorders but not necessarily intellectual disability (aka “mental retardation)
- I saw one teenage boy with an inoperable club foot deformity who, in my opinion was developmentally normal but had some features suggestive of a mild spastic diplegia.
- I met one pre-teenage girl with inoperable club foot deformity noted elsewhere in this report who may be at least cognitively normal, possibly above average or gifted. Surgical options to improve her ambulation include amputation of her feet with orthosis.
- I observed one male less than 10 years lying in a crib with cerebral palsy and microcephaly who appeared to be deaf and blind with developing joint contractures throughout.

There was once child of concern to this examiner. He is designated as (**# 021 MALE/SENAKI**). Please refer to the Appendix for a summary of his medical history and observation by permission of the Ombudsman. In addition to information reported in the Appendix, the following observations are made concerning this child:

He has body mass, posture, and the joint extremity involvement sometimes seen in children with severe spastic quadriplegic cerebral palsy. However, compared to similar children, in my opinion, *he is severely protein-calorie malnourished*. There are a number of reasons why this might occur.

- Inadequate oromotor abilities to take in the food being prepared and offered him as part of an appropriate diet and nutrition plan
- Inadequate calorie, protein, fat, and carbohydrate content in the food being fed to him
- Chronic hypermetabolic state (“burning up calories”) due to his upper motor neuron condition or other medical factors, including infection, gastrointestinal loss, malabsorption, and insufficient vitamin intake.
- Chronic vomiting with or without aspiration of food
- Error or other irregularities in the calculation, preparation, and/or delivery of his diet

- I suggest that a formal investigation into the nutritional status and plan for child (# 021 Male/Senaki) be undertaken to understand why he is so small and malnourished, and revision of his nutritional plan to reflect best practice for the nutritional support of a child his age with spastic quadriplegic cerebral palsy.

Concerning general observations and recommendations based on this visit, I offer the following:

1. Some children are cognitively far more capable than they appear to be on cursory observation. At least three boys under 10 years had developmental delays, but possibly not intellectual disability, and understanding their level of cognitive function will have a tremendous impact on what resources they need, and what their potential will be.
2. Approaches and supports needed to help them may be basic and not need to cost a lot of money. Not knowing this information may commit them to a life of unfulfilled potential.
3. One little girl appeared to me to have only one obvious significant abnormality—namely severe bilateral equinovarus foot deformity that was never corrected---and accounting for language barriers and the limited contact I had with her, my impression is that her habilitative potential is enormous, and not being addressed at Senaki.

For example, she is wonderfully verbal, engaged our group in very appropriate and well organized conversation, she attends a limited number of school days in a local elementary school each year, and “listens” in to the few children being given English lessons, and has independently taught herself English. She asked me if I could help her go to school in the village so that she can learn to read.

Sadly there were a number of severely delayed and non-verbal girls in the day room she occupied when we met her who had self-stimulating rocking behavior. After we left this room for an hour and returned to say “goodbye” to the children, this child was sitting on a chair rocking back and forth. This scenario indicates that this child is under stimulated and being deprived of an appropriate education. I question whether this facility is equipped to serve her developmental and educational needs.

4. The Senaki facility functions largely as an orphanage, and many of the children in it might and should not be there if there were a more robust system of community based foster and adoptive services in Georgia, and/or if resources could be configured to support them in their natural homes (if they have families able and willing to care for them). The issue, therefore, is a National one, and the debate needs to be not only about Senaki but about proactive intervention of persons with disabilities throughout the lifespan. That dialogue must include how a commitment to a continuum of care for disabled children could be carried out. Without such an approach, the net effect of resources such as Senaki will amount to little more than “warehousing” children whose parents could not care for them.

Visit to Makhinhauri Infant House

On June 29, 2012, I accompanied the DRI and Office of Ombudsman teams on a visit to this residential facility for infants, toddlers, and school age children (age's birth to 6 years). The methodology used at Tbilisi Infant House was not employed at Makhinhauri. No direct clinical evaluations were undertaken per se but residents of interest were noted and photographed with permission of the Office of the Ombudsman.

I participated in an informational interview with senior administrators of Makhinhauri and met with two physicians on duty that day who sought my professional advice concerning two children for whom they had concerns. As before, with the approval of the Ombudsman, we agreed that I would hear and review their histories, oversee their examining these children, but not examine them myself, and offer opinions and advice concerning further assessment and management.

One six year old male with chronic cough for two months was observed and evaluated. His cough is productive of mucous but he has no fever, and the cough is not seasonal but worse when he is asleep. A trial of antihistamines did not improve the symptoms. On examination I was told that his throat was inflamed and erythematous with exudate on slightly enlarged tonsils and I confirmed this finding watching the examination be performed. He had a bulging left ear drum with fluid behind the drum which I also observed.

My suggestion was that this child either had an allergic rhinitis/pharyngitis (less likely because of no response to antihistamines), chronic sinusitis, post-nasal "drip," or recurrent serous otitis media with cough. I further agreed with the physicians' plan to place this child on a 7-10 day course of Augmentin antibiotic and re-evaluate. I suggested that if the symptoms did not improve after this treatment, referral to a pediatric otorhinolaryngologist would be an appropriate next step.

An 18 month old male with a complex history from infancy was discussed next. He had a history of sepsis and shock in the first weeks of life, had respiratory distress during that illness, but was not intubated or mechanically ventilated. Discharge from the hospital was directly to an orphanage (not clear if this was Makhinhauri Infant House). Staff are concerned about his development. He has mild to moderate hypotonia, does not talk or walk but is very loving and sociable, enjoys being held by staff. He smiles socially, and attempts to engage others in play. On examination a significant finding was the inability to turn to or localize a range of sounds. He also had generalized hypotonia, and difficulty with visual tracking.

My own impression was that of a child with global developmental delay but some scattered strengths and abilities, but also strong evidence for deafness and possibly vision impairment. My physician colleagues agreed with this impression and were planning next to arrange for more formal hearing testing (they identified correctly the need for brain stem auditory evoked potential

hearing testing), and MRI, and an orthopedic consultation with attention to issues of seating, possible bracing, and orthopedic monitoring.

On the tour I observed infants in the infant room, some of whom had clear differences in behavior. One child was fearful of adults. I suspect he has experienced or witnessed abuse or neglect at home or elsewhere. Another had abnormal joint attention suggesting either problem with cognition or autism spectrum disorder. A third appeared to be depressed for unclear reasons.

Staff with the infants were women who cared for the children in shifts. Feeding was done with child on lap and spoon feeding as a pace too fast for their ages. I saw no gagging or vomiting, but this technique would put any child that age for vomiting and possibly aspiration.

I was unable to see what other activities were arranged for this group of infants, including what kind of socialization, one on one teaching, language learning, etc. was being conducted. It was evident, however, that these children divided most of their time between sleeping, being fed on schedule, and sitting in a playpen with others or in highchairs or walkers. I did not witness any infant stimulation during the one hour observation.

In the school age children's room were children with a range of developmental differences. This included one child with severe dysregulation disorder, and impulsivity. He spat at visitors and got other children agitated and copying him. He was identified as a child with severe emotional-behavioral differences, with whom a staff psychologist was working. This group reflected the kind of social "society" typically seen in preschool and Kindergarten settings where children relate to one another through a complex pattern of copying or avoiding one another, of aggressiveness, and passivity, and varying degrees of dependency on adults for safety and comfort.

Responsively to their needs appeared to be part of the center's program for this age group, and I was impressed that resources and facilities notwithstanding, this facility was doing the best it could with the materials it had to work with.

While some might consider it cute and novel to see a group of children "hamming it up" for visitors (camera play, attention seeking, mugging for pictures) I got the impression that this facility is being showcased to visitors, and the children are experiencing social experiences around these visits. My feeling about this is that as animated and engaging as these children might appear when in the spotlight, the real measure of the effectiveness of the Makhinhourl Infant House will be through a more systematic evaluation of interventions and outcomes for two very critical age groups.

I see this facility being able to try to meet best practice standards. I am concerned that the infant caregivers are not developmentally focused and need infant development training to provide as close to a "family-centered" approach as possible.

Again, were there ever action taken to close this facility or relocate the children, it will be critical that these children not be lost to follow-up, and be supported in a transition from an institution to a family environment. I do not see an acceptable trajectory for these children ever being one of graduating up to Senaki and Dzeri.

Conclusion

The Republic of Georgia is at the threshold of an important decision with respect to children and adults with disabilities, namely how to shift from a system of institutional care of persons with special needs to a community based, family focused, and culturally responsive model of service.

It has become the fashion over the past five to ten years throughout the world to say the best vision for persons with disabilities will be impossible to achieve because of limited funding, limited resources, and political constraints. As such, it is more likely to witness a striking dichotomy between what leaders policy makers know and believe is right to do, and what actually gets carried out.

In the case of persons with disabilities, especially children, private and public sector leaders in Georgia (as in any country) need to adopt an approach based around the belief that some of the most critical interventions are low cost and channel the education and energies that Georgian citizens in the field have to help this needy population of children. The Government then can focus on providing this potential workforce with a core infrastructure to serve persons more effectively. This examiner believes that they only way to apply a love and commitment to a society's children and fragile adults is to invest in the resources to support them. Lip service and motivational initiatives will not suffice.

I therefore recommend that the following contingencies be considered for future efforts to help children and adults from Georgia who have disabilities. That the Government of Georgia:

5. Adopt an official State position, in keeping with UN guidance, that the current system of institution-based care in Georgia is untenable, inappropriate, out of line with minimal practice standards put forth by the United Nations, and harmful to the people living in them
6. Make a commitment to completely eliminate this system and in its place, have ***ready to deploy*** a country wide system of community based networks of support for the health and support of children and adults with disabilities. This system will provide what the current health care system in Georgia cannot provide: a community resource for families of disabled children and adults to access when needed that identifies needs, and connects to and advocates for interventions that will make life better than if this resource did not exist. Essential elements of such a system should include:
 - ***An infant-toddler Early Intervention*** program, similar to what exists in the United States and United Kingdom. Children who have or who are at risk for

disabilities who are between the ages of birth to five years would be automatically referred to such a system. It would have regional coordination sites throughout the country, possibly reflecting the current Ministry of Health catchment areas. These sites would have space for coordination activities, state agency support staff, insurance advisors, developmental specialists, traveler-therapists who can make home visits, nurses skilled in disability care who can advise and consult.

An important role for this network would be to support and educate families in their natural environments, respecting and employing local cultural values and tools to achieve best outcome.

- ***Clinical care centers for children and adults with disabilities*** based regionally throughout Georgia to provide medical consultation, acute care stabilization and chronic care management. These would be equivalent to centers/clinics for children with special health care needs in existence in most developed nations. They would be staffed by pediatricians and adult physicians, nurse practitioners, and nurses with special training in disabilities care. These centers will be where one can go to know that diagnosis and treatment will reflect best practice standards.
7. There will continue to be children and adults whose health care needs who require skilled nursing facility care in ***skilled nursing care facilities***. Places like Tbilisi Infant House or Senaki are not examples of these.

To have such facilities is not to admit failure at being able to care for some individuals with very complex or life-ending disease. But they must be equipped skilled nursing care facilities, not versions of better equipped orphanages, ***and not confused with hospice care centers***. Examples of such skilled facilities exist around the world.

8. ***Educational programs*** in the universities and medical schools of Georgia must include curricula in the assessment and care of children and adults with disabilities, and this curriculum should be integrated into the required training of doctors, nurses, advance practice nurses, physical therapists (physiotherapists), occupational, and speech therapists. This should include required clinical rotations to the ***early intervention and clinical care centers*** (above). Among those rotating in these sites should be neurosurgeons in training. It should also be considered that as part of recertification to practice medicine (and other mentioned specialties), a short mini-fellowship or practicum course be undertaken at any of these regional sites. This could include clinical care consultation rounds in neighboring skilled nursing care facilities as part of the rotation.
9. Legislation should be passed in Georgia that duplicates initiatives in the USA, and Europe which support the rights of disabled persons to be recognized as legitimate citizens of Georgia, and safeguards their rights for safe, secure, and dignified care wherever it is delivered. This should include a legitimate Government and private sector

partnership that formally assures ways anyone who sees abuse, neglect, or malpractice in the care of persons with disabilities can have those concerns quickly and resolutely addressed.

Respectfully submitted,

Lawrence C. Kaplan MD, ScM, FAAP

VI. Endnotes

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²¹ Interview with Medea Kakachia, U.S. Agency for International Development-Georgia Mission, in Tbilisi, Georgia (Sept. 16, 2013)

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²³ Interview, *supra* note 21.

²⁴ Interview *supra* note 19.

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²³⁸ CRPD, *supra* note 11, art. 19.