Response to OHCHR consultation on support systems to ensure community inclusion

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*1(a). Does your country have laws, policies, plans, strategies or programmes at any level of government relating to individualized support for persons with disabilities? In particular initiatives related to:*

I will respond not with reference to my country but to the CRPD human rights framework, including the newly adopted Guidelines on Deinstitutionalization (CRPD/C/27/3).

1. *Communication: Support to overcome barriers that limit the ability to communicate and be understood (e.g., sign language interpretation, tactile interpretation, assistive technology and software, easy-to-read and plain language, captioning, augmentative and alternative communication, among others);*

Rather than technologies or techniques, the acceptance of diverse communication in general, understanding diversity of verbal and non-verbal communication as a matter of respect and solidarity whether the diversity is related to disability or otherwise, should be a basic starting point. Diversity that has been labeled as madness, mental illness or psychosocial disability should not be attributed to a health condition or impairment. For some people, the term ‘neurodiverse’, ‘neurodivergent’ or ‘mad’ will be a positive expression of identity that should be respected, for others it is simply their individuality as human beings that requires no label.

Empathetic listening by one person to another, without agenda or self-consciousness, seeking to connect with how the other person is experiencing the world at that moment and if relevant offering solidarity, help or simply presence, cannot be prescribed by law but it is the single most important practice to de-escalate conflicts of any kind and provide support free from any medicalized model.

1. *Decision-making: Support to make decisions and exercise legal capacity. This includes assistance to: (a) obtain and understand information, (b) evaluate the possible alternatives and consequences of a decision, (c) express and communicate a decision, and/or (d) implement a decision (e.g., support agreements, peer support, self-advocacy support, advance directives, crisis support, financial management assistance, among others);*

Similarly to above, empathetic listening is the most important requirement.

It’s good that you include crisis support, as I have conceptualized this as support to make decisions coupled with support to maintain oneself living independently in the community and support for healing. I don’t see this as only support to implement a decision, it is really support for both the discernment and action components of decision-making. The particularity of crisis support is that the need to make a decision may be felt as acute and incapacitating (not in a medical or judicial sense, but simply that the person feels simultaneously an urgent necessity to decide something and an ambivalence or uncertainty that makes deciding difficult to the point of impossible). It may be that decision-making is experienced in other ways in personal crisis as well, but it should be understood that such crisis is a situation that requires the person to engage in discernment and action for which they may or may not need support. The supporter’s role is to respond to the person’s expressed needs and to offer solidarity and support with empathetic listening as described above.

Personal crisis and crisis support should not be conceptualized or approached from a mental health perspective. To do so is contrary to the Guidelines on Deinstitutionalization (paragraphs 10 and 76, among others). Peer support, personal assistance and peer-run crisis respite are all avenues for offering crisis support including support in decision-making (DI Guidelines paragraphs 26, 70, 73 and 76).

Personal crisis and crisis support should also be de-linked from the need for inclusive practices of violence de-escalation and community safety (DI Guidelines paragraphs 10 and 102).

As stated in DI Guidelines paragraph 10,

Individual crisis should not be treated as a medical problem requiring treatment or as a social problem requiring state intervention, forced medication or forced treatment.

See also DI Guidelines paragraphs 6, 10, 32, 64, 72, 73, 103, 105, 143 rejecting medical model and highlighting forced medical interventions as a profound human rights violation.

1. *Mobility: Support for personal mobility and access to affordable and available quality mobility assistance (e.g., mobility aids, assistive technologies and products (prostheses, orthotics, wheelchairs), animal assistance, point-to-point and paratransit transport, among others);*

Assistance in navigating public space and transportation, and point-to-point and paratransit options, need to be available to people with psychosocial disabilities. It needs to be ensured that all people who need it can access such assistance rather than requiring eligibility criteria based on medical diagnosis or certification.

1. *Assistance with daily living activities: Support to assist persons with disabilities in a one-to-one human relationship to perform daily life activities like getting up, bathing, dressing, grooming, going out, cooking, cleaning, guiding, shopping, or doing laundry (e.g., full or part time professional personal assistance, third person support allowance, informal personal assistance, household cleaner, among others);*

This type of service needs to be available to people with psychosocial disabilities without medical diagnosis or assessment, on an ongoing or intermittent basis, and to any person experiencing such needs in relation to a personal crisis. (Such a person should be understood as a person with a psychosocial disability for that period of time if not otherwise, but this is not universally understood.) Going out into the community and navigating public spaces and public transportation, taking care of household tasks, or any other daily life activities may be areas where a person needs support. It should not be assumed that psychosocial disability relates to any particular area of life or needs, or that it implies a particular set of needs in relation to daily living. Such assistance is not ‘therapeutic’ and should be provided through the disability support system and not the mental health system.

1. *Housing and accommodation: Support in relation to housing and living arrangements in the community, including home modifications (e.g., housing information and assistance, home support, supported living services, financial support for housing, among others);*

See DI Guidelines paragraph 33 regarding forms of residential services that comply with the Convention.

Residential services are community-based support services aimed at ensuring equality and non-discrimination in the exercise by persons with disabilities of their right to adequate housing. Examples of residential services can include social housing, self-managed co-housing, free matching services, and assistance in challenging housing discrimination.

‘Supported housing’ provided by mental health services is contrary to the DI Guidelines, see paragraph 32.

1. *Family and household support: Support to families and households with members with disabilities (e.g., informal support for persons with disabilities, including care-related work leave and capacity building for informal care and support, community-based network and community mobilization programmes, peer-support groups, localized intervention programmes, circle of support, early childhood support, respite care, among others); and*

Peer support and community-based networks and programs are not the same as ‘family and household support’ and should be addressed separately or the heading changed accordingly. See DI Guidelines paragraphs 26, 45, 50, 70, 73, 74, 86 and 94 on peer support; consult the Guidelines as well for community-based networks and programs and informal support in general.

With respect to ‘respite care’, the DI Guidelines as adopted do not recognize ‘respite care’ as a service to families (compare paragraph 74 in adopted Guidelines with paragraph 72 of the draft circulated in June). As argued in the CHRUSP comments to the draft Guidelines, backup support services to a person with a disability when their regular supporters need a break (whether family or otherwise) cannot be viewed as a service to the supporters. The Guidelines only use the term ‘respite’ positively as an interest served by peer support (paragraph 73), while rejecting institutions for the provision of ‘respite care’. The Guidelines’ approach in paragraph 74 should be followed, viewing backup support as a service to the person using support and not to others.

Support arrangements can include a multiplicity of supporters acceptable to the person using support, and to the families of children with disabilities, ensuring continuity and quality of support.

1. *Disability-related extra costs: Financial support to pay services and goods, including personalized budgets and direct payments (e.g., cash transfers beyond income replacement, additional funds to cover support services, among others).*

*1(b). What are the government institutions, departments and ministries in charge of budgeting, financing and implementing the above?*

Disability human rights support and services should be in charge of budgeting, financing and implementing the above, ensuring that there is good, substantive input from people with psychosocial disabilities and survivors of psychiatric institutionalization to ensure full inclusion of that constituency without any discrimination. The mental health system should not be given a policymaking, expert, or programmatic role with respect to such supports, either in the public or private sector. (See DI Guidelines, paragraphs 6, 10, 32, 64, 72, 73, 76, 90, 103, 105, 122, 143).

*1(c). How is the social and solidarity economy (third sector, non-profit sector), particularly the disability sector, involved in budgeting, financing and implementing the above (1(a))?*

Same as response to 1(b). Community organizations and DPOs rather than mental health nonprofits should be involved, particularly those organized by and for people with psychosocial disabilities and/or survivors of psychiatric institutionalization and in which they take a leading role, which work based on a social model of acceptance of diversity of consciousness, communication, behavior and forms of distress as described above.

*1(d). How are persons with disabilities and their representative organizations involved in the design and monitoring of the above (1(a))?*

People with psychosocial disabilities and survivors of psychiatric institutionalization should be involved to ensure an inclusive approach to policymaking, legislation and programs at all phases. This includes DPOs organizationally and individual rights holders, including DPO leaders individually and those who are also experts in fields such as law, peer support, support services outside the health context and without mental health diagnosis.

*2(a). Does your country have legislation or policies, at any level of government, regulating and coordinating a care and support system that considers the areas mentioned in 1(a) above? Please provide references to the documentation.*

My book Reimagining Crisis Support: Matrix, Roadmap and Policy (2021) – see <https://www.reimaginingcrisissupport.org> – addresses potential avenues to legislating an entitlement to crisis support and rejects the option of using mental health or health legislation or policy for this purpose. My preferred approach is as part of disability support services under Article 19 that also encompasses Article 12 formal and informal supports (viewing the type of decision-making support provided as crisis support, as informal in that it does not depend on a prior agreement registered as a legal document).

*2(b). If yes, please describe how the care and support system is financed and what is the percentage of the eligible population covered.*

Eligibility for crisis support and other support services related to diversity of consciousness, communication, behavior and distress should be based on self-assessment and cannot require mental health diagnosis, medical criteria or the involvement of medical professionals. See DI Guidelines paragraphs 10, 75 and 76, read in conjunction.

*3. Does your country have a strategy to develop legislation, policies and programmes to enable the development of support systems as described in 1(a) above which includes targets, indicators and an accountability mechanism? Please provide references to the documentation.*

Accountability for institutionalization in all its forms as a complex human rights violation must be addressed through a reparations mechanism as called for in the DI Guidelines paragraphs 115-123. Perpetrators of institutionalization cannot have a role in creating, guiding or implementing any aspect of the reparations mechanism (DI Guidelines paragraphs 117 and 122). The reparations mechanism should inform and guide the development of new support systems and services, including the terms of reference for targets, indicators and future accountability mechanisms.

*4. Please provide data on persons with disabilities and families and households accessing care and support systems as described above in 1(a) and 2(a).*

Support systems outside the health context, accessed directly by the person who requests support from disability human rights services, without any requirement of mental health diagnosis, based on self-assessment, under the direction of the person concerned, is currently accessed rarely and mainly in the context of informally organized, unpaid peer support or mutual support networks. This needs to be amplified and would benefit from a reparative justice approach that starts by acknowledging at the community level and within families, the totality of harms done by institutionalization as a practice of segregation and medicalization of people with disabilities. Only in this way can society as a whole begin to approach survivors of institutionalization and those still victimized by this violation as full human beings and equal members of society who have been wronged due to systematic, widespread and entrenched legal and social discrimination. From that baseline, everyone can develop inclusive practices of support and solidarity on an everyday basis, and people with greater skill will emerge, including many who have lived through institutionalization themselves and those who have experienced personal crisis or diversity of consciousness or distress who will always bring needed depth to this work.

*5. Please provide data on the impact of the COVID19 pandemic on persons with disabilities and families and households with members with disabilities (death rates disaggregated by disability status, death rates in institutions compared to those living in the community, impact on income as a consequence of disruption in support or increased support and care demands, disruption in support services, among other).*