Investments Gone Wrong: International Cooperation in Transition to Community Care

Introduction

Article 32 of the CRPD commits international donors to support "national efforts for the realization of the purpose and objectives of the present Convention." Consistent with the Article 19, programs that segregate children with disabilities from society violate the core principles of the CRPD. Accordingly, international funding and support should promote the full community integration of children with disabilities and not be provided to create new separate or special schools or new residential institutions or programs that do not serve children in their families and communities.[1] National governments together with intergovernmental and international nongovernmental organizations and charities and financial institutions are falling short of achieving a meaningful change in respect of fulfilling article 19 requirements. A pattern exists in all states: while many actors are becoming more aware of the obligations to shift services towards community living, they frequently end up supporting institutional arrangements due to the lack of coordination and resistance of national authorities to a meaningful change.

The information presented on this issue here is not comprehensive, but it is illustrative of the trend in which international cooperation in community inclusion of persons with disabilities has been developing. The examples have been documented in the work and research of Disability Rights International (DRI) worldwide over the past decade. While some examples occurred prior to the CRPD's entry into force, DRI has been witnessing a continuation of practices regardless of the respective states' signatures or ratifications of the Convention. This may be confirmed by the most recent examples occurring Serbia, as well as reporting of other international advocacy organizations.[2]

Obstacle: Lack of coordination between different actors

One of the necessities of international cooperation is coordination of all donor efforts relating to the areas of care for persons with disabilities (that includes mainstream services) in one country. DRI's experience speaks to the fact that the actors' coordination consistently lacks. This usually leads to inadequate and partial solutions and non-sustainable projects with no guaranteed systematic incorporation.

a) One of the most obvious cases in this regard is **Kosovo** – entity where presence and engagement of a number of international actors failed to produce closure of a single institutional facility for long term residence of persons with disabilities, as well as comprehensive development of community alternatives. In fact, many international actors that were involved in functioning of this institution – Shtime - since 2000 (Norwegian Red Cross, USAID, UNICEF, Dutch government, World Health Organization) worked bilaterally with UNMIK authorities or in partnership with individual foreign organizations. Over the years through these uncoordinated efforts, several projects were implemented resulting in development of only isolated solutions to community care (at best) or renovating the institution itself (at worst).[3]

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[1] Rosenthal, E. & Mental Disability Rights International: *The rights of children with disabilities in Viet Nam: Bringing Vietnam's Laws into compliance with the UN Convention on the Rights of Persons with Disabilities* (2009), p.51; available from: http://www.disabilityrightsintl.org/media-gallery/our-reports-publications/

[2] See for example *Wasted Time, Wasted Money, Wasted Lives ... A Wasted Opportunity?* – A Focus Report on how the current use of Structural Funds perpetuates the social exclusion of disabled people in Central and Eastern Europe by failing to support the transition from institutional care to community-based services, European Coalition for Community Living (2010); available from http://www.community-living.info/documents/ECCL-StructuralFundsReport-final-WEB.pdf

[3] In more detail: Mental Disability Rights International: *Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo* (2002), available from http://www.disabilityrightsintl.org/media-gallery/our-reports-publications/

b) In **Serbia** for example, despite the fact that huge investments were made in institutions during the early 2000s, the authorities nowadays do not have an overview of past spending, nor can they state the exact purposes for which funding was spent. Still, no overview exists even for the current donor activities. According to the government, the list of current donor activities is being compiled only now in 2010, with a goal of "better coordination and direction of the activities…"[4]

Obstacle: Failing to resist to institutional system and culture

There are many examples where specific, targeted initiatives were fully supported by international donors (majority of supported initiatives are targeted for children with disabilities). Still, such initiatives did not fully integrate individuals into community. Following examples illustrate that international community fails to effectively influence national authorities in the process of transition from institutional to community based care, allowing preservation of institutional system and replication of its culture into the new services.

a) In mid 2000s the Inter-American Development Bank (IDB) was furnishing the Buenos Aires city government in **Argentina** with a loan of more than 40 million pesos (US$14 million) to renovate and equip the four large mental health hospitals in the city. This loan, however, allotted no money for the creation of community-based services. The amount of the IDB loan, at the time of its approval in 2004, was equivalent to 60 percent of the entire mental health budget of the city for one year (approximately 68 million pesos or US$22.7 million).[5]

b) In **Romania**, hundreds of new institutions for up to 50 children have been built – meaning that much of the reform in Romania merely transferred children with disabilities from larger to smaller institutions. UNICEF states that the number of new institutions increased from 123 in December 2000, to 330 in June 2003.[6]

c) In the beginning of the 2000s when international support for **Kosovo** was at its height, the initial focus was on refurbishing Shtime rather than immediate support for community alternatives for its residents. Norcross programs at Shtime were originally intended to provide emergency assistance to end the horrendous physical conditions in the facility.[7] Yet the assistance was also used to bolster a "Master Plan" developed by UNMIK that assumed the facility would remain the cornerstone of a system of institution-based services for people with intellectual disabilities. While for adults in this institution no plan was ever made to enable them to move to community setting, an initiative to de-institutionalize children was made. A program established by UNICEF and operated by Doctors of the World (DOW) and initially funded by the USAID, has removed children from Shtime, most of who were reported as showing signs of having been sexually abused while residing there. However, half of the children in the program are located in a group home just outside the perimeter of the fence at Shtime going to a school on the grounds of the

[4] *Sveobuhvatni plan transformacije rezidencijalnih ustanova socijalne zaštite za decu 2009-2013* ("Master plan"), UNICEF project: Transformation of residential institutions for children and development of sustainable alternatives, on file with MDRI Serbia

[5] Mental Disability Rights International: *Ruined Lives: Segregation from Society in Argentina's Psychiatric Asylums* (2007), p.17; available from http://www.disabilityrightsintl.org/media-gallery/our-reports-publications/

[6] Mental Disability Rights International: *Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities* (2006), p.2; available from http://www.disabilityrightsintl.org/media-gallery/our-reports-publications/

[7] While DRI does not oppose the use of international funds to end conditions that are imminently dangerous or life-threatening at any institution, international and national actors must avoid capital investments as well as those investments that serve to diversify functions of institutions.

facility. UNMIK regulations required that the children receive their medical care through Shtime, and the children remained under the legal authority of the institution[8]

d) As a separated sequence of events, a process with almost identical effects occurs in **Serbia.** While the package of humanitarian aid in the early 2000s was necessary for removal of inhuman and life-threatening conditions inside the institutions, it served to spur further domestic support to these systems. Donors' investments combined with national financing have turned institutions into self-sustained systems in theory offering education, work, medical care or entertainment to residents[9] thereby further isolating them from society. Nowadays, due to their own resistance to dismantle, these systems represent central basis at which additional services promoted as "community services" are to be provided. This is visible in the *Master Plan for transformation of residential social care institutions for children*, where the Ministry specified that existing institutions will remain in the system and most children who are currently placed there will "have to stay".[10] Financial plans for refurbishment and readjustment of old facilities into those of smaller capacities are envisaged, but still unknown to the public. This plan was developed in cooperation with UNICEF as a part of one of the three major programs, funded and supported by the European Union and Italian government in total value of 7,890,000 EUR.[11] This support would have huge potential to help Serbia through transitional period; unfortunately, all actions in future have to follow the deinstitutionalization strategy which was not created in compliance with the Article 19. In the meantime, Serbia's Ministry of Labour and Social Policy reports that in 2009 one new residential institution for persons with mental disabilities was opened, while works on another one – planned to house persons with autism – is in the process of being finalized.[12]

e) A very popular type of community service in **Serbia** is nowadays a day center. While this is certainly a service useful to persons with disabilities and their family members, it is being supported and promoted in the form in which it directly violates children's right to education, guaranteed by the new inclusive education law in Serbia. Day centers offer full-day stay, for the most part for children with disabilities. Children are not only excluded from any meaningful educational programs, but are again congregated based on the type of their disability and prevented from interacting with non-disabled peers. Several centers are set-up on the premises of institutions. Funding for their work comes from the European Union (UNICEF as implementing partner) and USAID's partners, as well as local governments.

Obstacle: Lack of political will and/or understanding of transformation to community care

Another interrelated obstacle to cooperation and full implementation of the article 19 and creation of adequate community services is lack of political will on the part of national authorities. While this may be evident from non-existence of relevant policies or complete non-implementation thereof, sometimes the lack of political will is hidden behind cosmetic changes in order to mask the inactivity of the national authorities. At other times, such superficial initiatives signal the lack of understanding of what it takes for transition, which again goes unaddressed by international donors.

a) Doctors of the World in their final report on the project implemented in **Kosovo** to deinstitutionalize children from Shtime explicitly state that "overall efficacy of DOW's efforts was further limited by the lack of UNMIK and MSW commitment to community-based care. Indeed, DOW lobbied constantly to have the two homes formally divorced from the Shtime Institution, and this request – which is based on international best practices – was repeatedly denied. UNMIK and the MSW felt that keeping the two

[8] Kosovo report, *supra note* 3 at 12, 18-20
[9] The existence of different equipment, rooms or services in institution does not imply that all or any of the residents in fact enjoy them.
[10] "Master plan", *supra note* 4 at 7
[11] DRI interview with UNICEF Serbia staff, on file with MDRI Serbia
[12] *Izveštaj o radu Ministarstva rada i socijalne politike – period od 01. januara-31. decembra 2009. god.* (Ministry of Labour and Social Policy Progress Report), p.15; available from http://www.minrzs.gov.rs/cir/index.php?lang=en

homes under the aegis of the Shtime Institution would minimize perceived threats to employment of institution staff and facilitate the homes' administration".[13]

b) In **Romania**, one of the changes was to be implemented by simply re-naming 51 medical laboratories that provide outpatient services in hospitals to "mental health centers", thereby establishing "new community services".[14]

c) In **Serbia**, operational plan for transformation of one institution envisages that it is organizationally divided into two working units. This measure was implemented by the Ministry for Labor and Social Policy in 2009[15] to solve the problem of having children placed in the same institution with adults.

Conclusion and Recommendations

Above stated facts show that one of the mistakes often made by international donors is to invest in programs that do not fully integrate children with disabilities into the community – as well as that most current programs assume that a number of individuals now living in institutions will remain segregated from society. Moreover, funders fail to exhibit influence over the national authorities to invest own resources into forms of care which would be fully compliant with CRPD.

International actors have the right and responsibility to ensure that their resources are not perpetuating segregate systems. In this sense, international donors should:

- Work together with national authorities to evaluate whether their reform priorities are set in compliance with the CRPD;
- Set precise requirements regarding their support to development and implementation of national strategies in community integration of persons with disabilities;
- Ensure guarantees from the national authorities that their resources will be directed towards full compliance with Article 19;
- Condition provision of resources on the progress and genuine commitment of authorities;
- Work with authorities to overcome the obstacles and not to bypass them (accepting arguments of staff resistance for transformation instead of deinstitutionalization process);
- Collaborate more extensively with national advocacy and self-advocacy organizations which can provide a critical input on the direction of the reform processes, genuine needs of the persons with disabilities in a country and implications which particular type of support might have within the national context (i.e. legislation).

[13] Doctors of the World – USA: Deinstitutionalization and Inclusion Project Kosovo, *Final Narrative Report* (December 2003), p.4&5; available from: http://pdf.usaid.gov/pdf_docs/PDABZ640.pdf
[14] Romania report, *supra note* 6 at 23
[15] Progress report, *supra note* 12 at p.15