**International Disability Alliance submission for OHCHR thematic report on: ‘Support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the COVID-19 pandemic’**

The International Disability Alliance welcomes the opportunity to provide inputs to the first of two thematic reports mandated by Human Rights Council resolution 49/12, on ‘Support systems to ensure community inclusion of persons with disabilities’, and would like to provide the following observations for OHCHR’s consideration:

We share the objective and perspective outlined in the background note, that “*Full inclusion of persons with disabilities, of all ages, requires ensuring the necessary care and support systems to live independently in their communities”* and this is to be achieved through: *“social protection covering support extra costs, human support, assistive technologies & products, transportation, individualized housing support, legal capacity supports, and other community-based support systems to prevent institutionalization”.*

**Convention on the Rights of Persons with Disabilities**

The CRPD is the framework for community inclusion for persons with disabilities (Articles 1, 3, 4, 19), and we consider that Article 19(b) and (c) of the CRPD should be the foundation for this thematic report, as interpreted by the CRPD Committee in General Comment No. 5 on Article 19 (2017), in particular paras 28 – 30. In addition, many other aspects of the jurisprudence of the CRPD Committee’ are essential building blocks for community support and inclusion, including General Comment No. 1 on Article 12, General Comment No. 6 on Article 5, the Guidance on Article 14, and the draft Guidelines on Deinstitutionalisation (to be adopted by the end of the 27th CRPD Session, 9 September 2022). This thematic report is an excellent opportunity to provide detailed and practical guidance for States on how to implement Article 19(b) and (c), including by developingpathways for human rights-based, gender and disability responsive care and support systems enabling community inclusion of persons with disabilities across the life cycle in different contexts.

**Views of Organizations of Persons with Disabilities**

It is essential that the call for strengthened efforts to ensure community inclusion of persons with disabilities is supported by a detailed articulation of the demand from the diversity of persons with disabilities, through their representative organizations, so that we can fully understand how the necessary change should take place. This could require regular and ongoing or permanent consultation with OPDs to fully understand what is meant when talking about ‘support services’ from their perspective, recognizing also that the demand side will depend on local contexts and will change over time. This will help ensure that the precise parameters and contour of the legal and policy measures proposed reflect the priorities, perspectives and needs of persons with disabilities. Holding thorough and meaningful consultations will have financial implications, but will help ensure the robustness and effectiveness of law and policy reform. Initial consultation processes could cover the following areas:

* Analyse what support is available/missing, what is effective, what should change and how this change should be undertaken.
* Assess individualized support services for participation and inclusion (human assistance, housing and resettlement, assistive technology, transportation etc.)
* Review strategies for mobilizing and transforming communities for inclusion (community awareness, creating circle of supports and accountability)

**Preliminary observations on support services and care systems**

In all regions, across their life-cycle, millions of persons with disabilities lack the basic support they need to live and participate in their communities. The lack of support is often due to financial barriers, lack of choice creating reliance on family members, and service provision primarily in segregated and congregate settings. The COVID 19 pandemic made evident the importance of participation in the community for everyone as well as the significant risks and harm of social exclusion and segregation, especially children, persons with disabilities and older persons.

The COVID-19 pandemic revealed to the world what persons with disabilities have known and experienced for many years – current care and support systems need a fundamental rethink and transformation. Persons with disabilities as well as their families are suffering under the weight of unsustainable and dysfunctional care and support system, based on patriarchal power imbalance and harmful stereotypes, with the effect that for many or even most, autonomy and independence remain aspirational principles and far from being reality.

When families are the sole source of support, the autonomy of persons with disabilities and their family members is reduced. Unpaid familial support affects relationships, income levels and well-being. Women and girls are disproportionately affected by this, as in practice they are the main providers of support within the household. The absence of appropriate support systems increases the risk of segregation and institutionalization, for many it seems like there is no other option.

In contrast, community support systems enable inclusion by mobilizing communities and coordinating a diversity of schemes and services (including cash transfers, housing, assistive products, personal assistance, support in decision making, peer support, family support, interpreters, transport) which if publicly resourced and organized can be sustainable and contribute to a fairer societal distribution of responsibilities*.* Community support systems are essential to overcome exclusion, prevent institutionalization, allow persons with disabilities to live independently in their communities, and improve support to families of persons with disabilities.

The above points are initial reflections on this important topic, and we look forward to OHCHR’s initial report on ‘Support systems to ensure community inclusion of persons with disabilities’, with recommendations for States which could include, *inter alia*:

* recognition of care and support as a right
* partnerships and community mobilization
* regulation of services and working conditions
* creation and expansion of formal services

comprehensive policies and intersectoral governance and coordination

* investment and financing mechanisms

It may also be useful to consider principles (building on the CRPD principles and views of the Committee) and clear statements of policy direction that should underpin efforts towards ensuring community inclusion, for example as found in some national-level initiatives such as [‘Enabling good lives’](https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/).

The International Disability Alliance takes this opportunity to express our appreciation for OHCHR’s work on the rights of persons with disabilities. We reiterate the need for consultations with Organizations of Persons with Disabilities to develop a detailed and evidence-based understanding of the demand side of support systems to ensure community inclusion from the perspective of persons with disabilities, and we hope to take a leading role in this important work.



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