



Testimony to the US National Council on Disabilities

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Submitted by

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Thank you for this opportunity to address the US National Council on Disability (NCD) on the matter of the UN Convention on the Rights of Persons with Disabilities (CRPD). NCD has taken a valuable leadership role in promoting US understanding of the CRPD and in building support for United States ratification and implementation, and I would like to thank you for your invaluable leadership in this area.

I particularly appreciate NCD's work on the recent report "Toward the Full Inclusion of People with Disabilities: Examining the Accessibility of Overseas Facilities and Programs Funded by the United States." This report provides valuable documentation of US foreign assistance programs abroad and calls on the United States to take action to ensure that US programs take better care to ensure full accessibility and appropriateness for people with disabilities. There is an important link between what the United States does abroad in its foreign assistance and how we demonstrate our commitment to the CRPD. Article 32 of the CRPD requires governments to ensure that foreign assistance programs promote the "purposes and objectives" of the convention. The United States

is a country that leads by example. We are widely regarded around the world as the country that set the standard for establishing that disability rights are a part of our own binding law. It is thus essential for the United States to set a high standard for human rights protection and enforcement as part of our foreign policy and development programs. Countries around the world are looking to the United States as a model.

Today, I'd like to suggest a few ways that NCD can continue to its leadership – both in terms of ratification and implementation.

1. Taking a stand on gross human rights violations against persons with disabilities abroad

Once we ratify the CRPD, we will report every four years to the United Nations Committee on the Rights of People with Disabilities on US compliance with the CPRD. While we certainly have a ways to go in fully enforcing our own disability rights protections, we also have a great deal to be proud of in the United States. By ratifying the CRPD, the United States agrees to allow itself to be judged by the world community by the same set of international human rights standards that apply to all other countries. Thus, US ratification greatly enhances United States credibility on the world stage.

One of the most important arguments for US ratification of the CRPD is to encourage the United States to take a strong stand on the widespread human rights violations taking place against people with disabilities around the world. My organization, Disability Rights International (DRI), has worked for twenty years to bring international attention to these concerns. We have investigated and publicized abuses in more than two dozen countries around the world, and we have trained activists to challenge abuses in their own countries. Our reports are posted on DRI's website at www.disabilityrightsintl.org.

2. Urgent attention needed to stop abuses, including segregation of children and adults with disabilities into orphanages and other institutions

As DRI's reports demonstrate, there is a worldwide problem of segregation of children and adults with disabilities. Throughout the world, people with disabilities are detained in orphanages, psychiatric facilities, nursing homes, and other social care facilities. Behind the closed doors of these institutions, atrocious human right violations take place. The following is a short summary of our recent findings:

- In the Republic of Georgia, children have been denied medical care on the basis of their disability. At one facility, there was a 30% mortality rate among children with disabilities in the institution because needed care – that is available in the country – was denied to children with disabilities. We were told by staff that children with disabilities were

considered “hopeless,” and to “have no future,” and thus doctors would not provide treatment to this population.

- DRI’s recent report on Mexico, *Abandoned and Disappeared*, shows that children and adults are systematically segregated from society in orphanages and psychiatric facilities. Thousands of individuals are detained in institutions because there is simply no care or support in the community. These individuals are referred to by mental health staff as the “*abandonados*” – people who are left in institutions because they are abandoned by their families and abandoned by society. In Mexico, as in many other countries of the world, children who are emotionally and physically neglected will eventually become self-abusive. And instead of providing attention, care, and treatment to these individuals, they are simply tied down. In Mexico, DRI found people who have been tied down for more than ten years. The United Nations has made clear that the prolonged use of physical restraints can constitute nothing less than torture.
- In both Mexico and Guatemala, DRI has found that women and children are trafficked from institutions. Our report on Mexico is dedicated to the memory of Ilse Michel, a girl who was placed in an orphanage because of domestic violence in her home. Her mother was declared unfit to keep her child, and she was placed in an orphanage. When Ilse Michel’s grandmother came to look for her, she was missing. Police raided the facility and found out that it was a front for organized crime. The institution had, in name, been run by an evangelical Christian organization that ran orphanages throughout Latin America. In fact, children were trafficked for sex from these facilities. Ilse Michel was never found. Babies were found who had been born in the same institutions. Their mothers were presumed to be the missing adolescent girls who had been placed in this orphanage.
- In Guatemala, DRI recently won a decision from the Inter-American Commission for Human Rights ordering Guatemala to institute life-saving measures to protect children and adults detained in the country’s main psychiatric facility, the Federico Mora Hospital. DRI’s investigation found that physical and sexual abuse was widespread in this facility. We heard numerous allegations that women were trafficked for sex from this facility.

As these cases demonstrate, the problem of institutionalization is closely linked to many broader issues that are a part of our international development efforts:

- Violence against women and girls;
- Trafficking;
- Creation of open and transparent government;
- Effective criminal justice systems and access to justice for all people.

Unless the abuses against children and adults with disabilities are addressed, our broader human rights policies will have significant gaps. And many of these abuses come down to the problem of institutions.

Worldwide, UNICEF estimates that there are 10 million children detained in institutions. Extensive psychological and psychiatric research has shown that raising children in a congregate setting is dangerous to their physical and mental health. Children need to grow up with the love and care of a family member. If they do not form emotional attachments at a young age, they can be psychologically damaged for life. Studies also show that any child placed in an institution is likely to become developmentally delayed as a product of such placement. The longer they are placed in an institution, the more they fall behind. Orphanages and other institutions are literally generators of disabilities.

Sadly, children are placed in an institution throughout the world because societies have not established the community-based supports to help families keep them at home and in the community. I have personally interviewed dozens of heart-broken mothers and fathers who wish to keep their children at home. But in many countries, these parents feel they have no choice but to place a child in an institution.

For this reason, DRI has launched a ***World Campaign to End the Institutionalization of Children***. We are working to bring about the day when no child is placed in an institution because of a disability – or for any other reason. Under international human rights law, all children have a right to grow up in a family. Our campaign is described in this year's UNICEF annual report, *State of the World's Children 2013*, which is dedicated this year to the concerns of children with disabilities.

3. US Action Needed

What can the United States do to support this Campaign? For starters, we are calling on the United States to cease and desist from funding segregated institutions for children. Whether we call them orphanages, boarding schools, psychiatric facilities, nursing homes, or other names, these places are dangerous for children. DRI has documented the use of US government funds – by both USAID and the Department of Defense – to rebuild institutions and perpetuate segregated services for persons with disabilities.

Unfortunately, the disability policy of the US Agency for International Development (USAID) does not specifically prohibit the use of US government funding to perpetuate segregation by funding institutions. We have asked USAID to adopt such standards, and we call on the US Congress to adopt binding legislation that would prohibit US government funds to be used for this purpose. Instead, funding should be used to support the right of every child to grow up with his or her family in the community. For children with disabilities, this may require the creation of community-based services and support systems, integrated education, and healthcare in the community.

As NCD has called for in ***Toward Full Inclusion***, Congress should assure that enforceable legal standards exist to ensure that the United States does not discriminate or perpetuate abuses as part of its foreign policy or international development programming. Existing US civil rights protections would go a long way to ensuring these protections. As described in ***Toward Full Inclusion***, US civil rights laws now require that all US government funds be used in a manner that is appropriate and does not discriminate against persons with disabilities. The US State Department has wrongly determined that these laws do not apply to US government funding abroad. Congress should direct the US State Department to review and change this determination to ensure the full protection of US laws to government programs overseas.

Recommendations – DRI asks the NCD to support the following actions to address the urgent and serious discrimination and abuse facing institutionalized children with disabilities worldwide. We ask for NCD support for:

1. Full accounting for the way that US programs abroad support institutions or orphanages and directly or indirectly perpetuate further segregation of persons with disabilities;
2. Revision of the USAID disability policy to prohibit the use of US government funding for segregated facilities, including orphanages or other institutions;
3. A similar ban on funding by other US government entities, including the US Department of Defense;
4. New USAID policy requiring human rights monitoring and reporting in health and social service programs funded by the US government abroad; consistent with CRPD article 16 requiring programs to prevent violence, exploitation and abuse, these programs are needed especially people with disabilities in institutions and community programs; such programs should be age and gender sensitive to address the needs of the most at-risk populations;
5. Assistance to governments to deinstitutionalize orphanages and facilities for people with disabilities; this initiative should be combined with support for targeted advocacy by people with disabilities and family members to end the problem of segregation in institutions and promote community integration;
6. Anti-trafficking programs as well as programs to protect against gender-based violence should be sensitized to the concerns of people with disabilities, including institutionalized children and adolescents who age out of orphanages and other institutions.

DRI is prepared to offer its assistance in helping USAID and the Department of Defense to craft programs to address these issues.

Finally, DRI asks NCD to take action to bring an end to human right violations against children and adults with disabilities at home. Unfortunately, serious human rights violations are taking place in the United States and immediate action is needed to end these abuses. These violations are documented in DRI's report, ***Torture not Treatment: Electric Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center***. Two

United Nations Special Rapporteurs on Torture, Manfred Nowak and Juan Mendez, have spoken out against these abuses and made clear that the practices taking place at the Rotenberg Center constitute nothing less than torture.

The US National Council on Disabilities has taken a strong and courageous stand against this abuse. It is shameful that, two years after the United Nations raised this issue with the US State Department, there has been no federal action to end these abuses. The State of Massachusetts has banned the most abusive forms of aversive treatment on new admissions to the Judge Rotenberg Center. But more than 200 children and adults with disabilities remain at the facility. Anyone whose treatment plan was approved before the ban can still be subject to electric shock and long-term restraint. We call on the US National Council on Disabilities to demand immediate action by the US Department of Justice to bring this torture to an end.

Last but not least, we would like to thank the US State Department for inviting a delegation of Mexican disability activists, human rights lawyers, and mental health authorities for a study tour to the United States. The delegation includes members of the *Colectivo Chuhcan*, the first advocacy organization in Mexico run by individuals with psychosocial disabilities. DRI is working with the State Department to introduce the delegation to US models of community integration and rights protections. DRI will be hosting a reception to welcome the delegation on May 13 at DRI's office in Washington, DC, 1666 Connecticut Ave. NW, Suite 325. We welcome you to join us and ask that you RSVP to emathews@disabilityrightsintl.org We hope to see you there.

Thank you.