# Disability Human Rights Research Network (DHRRN)

# Protocol for Rights-based Disability Research in all Fields

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## Disability human rights research is:

* Research that is consistent with the *Convention on the Rights of Persons with Disabilities*.

**Disability human rights research is not:**

* Research that conflicts with, undermines or contradicts the *Convention on the Rights of Persons with Disabilities*, even if it is claimed to be ‘rights-based’.

## Three Principles for Rights-Based Disability Research

1. **Initiated and led by voices from the disability community**
2. **Responds to a rights concern in the disability community**
3. **Outputs directly address the rights concern and are returned to the community in accessible formats**

## Initiating and Designing Research

Initiation of Research**:** Research is initiated by researchers either responding to, identifying, or being commissioned by the voices of the disability community, including:

* Policy documents or other statements from Disabled Persons’ Organizations (DPOs).[[1]](#footnote-1)
* Dialogue between researchers and DPOs, facilitated by formal avenues for interaction.
* Findings of other rights-based research from all parts of the world.
* Findings of the United Nations Committee on the Rights of Persons with Disabilities, the United Nations Special Rapporteur on the Rights of Persons with Disabilities, and other United Nations mechanisms and agencies.

Research Design: Research is primarily led and guided by the voices of the disability community.

* The disability community must have ownership and guidance of research in all phases of the research process – from research design to dissemination of findings.
* The involvement of the disability community must be undertaken with due recognition of intersectionality.
* Research methodology must involve researchers with disabilities and/or have involvement from the disability community through ‘community research fellows’ or other means.
* An advisory panel that is inclusive of the voice of people with disabilities and DPOs must be established.
* There must be equal reward for participation in research by disabled and non-disabled researchers.
* All aspects of the research process must be accessible, including research venues, materials, equipment and results.

**Remuneration for Experiential and Professional Experts with Disabilities**: all research with persons with disabilities shall be designed such that persons with disabilities are monetarily recompensed for their time and expertise.

* Monetary recompense must be independent of any expenses that the person may incur towards transportation, personal assistance or any other disability-linked expense;
* Monetary compensation shall be included in budget planning and funding applications, and funders should be apprised of this ethical requirement when considering an application.
* The principle of equal pay for equal work shall be followed when determining the pay rates of experts with disabilities in a project. Such equality would require that a disability accommodation allowance is paid to such expert with disability.

## Responding to a Rights Concern

Aims: Research responds to a rights concern. It should:

* take a human rights approach to disability;
* relate to the exercise and realisation of the rights guaranteed in the *Convention on the Rights of Persons with Disabilities* (CRPD);
* directly respond to current or historical violations or potential violations of one or more of the articles of the CRPD and instigate social change to rectify such violations;
* empower persons with disabilities and their representative organisations to pursue the realisation of the rights of persons with disabilities.

## Outputs Addressing the Concern and Returning to the Community

Outputs: Research directly promotes the social change necessary to secure the relevant rights and ensure the obligations under the CRPD are being met.

* Research outcomes and research data must be published in accessible formats.
* Research outcomes and research data must be made freely available to all stakeholders to the extent that access is consistent with privacy and confidentiality considerations.
* Agents of change must be identified and targeted to ensure that research findings are translated into action that advances the rights of persons with disabilities.

## Further Ethical Considerations

Policies and Guidelines: A university or research institution’s ethical policies or guidelines must:

* be made publicly available (for example, on the research institution’s website) **in accessible formats**;
* incorporate the principles of the CRPD.

Informed consent**:** All research must ensure the informed consent of participants.

* Research must comply with the prohibition on medical or scientific experimentation without informed consent in art 15 CRPD.
* Free and informed consent must be sought and obtained from all research participants at the beginning of the research process.
* Giving or refusing consent is an exercise of legal capacity, and research must recognise the universal right to legal capacity and comply with the prohibition on the denial of legal capacity on the basis of disability, in art 12 CRPD. This requires an assumption of legal capacity and every effort to be made to get full and informed consent from all research participants themselves.
* Supports necessary for giving or refusing consent must be provided to all research participants. For example, providing information in an accessible format, utilising supported decision-making procedures, allowing sufficient time to understand and respond to information, treating consent as a continuous process that can be withdrawn at any time, providing options for non-verbal communication of consent, using peer researchers, and using accessible venues.

Data collection and management**:** Procedures for research data collection, management and protection must be consistent with art 31 CRPD.

* Research must ensure confidentiality and respect for the privacy of persons with disabilities in data collection and protection.
* Research must comply with international norms and ethical principles in the collection and use of statistics.
1. The United Nations Committee on the Rights of Persons with Disabilities defines DPOs as, ‘those comprised by a majority of persons with disabilities - at least half of its membership -, governed, led and directed by persons with disabilities’: see *Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the work of the Committee*, April 2014, CRPD/C/11/2 Annex II, para 3. [↑](#footnote-ref-1)