



Human Rights Council**Fifty-second session**

27 February–31 March 2023

Agenda item 3

**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development****Transformation of services for persons with disabilities****Report of the Special Rapporteur on the rights of persons with
disabilities, Gerard Quinn***Summary*

In the present report, submitted to the Human Rights Council pursuant to Council resolution 44/10, the Special Rapporteur on the rights of persons with disabilities provides an overview of the activities undertaken in 2022, and presents a thematic study on reimagining services in the twenty-first century to give effect to the right of persons with disabilities to live independently and be included in the community.

In his study, the Special Rapporteur outlines how traditional service and support models often perpetuate dependency and lack of agency by focusing on impairments and considering persons with disabilities as passive recipients of care. This approach is at odds with the Convention on the Rights of Persons with Disabilities, which is grounded in personhood, autonomy and community inclusion. Against this backdrop, he argues that a wholly new philosophy of service and support is emerging and requires clearer articulation in law and policy. He elaborates on the wide range of policy tools at the disposal of States to do so, while highlighting key policy challenges and pointing to the potential of the business sector to be an actor for change. The Special Rapporteur then provides conclusions and recommendations on the ways in which different actors should advance the transformation of services and support for persons with disabilities.



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I. Introduction

1. The Special Rapporteur on the rights of persons with disabilities, Gerard Quinn, submits the present report to the Human Rights Council pursuant to Council resolution 44/10. It contains a description of the activities undertaken in 2022, and a thematic study on reimagining services in the twenty-first century to give effect to the right of persons with disabilities to live independently and be included in the community.

II. Activities of the Special Rapporteur

A. Country visits

2. Following the easing of travel disruptions caused by the coronavirus disease (COVID-19) pandemic, the Special Rapporteur was able to carry out his first country visits since his appointment in 2020. In March 2022, he visited the institutions of the European Union, and in September 2022 he travelled to Jordan. The Special Rapporteur is thankful to both for their respective invitations and cooperation. Reports on the visits will be presented at the present session of the Human Rights Council.

3. In 2023, the Special Rapporteur intends to carry out the previously postponed visit to Botswana, and he has made a request to visit Georgia.

B. Consultations, meetings and engagement with stakeholders

4. In line with his mandate, the Special Rapporteur participated in numerous events and meetings to exchange information, share good practices and raise awareness of disability-related issues. For example, in March 2022, the Special Rapporteur moderated the Human Rights Council annual debate on the rights of persons with disabilities. In June 2022, he took part in the fifteenth session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities and its parallel events.

5. Several activities centred on the interaction between human rights treaties, international humanitarian law and the visibility of persons with disabilities in armed conflict, leading up to the presentation to the Third Committee of the General Assembly in October 2022 of his report on the protection of the rights of persons with disabilities in the context of military operations.¹ In preparing the report, the Special Rapporteur engaged in extensive regional consultations, in Africa, Latin America, and the Middle East and North Africa. His statement on the International Day of Persons with Disabilities on 3 December 2022, issued together with the Chair of the Committee on the Rights of Persons with Disabilities and the Special Representative of the Secretary-General for Children and Armed Conflict, shone a spotlight on the need for adequate and targeted protection measures for children with disabilities in situations of armed conflict.

C. Communications

6. Summaries of communications sent and replies received during the period covered by the present report are available in the communications reports of the special procedures and in the public communications database of the Office of the United Nations High Commissioner for Human Rights.²

¹ [A/77/203](#).

² [A/HRC/49/3](#), [A/HRC/50/3](#), [A/HRC/51/3](#) and <https://spcommreports.ohchr.org>.

III. Reimagining services in the twenty-first century

A. Introduction

7. The purpose of this study is to inform and widen the policy imagination of States on giving effect to the rights enshrined in the Convention on the Rights of Persons with Disabilities (henceforth referred to as “the Convention”). Its specific focus is the need to transform services to ensure the effective exercise by persons with disabilities of their right to live independently and be included in the community, consistent with article 19 of the Convention.

8. The support needed to enable community living can be delivered directly by the State, via the not-for-profit social economy or through market forces. The exact mix will depend on local policy choices and circumstances and will always include a mix between formal (paid-for) and informal (family- or community-based) services.³

9. This report rests on three core predicates. First, the service paradigm in the field of disability that has evolved since the welfare state of the mid-twentieth century must change. A wholly new philosophy of service and support is beginning to emerge and is sharply distinguishable from past models. It is grounded on personhood (autonomy) and social inclusion and must be more clearly articulated in law, policy and programming. Moreover, a new vocabulary is required to optimize the potential of any new approach.

10. Second, States now have at their disposal a wide repertoire of policy tools to reimagine, design, implement and monitor a new service paradigm. Capitalizing on innovations of the early twenty-first century – chiefly to reshape the provision of services and to personalize delivery – makes the achievement of the new philosophy even more readily achievable. The options will vary depending on culture, history and resources. The main challenges are to do so without commodifying people or support or using the necessity for reform as a cover for the withdrawal of vital social support by the State.

11. Third, the business sector is increasingly regarded as an important human rights actor, which has direct implications for the multibillion-dollar service industry for persons with disabilities around the world. A major challenge will be to manage the for-profit motive with the potential of business in working for justice for persons with disabilities. A further challenge will be smart regulation, co-produced with persons with disabilities, to grow rights-based service models with the business sector. Persons with disabilities deserve a supportive legal and policy environment. The social economy – primarily private not-for-profit entities – already plays a key role in this respect, with its emphasis on social impact, democratic modes of governance and the reinvestment of profits towards social impact.

12. Taken together, these predicates – the need for a wholly new philosophy of service and a reinvention of the language and vocabulary of disability support, the need to utilize the full range of policy tools to reshape the sector and the need for business to be a partner for change – constitute an opportunity to breathe fresh life into the Convention.

13. There are clear lessons for building disability rights-related support structures from the ground up in countries that have not known them.⁴ The balance between formal and informal community support is crucial. International development assistance has a crucial role to play and must invest in innovation and avoid replicating old approaches.

14. The urgency of reimagining service models has clear resonance in the context of deinstitutionalization. However, it also speaks to the broader cohort of persons with disabilities who are not in institutions but who find themselves in living arrangements that

³ Domains of support may be categorized as including support to facilitate mobility, communication, decision-making, assistance with daily living activities, housing, and family support. See Xanthe Hunt and others, “Community support for persons with disabilities in low- and middle-income countries: a scoping review,” *International Journal of Environmental Research and Public Health*, vol. 19, No. 14 (July 2022).

⁴ See, generally, Hunt and others, “Community support for persons with disabilities in low- and middle-income countries”.

are not of their own making or choosing. Enabling them to live independently and be included in the community with the right kinds of responsive services is their right also.

15. This report highlights that hard policy choices will need to be made to evolve towards a new philosophy of service. These choices principally concern avoiding negative tendencies within market-based approaches, balancing formal and informal care with clear policy implications for families, ensuring that new technology does not become an end in itself and replace the vital human touch, and avoiding the use of new approaches as a pretext to remove State support.

16. Services and support are needed to realize the rights in the Convention. The particular focus of the report is services and support that directly enable the person to perform essential activities of daily living and to engage with the community. The provision of such services and support cannot be undertaken without the leadership and the skills of persons with disabilities themselves. It follows that the focus of the report is on the changes needed in the design and delivery of services to make article 19 a reality.

17. The intersectional importance of the issues cannot be overstated. Services are gendered. The services addressed in this report deal with moral agency and social inclusion, which are badly affected by patriarchy. Also of special concern is the availability of services for refugees and asylum-seekers. Population flows due to conflicts and climate change alone will make it a truly pressing issue. Addressing the income, health, housing and other disparities experienced by persons with disabilities from ethnic and racial minorities is likewise important. This report adopts a cross-disability approach while highlighting the critical importance of service redesign for particular cohorts (for example, for persons with psychosocial disabilities).

B. Towards a new philosophy of support

18. It is hard to talk about the formal right to live independently and be connected to the community without talking about the kinds of services needed to make it a reality. No amount of positive law reform will be sustainable unless the underlying ecosystem of support and services changes. Because the current ecosystem has evolved over decades, it may have acquired the appearance of inevitability even though it too was a creature of choice in the past. These ecosystems are not immune to change, especially when their underlying predicates no longer appear solid.

19. Our inherited disability service system owes much to the medical model of disability. It is commonly said to focus on deviations from a norm (how “normal” humans function) and then on the design of interventions to “fix” the deviation in the person. This contributed to a narrow social support philosophy mainly seeking to “compensate” the person with a disability for their “loss”. The focus was on the impairment, not the person. Moral agency, and legal capacity – the control of persons over their own lives – was not the goal. Still less was the goal to forge inclusive pathways into communal life. Left out altogether was the connection between the advancement of disability rights and community development.

20. In this sphere, as in so many others, the Convention is a game changer. The Convention departs radically from the medical model of disability. The various social models that helped pave the way for a human rights-based approach to disability challenged the underlying basis and effects of the medical model.⁵ Rejected was the fixation on impairment that devalued people. Instead, the starting point is the humanity and the just claims of persons with disabilities as human beings with equal rights, hopes and dreams.

21. Taking common humanity rather than impairment as the core departure point means taking the person seriously as an end in themselves and as a free moral agent. Thus, the objective of services must no longer be about maintenance, care or protection. Indeed, it is

⁵ Rannveig Traustadóttir, “Disability studies, the social model and legal developments”, in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Oddný Mjöll Arnardóttir and Gerard Quinn, eds. (Leiden, Martinus Nijhoff, 2009).

often said that the best form of protection is to have a friend.⁶ It should be about autonomy – voice, choice and control – and social inclusion. Services of the future should primarily be about enabling one to self-actualize in the world.

22. Second, in addition to the general rejection of the medical model, a web of core rights in the Convention points strongly to the need for the reconceptualization of services. Personhood and moral agency form the bedrock of the Convention. Article 12, on equal recognition before the law, seeks to give persons with disabilities the ability to shape their own lives and thus change the way in which the world interacts with them. The provision is an antidote to the tendency of traditional service systems to bypass the wishes of the person and to entrap them in a world not of their own making. It points strongly towards the personalization of services. This does not mean fixating on the myth of the completely atomistic individual, but taking human interdependence seriously, especially in support models for decision-making.

23. Article 19, on living independently and being included in the community, is intimately connected with this mission. It is directed at enabling the free development of one's personality, in a home of one's own, and with free interaction in the community: a mix of moral agency with social inclusion.⁷ Home is an intensely private place for repose and the evolution of identity, and it is spatially connected with the community, allowing one to engage on one's own terms.

24. The implications for the future of services are clear. For persons with disabilities to lead in all matters concerning their own lives, a reorientation will be required away from fixation on impairments and towards consciousness of the importance of the life choices of the person. Since social inclusion is vital to the evolution of our sense of self, it follows that services should stitch together social capital to ensure an equal right to belong, to grow and to be connected with others. Article 19 (b) speaks more directly to the need for personalized services and support.

25. It may be countered that ordinary persons do not have an open-ended right to draw on the public purse to underwrite their own life plans. Consequently, there has to be a finite limit to the obligations of the State in this regard. However, this argument obscures the many ways in which the State typically supports the lives and life chances of all its citizens, and it is no answer to whether the State bears a heightened responsibility towards those whose needs and rights require positive action. The State will have competing priorities even among different groups of persons with disabilities, which requires equity in the design of systems and is not a bar on how or whether the service paradigm should evolve.

26. It is true that any new philosophy of services cannot be completely open-ended. Inasmuch as resources are required, States are obliged to achieve the realization of economic, social and cultural rights only "progressively" (Convention, art. 4 (2)). However, this argument misses the point that current service paradigms must be reformed and be made to pivot on the broader goals of the Convention, especially on its notions of human personhood and social inclusion. The much vaunted interdependence and interrelationship of all human rights, of civil and political rights on the one hand and economic social and cultural rights on the other, must mean that both sets of rights are made to work together in harmony.⁸ Currently, they are not doing so, as reflected in how service systems disempower.

27. The above elements of a new philosophy – moving away from impairment and towards personhood and social inclusion – have been embraced by many authoritative bodies, including the former Special Rapporteur on the rights of persons with disabilities, the Committee on the Rights of Persons with Disabilities and other United Nations entities and agencies.

⁶ See, for example, Ethan J. Lieb, "Friendship and the law", *UCLA Law Review*, vol. 54, No. 3 (February 2007).

⁷ This notion is strongly echoed in article 29 (1) of the Universal Declaration of Human Rights, which proclaims that the community is the entity "in which alone the full and free development of [one's] personality is possible".

⁸ Vienna Declaration and Programme of Action (A/CONF.157/23), paras. 1–5.

28. The former Special Rapporteur added her voice to those critical of language such as “care.” In her 2017 report, she asserted that service models of care had traditionally treated persons with disabilities as passive objects or recipients of care, or as a “burden” for family and society, rather than as active holders of rights. She concluded by noting that, for many persons with disabilities, the notion of care bears a heavy historical connotation associated with oppression and invalidation.⁹

29. Two key outputs of the Committee on the Rights of Persons with Disabilities are especially noteworthy: namely, its general comment No. 5 (2017) on living independently and being included in the community (art. 19) and the guidelines on deinstitutionalization, including in emergencies (2022).¹⁰ In the general comment, the Committee identifies article 19 as integral to the full implementation of the Convention. Moreover, it notes the deleterious effects of inadequate service models that generate learned passivity and dependence. It endorses the view that the Convention generally – and article 19 in particular – honours both individual autonomy and social inclusion. The guidelines on deinstitutionalization underscore in more detail the need for and the specific direction of change in service systems. In them, the Committee frames institutionalization as a form of unequal treatment or discrimination and highlights some of the objectionable features of institutions, whether large or small.

30. In the guidelines, the Committee asserts that the central element in any new service paradigm is the moral agency of persons with disabilities. It calls for devolved budgets (with support) to be granted to individuals and more to be done to broaden the range and types of services on offer. Underscoring the shift from the medical model, the Committee insists that any new eligibility assessment criteria for support or benefits must be based not exclusively on impairments, but on the needs of the person. Further, it specifically calls for a rational workforce strategy to identify current and projected workforce needs and development.

31. Interestingly, the guidelines allow for informal family support but only with the express consent of the individual with the disability. Even though article 23 (respect for home and the family) makes no express allowance for it, in the guidelines the Committee calls for family support to enable families to meet their support-related responsibilities. The recent landmark Views adopted by the Committee in *Bellini v. Italy* underscores these principles.¹¹ The Committee found several violations under the Convention for a lack of support for Italian families in the role of caregivers. The Committee recalled that the right to live independently in the community was intimately linked with the right to family for children and parents with disabilities and that the absence of community-based support and services could create financial pressures and constraints for the family of persons with disabilities, and found a specific violation of article 23.¹² This finding should lead to further jurisprudence from the Committee in which it examines family policy issues more closely for their alignment with the Convention.

32. Other United Nations entities and agencies have added their voice to those calling for changes in service design and delivery. In a recent report, the Office of the United Nations High Commissioner for Human Rights highlighted the shortcomings of traditional care models and described emerging new models that sought to reconcile long-standing tensions between caregivers and care-receivers.¹³ In 2020, and in the context of COVID-19, the World Bank called for a wholesale reinvention of service paradigms to make them more resilient and responsive to persons with disabilities.¹⁴ Ensuring the continuity of support in times of

⁹ [A/HRC/34/58](#), paras. 23–24.

¹⁰ [CRPD/C/5](#).

¹¹ [CRPD/C/27/D/51/2018](#).

¹² This finding echoes the Views adopted in 2019 by the Committee on the Elimination of Discrimination against Women in *Ciobanu v. Republic of Moldova* ([CEDAW/C/74/D/104/2016](#)), in which that Committee found a violation of the Convention on the Elimination of All Forms of Discrimination against Women owing to the inadequacy of pension provisions for long-term family carers, constituting a form of gender-based discrimination.

¹³ [A/HRC/52/52](#).

¹⁴ See also Lena Morgon Banks and others, “Disability-inclusive responses to COVID-19: lessons learnt from research on social protection in low- and middle-income countries”, *World Development*, vol. 137, January 2021.

crisis was also a focus of a policy brief by the Secretary-General in 2020.¹⁵ In sum, the move away from the medical model directly challenges the fixation of service paradigms on impairments and their management. The new paradigm focuses on the person, the primacy of moral agency and the right to belong and to be connected in the world.¹⁶ As noted by the former Special Rapporteur, much of the language used in the field fails to capture this new philosophy. A new vocabulary is needed to avoid the drag of the past.

C. Key messages on transforming services from the call for written submissions and expert consultation

33. To inform this study, the Special Rapporteur issued a call for written submissions to all interested stakeholders¹⁷ and convened an expert consultation on 7 October 2022 in Geneva, at which a multi-stakeholder group focused on philosophy, policies and new market strategies. He wishes to express his gratitude to all those who provided contributions and shared observations in the preparation of the report. The highlights of both processes are summarized below.

COVID-19 pandemic highlighted the need for a new approach

34. Many State respondents observed that the pandemic had left their support systems eroded and had also resulted in workforce shortages, a slowdown in planned reforms and delays in the deinstitutionalization process. COVID-19 forced a realization that the old models of the past were not fit for the future.

Voice, choice and control

35. The Human Rights Commission of Mexico City emphasized the necessity to embed Convention principles into the disability service system and viewed moral agency as critical to the right to live an independent life. Some State respondents acknowledged practices of restricting or managing the choice of persons with disabilities. The Threshold Association, of Finland, expressed ongoing concerns about how the provision of services for persons with disabilities was typically imposed against their own articulated needs.

Moving from impairments to personhood and social inclusion as the goal

36. Inclusion Europe noted that persons with disabilities should not be reduced to their physical needs, as if impairment was the only thing that defined them. With respect to language, it asserted that terms such as “service users”, “clients” or “care receivers” served to reinforce that stereotype. It asserted that services and support should not focus on security and protection in a narrow sense. It emphasized that services tended to be delivered in groups, in a one-size-fits-all-fashion. La Chrysalide, an association for the integration of persons with intellectual disabilities in Benin, focused on attitudinal barriers that inhibited support in the community.

37. Discussants at the expert consultation indicated that the realization of rights protected by the Convention was currently constrained by an old welfare model based on impairments and charity, under which persons with disabilities were still seen as objects of care. All discussants agreed that the shift to a system in which people managed their own support had yet to be fully realized. It was emphasized that important policy conversations were about to take place in the United Nations system concerning reforms in the general “care economy”

¹⁵ See https://www.un.org/sites/un2.un.org/files/2020/05/sg_policy_brief_on_persons_with_disabilities_final.pdf.

¹⁶ The concept of belonging is the theme of the following book, which is due to be published in 2023: Kelley Johnson and Jan Walmsley, *Belonging and Social Inclusion for People with Intellectual Disabilities* (forthcoming).

¹⁷ The written submissions received will be made available at <https://www.ohchr.org/en/calls-for-input/2022/call-inputs-report-special-rapporteur-rights-persons-disabilities-52nd-session>.

and that the disability community needed to engage in that dialogue, which placed a premium on agreeing a new philosophy with a new vocabulary to match it.

38. There was agreement that the social support needed in the future should be offered to all persons with disabilities, regardless of diagnosis, and should be available outside of traditional medical or care systems. It was emphasized that that cross-disability perspective underlined the importance of the more general move against any involuntary loss of liberty and forced treatment for persons with psychosocial disabilities. A strong argument was made to remove traditional mental health services from their historic base within health systems and to reinvent them in the community.

Devolved budgets

39. Only a few States reported that they provided some form of devolved or personalized budget controlled by the individual. The World Health Organization (WHO) submitted detailed information on its model of personalized budget initiatives. To move the transformation agenda forward, it has made detailed recommendations, including: (a) enabling integrated, person-centred, accessible support and services across the life course; (b) ensuring universal access to assistive technology; (c) investing in support persons and personal assistants; and (d) developing comprehensive service delivery mechanisms. The submission also provided examples of small-scale devolved budgets, such as in the Italian city of Trieste,¹⁸ and a 2015 “personal budget pilot programme” in Israel that benefited 300 persons with disabilities. The project of the European Association of Service Providers for Persons with Disabilities entitled “UNIC: Towards user-centred funding models for long-term care” shows much promise.¹⁹

Boosting consumer power through positive wealth accumulation strategies

40. When queried about positive wealth accumulation strategies to enhance the consumer power of service users, most States simply pointed to general income-support policies. These responses point to a need for further work in this area.

Using public procurement to reshape the market

41. Finland reported that, as currently practised, public procurement policies tended to favour large providers and contributed to the consolidation of services and the closure of smaller disability organizations. Discussants at the expert consultation agreed that public procurement policy tended to be disconnected from the need to transform services and that procurement policies should require disability service providers to do meaningful human rights impact assessments.

42. Further, contract compliance procedures should be taken seriously, and those who fail to meet standards should be automatically disqualified from applying for, or obtaining, public contracts. Discussants asserted that public procurement systems needed to move decisively away from supply-side thinking that treated people like commodities to demand-based designs that took into consideration what persons with disabilities actually wanted. Whether such a move was possible was left open-ended. It was asserted that there could be alternative approaches to achieve the same ends.

Workforce challenges

43. Virtually all State respondents reported on workforce challenges and on the need for additional professionals. These challenges should be addressed in redesigning the service landscape. The Bahamas noted that its workforce needs were, in that regard, disproportionately reliant on immigrant labour.

¹⁸ See also Pina Ridente and Roberto Mezzina, “From residential facilities to supported housing: the personal health budget model as a form of coproduction”, *International Journal of Mental Health*, vol. 45, No. 1 (May 2016).

¹⁹ See <https://easpd.eu/project-detail/unic/>.

Role of families

44. Many States highlighted the pivotal role that families played in providing informal support. Inclusion Europe emphasized that formal services ought not to be the ultimate objective and stressed that as much as 80 per cent of all long-term support was provided by informal carers. It underscored that support policies and provision must take that fact into account and ensure that families did not bear the brunt of caregiving, including becoming “care managers, care administrators and service coordinators”.

45. The expert consultation participants noted that families had been taken for granted by States to make up for gaps in services, which had a disproportionate impact on women who typically took time out of the labour market to care for a family member with a disability, in turn potentially affecting their life goals and pension rights. In designing any new system, assumptions about the family taking on essential tasks must be set aside. There must be a much more intentional focus on the relationship between informal, family-led support and other, formal support. States should recognize the intersection of gender in the service paradigm and the largely unpaid role that women and girls play, and create more equitable policies.

46. The expert consultation participants also recognized that for some persons with disabilities, family could be a source of conflict, trauma and loss of agency. Overreliance on families may therefore hamper recovery, and a delicate balance is required. Certainly, the policy posture of the past – simply relying on families to absorb all and every support need – is not adequate for the future. There was a general agreement that family support must be based on the active consent of the service user.

Enforceable standards for service providers

47. With respect to the kinds of standards on which States insist for service providers, a minority of State respondents reported that they required providers to use person-centred practices and support for inclusion and choice. Other States reported that their standards were aimed primarily at accessibility and at health and safety. Many States conceded that the ongoing monitoring of service providers to ensure that they met the relevant standards was either non-existent or not systematic. Essentially, those services that were keen on change were left without a supporting policy ecosystem.

Services in the context of armed conflict

48. Some States experiencing armed conflict noted the support provided by international organizations to persons with disabilities and their families, including cash assistance programmes. Little thought has been given to developing services in the context of armed conflict or in their immediate aftermath.

Data for rational policymaking

49. Very few States reported collecting data on the impact of services on the daily lives of persons with disabilities. With respect to those State respondents that did, the data collection was primarily focused on the prevalence of specific impairments, reflecting the medical model. Australia reported on its ongoing practice of conducting surveys to understand how its National Disability Insurance Scheme was performing. Ireland conducted participant forums to solicit feedback on its individualized budgets pilot project. India noted that collecting outcome data was something that it aspired to initiate in the future.

Role of technology

50. Some States reported innovations used during the pandemic, including telehealth, allowing for virtual connections with clinicians and service providers. Such innovations point to the role of technology in the future in changing service paradigms. Mexico emphasized the impact of the digital divide. Some respondents expressed concerns that technology would “dehumanize” services, worsen isolation, damage mental well-being and eliminate choice. Curiously, few respondents pointed to the potential of artificial intelligence to help reshape and personalize services, which is a significant missed opportunity.

Cultural differences

51. Transforming Communities for Inclusion reported on its experience from the Asia-Pacific region and emphasized that certain elements of the goal of “living independently” might not fully capture the depth and spread of communal support that was essential in societies that were not Western or individualistic. Doubtless, cultural differences help shape the balance between formal and informal care worldwide.²⁰ Drawing on its experience in South Asia, Transforming Communities for Inclusion underscored the importance of moving mental health services out of the health sector and into the social support system.²¹

Cost–benefit analysis

52. Like many countries, Ireland has put into place a deinstitutionalization strategy.²² It reported that smaller, community-based support was more expensive than congregate facilities. While much has been done on the costs of change, there has been very little cost–benefit analysis on the overall benefits of developing new service models.

Role of development assistance

53. Nauru highlighted the particular challenges that small States in the South Pacific tended to face. The Government is the biggest employer in Nauru. Small island States face unique challenges in respect of promoting rights-based services aligned with the Convention. They are highly dependent on international aid, and they assert that they do not have the capacity to establish services in the absence of that support, which places a premium on what the role of investment through development assistance ought to be. Discussants at the expert consultation agreed that development assistance funding should be monitored to uphold human rights standards and not just compliance with narrow financial requirements. It was agreed that funding should not prolong legacy services such as group homes.

Housing

54. The availability and accessibility of housing was consistently noted by States as a challenge to providing support for people in the community. This challenge points to the need for much closer alignment between services policy and housing policy, which remains a major gap right around the world.

Assessment

55. Feedback from the call for input and the expert consultation strongly supported the following propositions.

56. First, progress towards centring persons in their own lives and their inclusion in the lives of their communities is constrained by an outdated service model, which sees persons with disabilities as passive recipients of largesse. There is a need for a new philosophy of services aimed at transformation and innovation, taking personhood and social inclusion seriously. A promising example is the recently adopted law in Israel on social services for persons with disabilities, which should enter into force in 2024.

57. Second, formal rights are not enough. Effective policies are needed to ensure that the human rights framework penetrates and changes the service delivery model. Most States have not included principles aligned with the Convention in service provider standards or procurement policies or their equivalent. There is little oversight of providers to determine whether they are adhering to human rights standards. Those many providers that do want to

²⁰ On culture and the Convention, see Emily Julia Kakoullis and Kelley Johnson, eds., *Recognising Human Rights in Different Cultural Contexts: The United Nations Convention on the Rights of Persons with Disabilities* (Singapore, Springer Nature, 2020).

²¹ Tina Minkowitz, *Reimagining Crisis Support: Matrix, Roadmap and Policy* (Chestertown, New York, Lilith’s Warrior Press, 2021).

²² See <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings—a-strategy-for-community-inclusion.pdf>.

change are constrained, if not penalized, by outdated policies and laws. That situation can and must change.

58. Third, the written submissions and expert consultation strongly suggest that innovations – when they exist – are unevenly used. Personalized budgets, positive wealth accumulation strategies, supported decision-making and the innovative use of artificial intelligence are still underutilized

59. Lastly, the move to a new paradigm requires intentional policies on the part of States that go beyond the mere assertion of rights to the development of a robust service. The lessons for international development assistance are clear.

D. Policy tools to reshape the market for services

60. In practical terms, then, what can and should States do to initiate the transition, and the change in mindset, towards a different model of services? States have a much wider repertoire of policy tools available to them than in the past to reshape the sector. What is needed is political will to redefine what the “public interest” demands against the backdrop of public investment. It requires a much more intentional approach to utilizing all available policy tools to reshape the sector accordingly. Some of these tools are highlighted in this section. An outstanding example of blue-sky thinking on new models is the 2022 research paper by the New Zealand Law Foundation entitled, *Removing Disabling Experiences: A Vision for the Future of Our People*.²³

Voice, choice and control: legal capacity reform

61. Reform of the service sector is directly connected to the full restoration of power to persons with disabilities over their own lives. At a minimum, it is what article 12 of the Convention requires. Legal incapacity laws substantially erode the power of an individual to control and direct their own lives.

Voice and the co-design of future service paradigms

62. Transitioning to any new service paradigm requires co-design from the outset and requires diverse voices around the table, those of representative of persons with disabilities as well as those of providers keen on change. Many States reported that they had established broad advisory groups that included persons with disabilities and family members. These forums need to be specifically tasked with ensuring the co-production of service redesign. Usefully, in the United States of America, the National Center on Advancing Person-Centered Practices and Systems has identified several strategies on how to successfully engage persons with disabilities in the co-design of services.²⁴

Power to the person: devolving budgets

63. The devolution of budgets to individuals with disabilities who can use them to hire the staff and purchase the goods and services that they need (as opposed to what others assume that they need) is a promising approach. It requires the handover of control of a notional budget from a service provider to the individual. In some systems, a service-broker role has evolved to negotiate services between providers and participants. A major challenge is how wide or narrow the spending discretion is (for example, whether it is confined to certain categories of expenditure) and the burden of management and accounting

²³ See https://www.lawfoundation.org.nz/wp-content/uploads/2022/08/2017.IRF_2-Removing-Disabling-Experiences-10-August-2022.pdf.

²⁴ National Center on Advancing Person-Centered Practices and Systems, “Engaging people who receive services: a best practice guide”, August 2020). Available at <https://ncapps.acl.gov/docs/Participant%20Engagement%20Guide%20200904.pdf>.

responsibilities imposed. Minimizing the management burden is especially important to ensure that personalization is available to all social groups.²⁵

64. Some countries have already innovated with personalized budgets.²⁶ Australia has made personal budgets the lynchpin of the delivery of services to persons with disabilities under the National Disability Insurance Scheme, enacted in 2013, which enables individuals to manage their own budgets, a provider organization to do so, or an agent to provide assistance. While the Australian reform is significantly more ambitious than other budget devolution initiatives, the numbers of people self-directing their own budgets is still relatively low. There is a reported resistance from some providers who prefer doing business in traditional ways, and the process has become bureaucratic. Concerns have arisen that the scheme has provided a cover for the withdrawal of some services. A review is now under way in Australia to rectify these challenges.²⁷

65. Ireland published the report of a major government task force on personalized budgets in 2018. The task force conducted extensive comparative research and led pilot projects to demonstrate the effectiveness of self-directed support.²⁸ The International Initiative for Disability Leadership, which combines leadership from both the disability community and the service sector, convened a workshop on personalized budgets in 2019.²⁹ It recommended reducing the complexity of the process, increasing outreach of information about the benefits of self-direction and ensuring that disadvantaged communities had access to personalized budgets. While much of the research points to many successes of devolved budgets,³⁰ there are reasons to be cautious. For one thing, the administrative burden can be overwhelming. It is not a solution for all. More careful study is needed on ways to make it work more effectively.

Novel ways to enhance consumer power

66. Traditional approaches to social services and income support tend to assume economic inactivity on the part of many persons with disabilities and therefore respond with passive income support. Typically, capital threshold rules apply, whereby an individual loses entitlement once savings or other assets reach a certain level, invariably meaning that individuals with disabilities must impoverish themselves to remain entitled.

67. The spectre of loss of benefits is a disincentive to employment and makes it impossible for individuals on social assistance schemes to build a financial cushion for such things as education and housing. Limiting resources is also a way that the traditional welfare model fosters the permanent dependence of individuals and relegates them to near poverty. It also deprives individuals of the ability to develop their own financial management skills.

68. One answer is to simply raise the capital thresholds. Another, however, is to find ways of enabling persons with disabilities to accumulate assets without any impact on their underlying social entitlements. One innovative programme that has addressed this disincentive is the Achieving a Better Life Experience, or ABLE, Act of 2014 in the United States.³¹ This legislation allows individuals receiving some social security benefits to set

²⁵ Gemma Carey, Brad Crammond and Eleanor Malbon, “Personalisation schemes in social care and inequality: review of the evidence and early theorising”, *International Journal for Equity in Health*, vol. 18, art. No. 170 (2019).

²⁶ Some examples are provided in the following study: Andrew Power, Janet E. Lord and Allison S. deFranco, *Active Citizenship and Disability: Implementing the Personalisation of Support* (New York, Cambridge University Press, 2012).

²⁷ See <https://www.ndisreview.gov.au/>.

²⁸ Ireland, Department of Health, *Towards Personalised Budgets for Persons with a Disability in Ireland: Report of the Task Force on Personalised Budgets* (Dublin, 2018).

²⁹ Valerie Bradley and others, “International advances in self-direction: themes from a disability leadership exchange”, *Journal of Integrated Care*, vol. 29, No. 3 (July 2021).

³⁰ Valerie J. Bradley, Marc H. Fenton and Kevin J. Mahoney, *Self-Direction: A Revolution in Human Services* (Albany, State University of New York Press, 2021).

³¹ See <https://www.ssa.gov/ssi/spotlights/spot-able.html>. See also David A. Rephan and Joelle Groshek, “ABLE Act accounts: achieving a better life experience for individuals with disabilities with tax-preferred savings (and the old reliable special and supplemental needs trusts)”, *Mitchel Hamline Law Review*, vol. 42, No. 3 (June 2016).

aside funds in an account that can be used to purchase goods, services and support without affecting their social entitlements. Third parties can invest in the account, often with tax incentives for those who contribute to the funds. It is a fiscally neutral innovation that enhances the consumer power of individuals with disabilities.³² It should never, however, be used as a substitute for adequate social provision.

Intentionally aligning disability rights with family policy

69. Across the world, at least 80 per cent of persons with disabilities are supported by families. There is now a consensus that the balance between formal and informal support needs to be thought through and not simply left to inference or policy defaults. If and when States rely on family support in the absence of formal provision, a unique set of challenges arise, such as whether family carers should be treated as professional caregivers, with payment and training. Some States, in their submissions, suggested a range of responses, including paying old-age pensions to long-term caregivers and providing them with human rights training to ensure the inclusion of their family members in their communities. On the other hand, Inclusion Europe argued that families should be able to be families, and not professional caregivers. The ultimate decision regarding the balance between formal and informal care and family support policy will, of necessity, depend on the resources and cultural norms of the State.

70. Finding the right balance is complicated as, in many parts of the world, the family is the paramount reference point for support, partly reflecting culture and partly reflecting the absence of funding resources for more formal systems. At a minimum, reliance on families requires some intentional policies dealing with family support. By definition, intensive consultation with families and with persons with disabilities is required. Furthermore, the disproportionate impact on women needs to be frankly acknowledged and addressed. An excellent resource and a model of sorts is the 2022 National Strategy to Support Caregivers, in the United States, and especially goal 3, to strengthen services and support for family caregivers.³³

Facilitating personal support plans

71. One way to provide assistance is to help people to devise a personal support plan that identifies paid support as well as informal and unpaid support. Plans can identify the support needed to reach goals over time and can also anticipate issues and challenges. Personal support plans can be beneficial in all economic contexts.

Public procurement

72. Through public procurement law, States can reshape markets (if markets are relied upon) to ensure better outcomes for persons with disabilities.³⁴ Clear standards can be developed, linking social support goals with procurement policies, gathering data to ensure compliance and imposing clear penalties for lack of compliance. Public procurement laws should reflect a vision of the type of services and support needed in the future and should give a preference for smaller-sized service organizations.

73. Standards should include person-centred principles, decision support, choice and control, administrative practices such as soliciting participant satisfaction, the inclusion of persons with disabilities as advisors, and workforce training. Standards should also be based on support approaches that have proven to be effective. Another approach that States may

³² See Sinéad Keogh and others, “Towards positive wealth accumulation strategies for persons with disabilities: linking social protection with social inclusion”, in *Active Citizenship and Disability in Europe*, vol. 1, *The Changing Disability Policy System*, Rune Halvorsen and others, eds. (London and New York, Routledge, 2017).

³³ See https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf. See also, more generally, Arie Rimmerman, *Family Policy and Disability* (Cambridge, Cambridge University Press, 2015).

³⁴ See, for example, Christopher McCrudden, *Buying Social Justice: Equality, Government Procurement and Legal Change* (Oxford, Oxford University Press, 2007).

want to consider is to designate a non-governmental entity to accredit disability providers based on best practice standards.

Competition law: reshaping the market for services

74. The service industry is currently exempt from many competition law regimes. The concentration of ownership in the form of large service entities militate against genuinely person-centred services. Further, anti-competitive practices and the abuse of the dominant position in the market tends to disincentivize newer organizations with innovative business models. Anti-competitive practices may also crowd out community-based organizations serving Indigenous and other racial and ethnic minorities. As States seek to attract new types of services, it is important that better use be made of competition law to reshape the market in the public interest.

75. A more intentional strategy is needed to grow and attract new providers. States cannot expect new providers to appear overnight. Public managers – in conjunction with disability organizations – can develop ways to build capacity among prospective and existing organizations. Materials and training protocols should be developed that spell out the expectations that surround the support ideology of choice and control with social inclusion.

Role of new technology

76. Advances in technology have made it possible for many persons with disabilities to more fully realize the promise of the Convention. Technological support include augmentative and alternative communication devices, sensory technology, smart homes, remote work, remote support, Global Positioning System navigation, voice-recognition programs, screen readers, screen-enlargement applications and adaptive equipment.

77. Artificial intelligence and machine learning promise enormous benefits for persons with disabilities, through such aids as Global Positioning System tracking and voice recognition. Crucially, the algorithms that drive the machine learning behind such devices do not routinely include valid data on persons with disabilities. For example, voice-recognition devices may not recognize deaf speakers. As the Special Rapporteur noted in his previous annual report to the Human Rights Council,³⁵ States have yet to grasp the balance of risks and opportunities presented by this new technology. The reshaping of services to make them much more personalized is one of the big prizes.

Rational workforce planning

78. The limited progress made on closing institutions and creating support in the community is being threatened by the continuing workforce crisis. Many service providers were forced to close programmes during the pandemic and now face challenges to reopen given staff shortages. This workforce largely comprises women and draws heavily from minority and immigrant communities. Without increases in compensation, training and recognition of the work provided, turnover and worker shortages are likely to continue, not to mention the disruption to the lives of persons with disabilities.³⁶ In many contexts, giving persons with disabilities the ability to hire people from their immediate community would both increase the availability of support and enhance cultural acceptability.

79. Workforce planning must become a key part of any future service paradigm. The European Association of Service Providers for Persons with Disabilities has highlighted the need for workforce development strategies, with many practical suggestions.³⁷

Government as a learning organization

80. Meaningful data must be collected on the impact of system changes on the lives of persons with disabilities. The 2021 report of the Office of the United Nations High

³⁵ A/HRC/49/52.

³⁶ For more information on the changing workforce context, as a result of both the pandemic and new technology, see <https://www.mckinsey.com/featured-insights/future-of-work> and <https://www.worldbank.org/en/publication/wdr2019>.

³⁷ See <https://www.easpd.eu/key-areas-of-work/workforce-development/>.

Commissioner for Human Rights on data for rational policymaking is an excellent start.³⁸ Few States reported that they canvassed persons with disabilities who were receiving services. States must acquire this data. The United States National Core Indicators on Intellectual and Developmental Disabilities,³⁹ which tracks the performance of State service systems, is but one example.

E. Business and human rights: the service sector as a partner for change

81. The provision of services for persons with disabilities in those countries that rely on market forces, and indeed not-for-profit services, is a multibillion-dollar industry. Despite some notable exceptions, the overall trend towards raising business's awareness of human rights over the past 20 years has hardly touched the disability service industry. An enhanced appreciation of the role of business in respecting human rights could potentially have dramatic effects in the service provision industry.

82. The primary bearers of human rights obligations are States. Yet, in many instances, private corporate power has more direct impact on ordinary lives than State power. A gap therefore arises in the application of international human rights norms to purely private relationships or entities. The Guiding Principles on Business and Human Rights were adopted by the Human Rights Council in 2011 to address corporate responsibilities, with clear implications for service delivery.⁴⁰

83. Principle 11 holds that businesses should avoid infringing on human rights and should address adverse human rights impacts with which they are involved. Business enterprises will need to consider additional standards, especially in relation to individuals belonging to groups that require particular attention, including persons with disabilities. Human rights due diligence and policy statements on human rights with respect to their activities are required and must be put in place as early as possible in the business cycle for the development of new products or services. Businesses should directly consult those who are most affected by their activities.

84. Many important elements of the service provider community around the world have already accepted these responsibilities. Importantly, in 2019, the European Association of Service Providers for Persons with Disabilities stated that care and support services in the disability field were key to unlocking the rights of persons with disabilities by contributing to the implementation of the Convention.⁴¹ The Association now presents "innovation awards" to service providers that excel in advancing the full inclusion of persons with disabilities. This highly imaginative practice ought to be emulated in other regions around the world.⁴² The industry-led accreditation bodies should explicitly factor the Convention into the mix.

85. Whether private or not-for-profit, services inhabit and respond to the prevailing policy and funding regime. They cannot change alone, and must be supported by an enabling policy landscape, which is the responsibility of the State. Under the European Union Strategy for the Rights of Persons with Disabilities 2021–2030, a specific framework for social services of excellence for persons with disabilities is to be produced by 2024.⁴³ This flagship initiative seeks to build on a voluntary framework developed by the European Commission's Social

³⁸ See <https://www.ohchr.org/sites/default/files/Documents/Issues/HRIndicators/GuidanceNoteonApproachtoData.pdf>.

³⁹ See <https://www.nationalcoreindicators.org>.

⁴⁰ A/HRC/17/31, annex.

⁴¹ See <https://www.easped.eu/key-areas-of-work/inclusive-living/>.

⁴² European Association of Service Providers for Persons with Disabilities, "EASPD Innovations Awards: 25 innovative practices for the inclusion of persons with disabilities" (2021), p. 5. See also <https://www.easped.eu/resources/innovation-awards/>.

⁴³ European Commission, *Union of Equality: Strategy for the Rights of Persons with Disabilities 2021–2030* (Luxembourg, Publications Office of the European Union, 2021), p. 12.

Protection Committee in 2010.⁴⁴ It is hoped and expected that the new framework will crystallize the responsibilities of European Union member States to reconfigure services to achieve outcomes that are more closely aligned with the Convention.

F. Policy dilemmas in the process of change

86. It is important to acknowledge that any process of transition will involve some hard policy choices. Some of the more important ones are highlighted below.

Market as a means and not as an end

87. The social economy – including, for instance, not-for-profit associations, mutuals, cooperatives and foundations – has the potential to align with the Convention. Where countries rely or partly rely on market forces, great care is needed to ensure that voice, choice and control do not automatically lead to an open-ended and effectively unsupervised marketplace. Particular care is needed to avoid reducing individual rights to consumer transactions and the commodification of the person. The State must always retain the role as supplier of last resort. There are some for whom markets will never be enough, and some substantive needs, such as housing, cannot be safely left to market forces.

Striking a balance between formal and informal support

88. The balance must be thought through, reasoned and made public, and cannot be left to inference or simply as a matter of default. Persons with disabilities must be placed at its centre: that is, their voice must be primary in any mix between formal and informal support and must be crucial in mapping the future.

89. The issue of family support tends to be divisive. Some advocates for organizations of persons with psychosocial disabilities make the point that families can be the source of trauma and conflict. They argue for policies that do not simply assume that the family is the best source of support for the individual. One eminent commentator, Yvette Maker, challenges the dichotomous nature of thinking between the rights of persons with disabilities and the “ethics of care” for carers.⁴⁵ She puts forward six principles to guide the development of a rights-based support policy in a highly imaginative approach, seeking to avoid the excesses of market economics in a field that ought to be animated by mutual dependency.

Need for equity between individuals and between groups of individuals

90. Mechanisms for the allocation of resources will still exist even after the individualization of services and support. While there will never be mathematical equivalence in resource allocation, since every person has different needs, there will still be a need to assure equity across and within groups. States will still have to find a balance that channels resources to those with the most pressing needs while trying to ensure the broadest possible provision of support. General principles in the application of economic, social and cultural rights should apply, especially when it comes to the ongoing obligation for progressive realization and the need to avoid retrogressive measures that create backward movement during periods of economic entrenchment.

Need to provide for continuity of support while changing the support landscape

91. The transition to a new support landscape will be risky and may create gaps. It will take service providers time to change their business models and practices. It will take time to attract new kinds of service providers with new business models. In the meantime, traditional support will be present. For a time, States may need to continue supporting elements of an old paradigm alongside a new paradigm that will need time to establish itself. In the long run, this kind of investment more than pays for itself, which places a premium on the partnership

⁴⁴ European Commission, Social Protection Committee, “A Voluntary European Quality Framework for Social Services” (document SPC/2010/10/8 final).

⁴⁵ Yvette Maker, *Care and Support Rights after Neoliberalism: Balancing Competing Claims through Policy and Law* (Cambridge, Cambridge University Press, 2022).

for change that should exist between States, persons with disabilities and their representative organizations and the service sector. The obvious need to maintain standards in any new service paradigm should not be used as a pretext simply to continue funding old models.

IV. Conclusions and recommendations

A. Conclusions

92. **There is a clear need to adopt a new philosophy to govern the design and delivery of support to persons with disabilities based on their moral agency, autonomy and social inclusion. States must transition away from service models based exclusively on impairment.**

93. **New kinds of partnerships are needed to realize this new philosophy. States must redefine the “public interest” and determine how to invest in and shape the provision of services, whether market-based or otherwise. Support must shift from medically dominated systems that rely on coercion to support that is freely chosen. Active consultation with persons with disabilities is therefore required, to determine what persons with disabilities need and want. The business sector must embrace its human rights responsibilities and become a partner for change.**

94. **Change requires a new lexicon that rejects labels such as “client”, “consumer” and “service user” and focuses on the core rights of citizenship. Policy tools to manage change include supported decision-making models to create individualized support, peer support networks, independent living centres, standards for public procurement and contract compliance, competition law to create space for new market entrants, and new technology, including artificial intelligence. The provision of support for families, collection of data on system performance, incentivization of new support providers, adoption of standards for service providers and enhancement of oversight and monitoring are likewise needed.**

95. **Lastly, donor countries and development assistance agencies must review their programming to ensure that funds – especially in the global South – are not prolonging legacy services. Instead, donors should be supporting initiatives that prioritize inclusion rather than separation and stigmatization.**

B. Recommendations

96. **The Special Rapporteur makes the following recommendations to States, the business community, civil society and the international system to begin the transition towards a new model of service design and delivery in the twenty-first century.**

97. **The Special Rapporteur recommends that States:**

(a) **Map existing services, both formal and informal, to identify gaps, tensions, funding models and expectations;**

(b) **Reconsider funding models, legal frameworks and reporting requirements to provide a supportive policy environment to enable providers to change;**

(c) **Redesign procurement policies or their equivalent to encourage and incentivize support providers whose practices align with the Convention;**

(d) **Redefine the “public interest” in public investment in the market for services consistent with the Convention and the needs of persons with disabilities to exercise moral agency and legal capacity and to experience social inclusion;**

(e) **Develop, in active consultation with the disability community, a new policy strategy aimed at the transformation of services, with clear aims, timelines, monitoring mechanisms and dedicated resources;**

(f) Explore the right balance between formal support and informal care and, where informal care is relied upon, work towards a new social contract to ensure that families, including siblings, have access to formal support as needed and that the persons with disabilities consent to family support;

(g) Match any new transformation strategy with a media campaign to introduce the general public to its aims and methods and highlight its benefits for all;

(h) Introduce devolved budgets, with appropriate support, to transfer financial agency to persons with disabilities, granting maximum possible discretion in spending and minimizing burdensome administrative responsibilities;

(i) Develop protocols on supported decision-making in the specific context of services;

(j) Develop positive wealth accumulation strategies to enhance the consumer power of individuals with disabilities without jeopardizing or withdrawing existing social entitlements;

(k) Create service standards and licensing requirements that are based on the Convention;

(l) Adopt a supportive policy environment to incentivize and motivate providers;

(m) Hold providers accountable to standards by monitoring performance;

(n) Nurture and support new service provider organizations led by persons with disabilities and aligned with service standards and requirements based on the Convention, and foster entrepreneurship;

(o) Study the potential of public procurement policy closely and consider how it might be switched from being fixated on costs to positively attracting and incentivizing new models of service with different business models based on the Convention, and examine all alternatives;

(p) Harness the licensing power of the State to grant licences only to those business organizations that are committed to change and to the Convention;

(q) Rethink the utility of competition law in this field, and study its potential in reshaping the field;

(r) Design a workforce development strategy that is realistic, has clear and sustainable career structures, creates space for the work (as opposed to creating excessive reporting requirements on the work) and supports a decent wage;

(s) Explore the optimal role of new technologies, including artificial intelligence, in assisting in the personalization of services while ensuring that technology does not become a substitute for the human touch;

(t) Provide access to independent complaints mechanisms that service users can utilize without fear of retaliation or reprisals, and take the results seriously when making public contracts;

(u) Ensure that Government is equipped as a learning organization with the means and data necessary to assess whether the new strategy is improving the lives of persons with disabilities and to make appropriate corrections.

98. The Special Rapporteur recommends that businesses in the not-for-profit and private sector:

(a) Conduct human rights impact assessments to ensure maximum compliance with the Convention, with the active involvement of persons with disabilities;

(b) Develop and publicize policies that specify how the businesses will contribute to the human rights of persons with disabilities and avoid or mitigate human rights risks that may negatively affect them;

(c) **Review organizational missions and business models to ensure that activities are aligned with the Convention;**

(d) **Ensure that compliance with the Convention is a core requirement of engagement with any accreditation mechanism;**

(e) **Introduce independent mechanisms for the users of services to submit feedback and complaints;**

(f) **Set aside places for persons with disabilities on governing boards;**

(g) **Ensure that the process for designing new models of services includes persons with disabilities, with adequate support where needed;**

(h) **Respect the contributions of support staff through the provision of training on the Convention, the creation of clear career ladders, their involvement in decision-making, and the provision of a decent wage;**

(i) **Encourage the growth of regional networks of providers around the world that are committed to the Convention.**

99. **The Special Rapporteur recommends that organizations of persons with disabilities:**

(a) **Organize locally and nationally to advocate innovation based on a new support philosophy, and adopt a media strategy to support the transformation process;**

(b) **Contribute actively and directly to all processes leading to new national strategies in the transformation of services;**

(c) **Seek common ground in coalitions with other organizations of persons with disabilities that are inclusive of the broad diversity of the disability community in order to maximize voice and impact;**

(d) **Provide training and assistance to persons with disabilities to equip them with the information that they need to participate effectively in the co-production of public policy;**

(e) **Assist in the growth of user-led enterprises to take a leading role in pioneering new business models;**

(f) **Enter into alliances with the business sector, in the spirit of the Guiding Principles on Business and Human Rights, to assist in the process of change;**

(g) **Take an active role in the licensing and accreditation procedures of both Government and networks of enterprises, and monitor their outcomes closely.**

100. **The Special Rapporteur recommends that the United Nations system:**

(a) **Encourage the Committee on the Rights of Persons with Disabilities to continue its efforts to connect service transformation with the underlying obligations of States parties under the Convention, and to provide useful guidance to States parties;**

(b) **Encourage the World Bank to continue its efforts to guide States as they develop more inclusive and resilient service models and to highlight the benefits of such models for all;**

(c) **Ensure that United Nations specialized agencies with a focus on service development, such as the United Nations Development Programme and WHO, work to ensure that services meet the goals of moral agency and social inclusion;**

(d) **Ensure that a wholly new philosophy of support and services is developed in United Nations dialogue on the future of “care”, taking its cue from the Convention.**

101. **The Special Rapporteur recommends that the international donor community:**

(a) **Cease investment in outmoded service delivery models and assist in the development of new models from the ground up, based on moral agency and social inclusion;**

(b) **Continue efforts to generate a more resilient service landscape in the future and to provide technical assistance on how to do so in compliance with the Convention;**

(c) **Invest in the capacity of the community of persons with disabilities to advocate Convention-compliant service paradigms and to implement services run by and for persons with disabilities, including centres for independent living, and encourage entrepreneurship in the community;**

(d) **Monitor funding to assess the human rights impact of development cooperation and assistance.**
