

Committee on the Rights of the Persons with Disabilities

Regional Consultation on Deinstitutionalization for North America and the Caribbean

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Keystone Human Services is an INGO that works in Moldova, India, and the United States. Our work is focused on dismantling institutions and building inclusive communities with and for people with intellectual and developmental disabilities and people who have lived experience of mental ill-health.

Today, in the United States, we can see the results of the efforts of disability rights activists, families, and self-advocates over the past five decades in the significant reduction of large state-funded residential institutions, the increase of inclusive community living options, and an emphasis on person-centered care. Tragically, the COVID-19 pandemic has threatened these advances, echoing the days when isolation and discrimination were the norm. Through preventative efforts (“social distancing”), we have seen people with disabilities become increasingly isolated from community supports and unable to be supported when accessing health care. Those living in nursing homes or group homes were not allowed to leave or to have visitors. Social distancing is the opposite of inclusion, and when strictly enforced for an already marginalized population, it endangers the access to the community that we have worked together to build.

Over the past decades, supporting people through deinstitutionalization required a shift from the medical model of disability to a rights-based approach to service provision. The principles that

made that process successful are similar to those that ensure that people with disabilities maintain independence and control over services and supports, during times of crisis and in typical times:

- Practice supported decision-making. Self-determination is at the core of the CRPD. With the support of friends, family, and properly trained caregivers, everyone should maintain the right to make choices for themselves.
- People with intellectual and developmental disabilities should have a right to access health care accompanied by a support person familiar with their history and communication style. Some people with disabilities may have difficulty expressing their needs and feelings, or health professionals may have trouble understanding or communicating in an accessible way if they do not have an existing relationship and ease of understanding. To deny the person with disability access to support if they choose it, denies them equal access to healthcare. This happened quite often during the COVID-19 pandemic restrictions.
- People must be supported through the transition from institutions to the community on an individual basis. Desires, challenges, and supports will be different for every person. Get to know them as people. Make them central to the process. Get to know their families. There is not a cookie-cutter process that will work for everyone.
- Once people move out of an institution and have the opportunity for independence and agency, they are likely to embrace it. This looks different, often in unexpected ways, for everyone. Everyone should be encouraged to explore their individual identity and preferences. This is how we all grow.