

Call for inputs:

Re-Imagining Services in the 21st Century to give effect to the right to live independently and be included in the community for persons with disabilities.

Purpose: To inform the thematic report of the Special Rapporteur on the rights of persons with disabilities to live independently and flourish in their communities. A necessary part of this goal is to critically examine and re-imagine the service paradigm that has evolved up over the past several decades and to put in its place a new agenda for change that stands a better chance of realizing the underlying vision of the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

Background

Twice a year, the Special Rapporteur on the rights of person with disabilities issues calls for inputs to inform his thematic studies to be presented to the Human Rights the General Assembly.

Objectives

Pursuant to Human Rights Council Resolution 44/10, the Special Rapporteur on the rights of persons with disabilities has begun the preparation of his thematic report to the 52nd session of the Human Rights Council which will be presented in Geneva, Switzerland, and will look **at innovation around the world in the design and delivery of services that underpin the right to live independently and be included in the community.**

The UN CRPD points to a radically different use of social support to promote personal autonomy and community inclusion. It calls for a personalization of those services. It calls for re-building services on the basis of voice, choice and control. It calls for those services to be built in a way that is visibly connected with broader policy goals of community inclusion dealing, for example, with housing, employment, transport and other generally available public services.

This overall set of policy goals is important in itself. An added impetus for change arises due to the exigencies of the post pandemic period. COVID-19 revealed the extent to which traditional service paradigms lack resilience in times of crisis. This means the imperative to re-invent the service paradigm is driven both by the UN CRPD in combination with the observation that the traditional approach to services is no longer fit for purpose in the 21st century. The added new technology as well as more sophisticated financial instruments means that States increasingly have the means to re-imagine and re-invent services. Expanding the imagination of policymakers to encompass this is the main goal.

This ‘call for inputs’ seeks to gather together the new thinking and innovation that is already happening around the world on re-imagining the service paradigm. From this, it is hoped to detect trends, to identify critical success factors for change and to make useful recommendations on how to carry the process forward.

We are mindful that the service delivery paradigm is not well developed in many lower income countries. Paradoxically that gives us an opportunity to identify real innovation on the ground as well as an opportunity to avoid some of the costly mistakes made elsewhere in the world.

Key question and types of inputs sought

The UN Convention on the Rights of Persons with Disabilities includes a powerful emphasis on the personhood of people with disabilities and asserts a range of rights including the right to autonomy (Article 12) and to live independently and to be included in the community (Article 19). People with disabilities may require support to live and be included in their chosen community, and to achieve the level of independence that they desire.

The service paradigm is shifting from a system-centered approach in which service users must demonstrate their disability to access pre-determined disability supports to a person-centered approach in which the individual strengths that a person brings to their community are recognized and supports are individualized so service users can be included as valued community members.

In recognition of these person-centered values, the Special Rapporteur seeks inputs on strategies to re-imagine services in ways that empower persons with disabilities to make their own life choices and to live in communities alongside their fellow citizens without disabilities.

Inputs are sought to the following **inquiries and questions**:

A: Policy Goals and Principles

1. What are the primary principles and goals that govern the provision of services to people with disabilities in your State?
2. Have these principles and goals been modified to take explicit account of Article 19 of the CRPD on the right to live independently and be included in the community (e.g., personalization of services, personal and human support, assistive technology, accessible transport, access to housing, expansion of community-based services, emphasis on personal empowerment and choice).
3. Are these goals linked directly to broader policy imperatives to ensure people with disabilities can take meaningful advantage of being in the community – such as the opportunity for employment and education, access to health care, promotion of natural or unpaid supports or community assets available to citizens without disabilities? If so, how?

B: Service Delivery

4. Who primarily *delivers* services to people with disabilities (State, local government, private providers commissioned by the State, religious organizations, other, or a mix?). How do you see this mix changing if at all as a result of the UN CRPD in your country?
5. Who primarily *pays for* services to people with disabilities (State, local government, private providers commissioned by the State, religious organizations, other, or a mix?). How do you see this mix changing if at all

6. Describe generally *how* community-based providers are paid for the services they deliver (e.g., through general grants, through per capita funding, based on specific services rendered, other means?). What changes, if any, are anticipated regarding the present payment methodology?
7. In what ways are principles and service goals communicated to the service system (e.g., in laws, service standards, staff training, funding incentives, means for compensating/penalizing service providers, and/or for assessing the quality of services?). Please describe.
8. What new services, including those to support families, have been added to the available service array to advance principles consistent with Article 19?
9. What practices, if any, have been adopted/encouraged to promote greater use of technology to personalize support to persons with disabilities (e.g., telehealth, remote monitoring, adaptive communication, artificial intelligence, etc.)?
10. In what ways are caregivers (e.g., family members, other informal caregivers) recognized and supported?
11. Do you have a policy of personalizing/tailoring services to individual needs? How is the policy implemented? (e.g., through individual planning requirements? etc.).
12. Describe how much control people with disabilities have regarding the services that they receive (e.g., choice of who provides support, choice of where they live and with whom they live, control over budgets).
13. In some disability support structures, service users or families have an allocated budget which is devolved so they have control over how the funds are used to purchase eligible disability supports. Do you have or anticipate a policy of devolving budgets to the service user? Describe.
14. If budgets are devolved to the user, what kinds of supports are available to assist them, how are the administrative tasks minimized and is the individual given wide discretion on how the funds are spent?
15. Have you adopted any positive “wealth accumulation strategies” (e.g., innovative trust funds) to complement social provision? Describe.

C. Monitoring and Oversight

16. Describe the types of data you collect on people with disabilities receiving services (e.g., numbers of service users, types of disability, service utilization, costs per person, quality of life outcomes, health outcomes, incidence of abuse, neglect and exploitation). Are these data gathered and reported in aggregate only or may it be disaggregated per person?
17. How do you enforce standards as they apply to service delivery providers (law, standards, incentives)? What do these standards focus on in the main? How are they measured?
18. Do your compliance rules make it possible to disqualify those providers in breach of the standards from competing for future State support?

D. Re-Shaping the Market/Challenges and Opportunities

19. Describe the major challenges you face in endeavoring to reform your system of services and supports for people with disabilities. Barriers might include workforce shortages, inadequate

resources, lack of knowledge and training, weak infrastructure, and/ history of institutionalization.

20. How is the COVID-19 pandemic and its aftermath reshaping the service delivery market? Explain in terms of changes in service expectations among service recipients and regarding impacts on the services available.
21. Do you pro-actively seek out new kinds of service providers with new business models that emphasize person-centered practices?
22. Do you encourage service providers to adopt a 'business and human rights approach' to their endeavours?
23. How do you incentivize innovative person-centered new providers to enter the market? Describe.
24. Do minimum wage laws apply in this sector? Is there a career advancement structure for workers in the sector?

E: Process of Reform

25. What lessons have been learned to build momentum, while minimizing resistance, for systems change consistent with Article 19?
26. Did you have an initiative to re-imagine services that includes service users (e.g., have you commissioned a Task Force?).
27. In what ways do you solicit the input of people with disabilities and family members in policy making, program oversight, strategic planning, etc. (e.g., national advisory councils, regional/local forums, surveys, webinars, etc.).
28. What are the two or three strategic objectives you have to enhance the quality, availability, and effectiveness of services to people with disabilities in your state?