IDA
International
Disability Alliance

GUIDE FOR ORGANISATIONS OF PERSONS WITH DISABILITIES:

Driving health equity for persons with disabilities through inclusive health system strengthening

Guide for Organisations of Persons with Disabilities:

Driving health equity for persons with disabilities through inclusive health system strengthening

A. Introduction

This guide is designed to encourage Organisations of Persons with Disabilities (OPDs) to actively participate in health system strengthening processes to ensure health equity for persons with disabilities. The approach, grounded in the Convention on the Rights of Persons with Disabilities (CRPD), is to use OPD advocacy for disability-inclusive approaches at every stage of health system planning, policy design, implementation, service delivery and monitoring and accountability. The ultimate goal is to have active and meaningful participation of OPDs across the health system, which will help create sustainable, inclusive, accessible, and equitable health policies and practices, to realise the right to the highest attainable standard of health of persons with disabilities.

B. Objectives

i. Strengthen OPD participation across health sector planning, assessments, implementations, and monitoring processes.
ii. Advocate for health systems, laws, policies, processes and health services that are accessible, affordable, quality, and ensure health equity for persons with disabilities.
iii. Develop OPD-led partnerships with Ministry of Health (MoH), healthcare providers, and other stakeholders to promote an enabling environment for disability inclusion in the health agenda.

C. Key advocacy areas for OPDs

National legislation and policy: advocate for the integration of disability rights within national legislation and policies, leveraging the CRPD, to provide legal protections for persons with disabilities in the health sector.

Health strategies and plans: work with health authorities to embed disability inclusion within national health strategies, policies, and strategic plans, ensuring that persons with disabilities are a priority in public health goals and outcomes.

Governance and coordination: promote governance structures that incorporate OPD representation in oversight, accountability, and decision-making mechanisms, ensuring that disability-inclusive health initiatives are systematically prioritised and monitored.

D. Phases of engagement

Phase 1: preparation for engagement

Building partnerships

- Identify key partners: build connections with government health bodies, healthcare providers, and other stakeholders.
- Formulate multi-stakeholder groups: ensure OPD representation in multi-stakeholder decision-making bodies to advocate for inclusive health policies, including feminist organisations and other civil society groups/movements.
- Share knowledge: actively disseminate insights regarding disability-related barriers and potential solutions with these partners to foster understanding and collective action.

Clarifying roles and responsibilities

- Define group roles: clearly outline roles within multi-stakeholder groups, with an emphasis on disability-inclusive objectives.
- Secure resources: advocate for resources to support OPD participation, such as funding for accessible transportation, interpreters, and technology for participation.

Resource mobilisation

- Identify funding sources: seek government, international organisation, or NGO grants to fund OPD activities.
- Allocate internal resources: dedicate funds for OPD training and awareness initiatives to build capacity and expertise within the organisation.

Phase 2: assessment of health systems

Conduct community consultations

- Organise inclusive consultations: use focus groups or surveys to understand the specific barriers persons with disabilities face in the health system.
- Ensure diverse representation: include perspectives from different age groups, genders, and disability types, especially underrepresented groups like those with psychosocial or intellectual disabilities.

Participate in health sector assessments

- Engage with health authorities: join data collection and assessment efforts led by the MoH and other health bodies.
- Provide insight on barriers: share findings from OPD-led consultations that highlight common barriers such as inaccessible facilities and discriminatory practices.

- Promote disability-disaggregated data: recommend disability-specific data collection in national health surveys to capture health inequities and needs accurately.
- Support data on disability types and health barriers: propose detailed data collection on different disability types to identify gaps in health equity.

Phase 3: designing disability-inclusive health actions

Identify and prioritise actions

- Work with health authorities: collaborate with the MoH to select impactful disability-inclusive actions, like enhancing facility accessibility and training health staff.
- Prioritise based on urgent needs: focus on high-impact areas identified during consultations, such as primary care access, maternal health services, and mental health care.
- Develop a monitoring and evaluation (M&E) framework.
- Advocate for disability indicators: suggest specific disability-inclusive indicators, such as the number of accessible facilities and percentage of trained health workers.
- Monitor outcomes for persons with disabilities: ensure that the M&E framework comprehensively tracks outcomes and areas for improvement.
- Review health action plans: offer feedback to ensure OPD priorities are reflected in the final action plan.
- Ensure resource allocation: confirm that the action plan includes necessary resources, clear timelines, and transparent progress reporting.

Phase 4: implementation and sustenance of inclusive practices

Promote awareness and capacity-building

- Conduct disability inclusion training: work with the MoH to deliver disability inclusion training for health workers to improve understanding and skills in providing inclusive care.
- Educate OPD members on health rights: equip OPD members with knowledge about health rights and the health system to empower local advocacy.

Monitor progress and report outcomes

- Track implementation using M&E framework: regularly document successes, challenges, and lessons learned to assess the effectiveness of inclusive policies.
- Share success stories: highlight stories from individuals benefiting from inclusive health policies to build momentum and demonstrate the impact.

Advocate for reviews and further change

- Promote regular reviews: encourage the MoH and stakeholders to review disability-inclusive actions periodically and incorporate new findings into national health strategies.
- Ensure sustained engagement: maintain active partnerships with the MoH and other stakeholders to uphold a continuous commitment to disability-inclusive health practices.

E. Suggested indicators on health equity for persons

a) Disability inclusive national health policies, strategies, and plans (NHPSPs): percentage of NHPSPs developed over a defined time period with concrete actions on disability inclusion.
b) Governance: existence of a focal point/committee to oversee disability inclusion in the health sector.
c) Disability inclusive health budgeting: expenditure on disability inclusion in health (including reasonable accommodation, making healthcare facilities, and services accessible).
d) Health insurance coverage among persons with disabilities: percentage of women, men, and children with disabilities with any type of health insurance.
e) Multi-stakeholder coordination on disability inclusion: existence of a coordination mechanism to ensure disability-inclusive health services.
f) Participation of persons with disabilities in health service decision-making: existence of national, subnational, and local strategies for participation of persons with disabilities and their representative organisations in community decision-making on health services.
g) Standards and guidelines on accessible health facilities and services: existence of accessibility standards or guidelines for health facilities and services.
h) Physical accessibility of health facilities: percentage of health facilities that meet accessibility standards and guidelines.
i) Accessible health information and communication: percentage of health facilities which have health information and communication available in accessible formats, e.g., Braille, Easy-Read, captioning, sign language.
j) Health worker training on disability inclusion: percentage of accredited health training courses (pre- and in-service) with an appropriate disability inclusion module.
k) Health workforce diversity: percentage of health workforce who identify as having a disability (disaggregated by sex, age, and type of role).
l) Standards on digital accessibility: existence of national-level digital accessibility standards, aligned with international standards and guidelines.

m) Access to telemedicine services for persons with disabilities: percentage of persons with disabilities reporting access to telehealth services (disaggregated by sex, age, and type of service).
n) Inclusive essential health service package planning: guidelines on disability inclusion in the essential healthcare package are adopted.
o) Proactive population outreach includes persons with disabilities: percentage of community-based health service guidelines with concrete actions on disability inclusion.
p) Disability-inclusive quality improvement and safety planning at national levels: national policy, strategy, or plan for improvement of quality and safety includes concrete actions relating to the rights of persons with disabilities.
q) Disability-inclusive quality improvement mechanisms in health facilities: percentage of facilities with disability integrated into systems to support quality improvement.
r) Existence of strategies to maintain essential health services for persons with disabilities during health emergencies: national health emergency and disaster risk management strategy or plan includes concrete actions to ensure continuity of services and emergency-related health support for persons with disabilities.
s) Inclusive essential health service delivery: percentage of health facilities implementing guidelines on disability inclusion in the essential healthcare package.
t) Barriers to accessing health services: perceived barriers to access (geographical, financial, sociocultural) for persons with disabilities.
u) Experience of care: (a) percentage of persons with disabilities reporting satisfactory care; (b) percentage of complaints from persons with disabilities, disaggregated by sex, age, and type of complaint.
v) Poverty: percentage of persons with disabilities living below the international poverty line.
w) Social protection: percentage of persons with severe disabilities receiving cash benefits, by sex.
x) Education: percentage of persons with disabilities accessing different levels of education, disaggregated by sex and age.
y) Employment: percentage of persons with disabilities who are unemployed, disaggregated by sex and age.
z) Health risk factors: percentage of persons with disabilities who have tracer risk factors for poor health (e.g., child stunting/wasting, tobacco use, prevalence of hypertension).
aa) Health service coverage for persons with disabilities: percentage of persons with disabilities receiving tracer health service interventions, disaggregated by sex and age.

bb) Catastrophic health expenditure: percentage of persons with disabilities who live in households with catastrophic health expenditure and/or impoverishing health spending compared to those without disabilities.
cc) Emergency vaccination: percentage of persons with disabilities who receive routine and emergency vaccines compared to those without disabilities.
dd) Emergency health interventions: percentage of persons with disabilities who receive emergency-related interventions compared to those without disabilities.
ee) Public health intervention coverage for persons with disabilities: percentage of persons with disabilities who receive tracer public health interventions, disaggregated by sex and age.
ff) Life expectancy at birth: life expectancy at birth in years for women and men with disabilities.
gg) Maternal mortality ratio: number of maternal deaths during a given time period per 100,000 live births during the same time period among women with disabilities.
hh) Mortality due to NCDs: percentage of deaths among women and men with disabilities due to NCDs (cardiovascular, cancer, chronic respiratory disease, and diabetes).
ii) Health conditions due to avoidable causes: percentage of persons with disabilities who acquire tracer avoidable conditions, disaggregated by sex and age.

F. Questions OPDs can ask Ministries of Health

1. Political commitment, leadership, and governance
    - What are the MoH's main leadership and governance priorities for the upcoming years?
    - How is disability inclusion incorporated into these priorities?
    - Is there evidence of implementation (reports, evaluations, data)?

2. Health financing
    - What are the key health financing priorities (e.g., healthcare packages, insurance schemes)?
    - How is disability inclusion considered in these financial plans?
    - Is there evidence of implementation?

3. Stakeholder and private sector engagement
    - What are the priorities for engaging stakeholders and private sector providers?
    - How is disability inclusion addressed within these engagements?
    - Is there evidence of implementation?

4. Models of care
    - What are the priorities for models of care across primary, secondary, and tertiary levels?
    - How is disability inclusion integrated into these models?
    - Is there evidence of implementation?

5. Health and care workforce
    - What are the workforce development priorities (e.g., training, accreditation)?
    - How is disability inclusion reflected in workforce planning?
    - Is there evidence of implementation?

6. Physical infrastructure and communication
    - What are the priorities for health infrastructure and communication (e.g., facility construction, health campaigns)?
    - How is disability inclusion incorporated into infrastructure plans?
    - Is there evidence of implementation?

7. Digital health technologies
    - What are the digital health priorities (e.g., telemedicine, e-learning platforms)?
    - How is disability inclusion considered in digital health strategies?
    - Is there evidence of implementation?

8. Quality of care systems
    - What are the priorities for improving quality of care (e.g., user satisfaction, facility assessments)?
    - How is disability inclusion embedded in quality care initiatives?
    - Is there evidence of implementation?

9. Monitoring and evaluation
    - What are the priorities for health monitoring and evaluation (e.g., health information systems)?
    - How is disability inclusion integrated into M&E frameworks?
    - Is there evidence of implementation?

10. Health policy and systems research
    - What are the health policy and systems research priorities?
    - How is disability inclusion reflected in research priorities?
    - Is there evidence of implementation?

G. Draft model letter to write to Ministry of Health

Dear *Minister of Health*,

On behalf of [*OPD]* I'm reaching out to express our commitment to creating a health system that fully includes and addresses the needs of persons with disabilities in [X Country]. We recognise and appreciate the government's dedication to equitable health services, and we respectfully urge further action to integrate the rights of persons with disabilities into the heart of our national health policies, strategies, and decision-making processes.

Our nation's commitment to disability rights and the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) is an excellent basis to advance in delivering inclusive health services. We wish to highlight the importance of World Health Assembly resolution 74.8 and the WHO Global Report on Health Equity for Persons with Disabilities (2022), which provides important technical guidance on this important topic. While we have made strides in many areas of disability rights in [X country], persons with disabilities still face barriers that prevent equal access to quality healthcare.

We respectfully suggest that by formally incorporating the rights of persons with disabilities into health laws and policies, we can establish a strong legal foundation that holds everyone accountable. Additionally, updating policies to address barriers faced by persons with disabilities will provide clear direction and support for healthcare providers across the country.

To truly meet the needs of all, we urge the Ministry to place disability inclusion at the centre of its health strategies and planning. We propose that the Ministry of Health define specific, measurable goals to guide our progress. Setting these objectives will help keep us on track. As we know well, the targets must be resourced, including resources to improve accessibility and train health professionals in disability-inclusive practices are crucial steps to achieving an equitable system.

We strongly advocate for the inclusion of persons with disabilities through their representative organisations (OPDs) in governance and decision-making. Involving OPDs will help ensure that health services genuinely reflect the needs and experiences of the people they are designed to serve. We suggest the creation of a national Disability Inclusion and Health Equity Committee, which would have OPD representatives as well as Ministry of Health staff, and the Committee could lead efforts to coordinate and advance disability-inclusive policies. Beyond this, routine consultations with OPDs will provide valuable feedback, allowing the Ministry to adapt and improve services based on the lived experiences of persons with disabilities.

We wish to advocate for the Ministry to establish a monitoring and evaluation framework that includes specific indicators to track the impact of these disability-inclusive actions and identify areas for improvement. This would involve setting disability-inclusive indicators**.** For example, measuring the number of accessible facilities and the percentage of trained health workers would provide clear data on progress. The health action plan should allocate resources and set clear timelines to ensure implementation and transparency.

We also believe that OPDs should actively participate in health assessments, as they can offer valuable insights into the barriers faced by persons with disabilities. To facilitate this, stronger data-disaggregation efforts are needed. This data is crucial to understanding health inequities and better designing targeted interventions. OPDs can highlight common challenges, such as inaccessible facilities and negative attitudes, which will inform efforts to improve accessibility and inclusion.

Lastly, it's essential that we foster a culture of disability inclusion within the healthcare sector. This could include OPDs working with the Ministry to provide training would give health workers the knowledge and skills to provide more inclusive care.

In closing, we believe that by embedding disability rights and inclusion within the health sector's policies and daily practices, we can build a health system that serves everyone equally. [*OPD Organisation's Name*] welcomes the opportunity to collaborate with the Ministry of Health to make these changes a reality.

Thank you for your dedication to promoting health equity, and we look forward to working together on this essential effort.

Yours sincerely,

OPD

References

1. World Health Organization (2022) *Global report on health equity for persons with disabilities*. Geneva: World Health Organization. Available at: https://www.who.int/publications/i/item/9789240063600
2. World Health Organization (2020). *Disability-inclusive health services toolkit: a resource for health facilities in the Western Pacific Region*. Geneva: WHO. Available at: https://www.who.int/publications/i/item/9789290618928
3. World Health Organization (2018). *Primary health care measurement framework and indicators: monitoring health systems through a primary health care lens*. Geneva: WHO. Available at: https://www.who.int/publications/i/item/9789240044210
4. World Health Organization (2012). *QualityRights Toolkit: assessing and improving quality and human rights in mental health and social care facilities*. Geneva: WHO. Available at: https://www.who.int/publications/i/item/9789241548410
5. World Health Organization (2019). *Voice, agency, empowerment – handbook on social participation for universal health coverage*. Geneva: WHO. Available at: https://www.who.int/publications/i/item/9789240027794
6. World Health Organization (2016). *The Innov8 approach for reviewing national health programmes to leave no one behind*. Geneva: WHO. Available at: https://www.who.int/publications/i/item/9789241511391
7. World Health Organization (2019). *Handbook for Conducting Assessments of Barriers to Effective Coverage with Health Services – in support of Equity-oriented Reforms towards Universal Health Coverage*. Geneva: WHO. Available at: https://www.who.int/publications/i/item/9789240094765
8. World Health Organization (2016). *Strategizing national health in the 21st century: a handbook*. Geneva: WHO. Available at: https://www.who.int/publications/i/item/strategizing-national-health-in-the-21st-century-a-handbook
9. World Health Organization (2018). *Health Systems Performance Assessment Framework for Universal Health Coverage*. Geneva: WHO. Available at: https://www.who.int/publications/i/item/9789240042476
10. World Health Organization (2020). *Harmonized Health Facility Assessment (HHFA): comprehensive health service availability and readiness assessment methodology*. Geneva: WHO. Available at: https://www.who.int/data/data-collection-tools/harmonized-health-facility-assessment/introduction

IDA
International
Disability Alliance