Monitoring Methodology

DIS-CONNECTED: DISABILITY-BASED CONNECTED FACILITIES AND PROGRAMMES FOR PREVENTION OF VIOLENCE AGAINST WOMEN AND CHILDREN

101049690- DIS-CONNECTED

Disability-based connected facilities and programmes for prevention of violence against women and children (101049690 – CERV-2021-DAPHNE)

HUNGARY: Monitoring Methodology

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INTRODUCTION

About DIS-CONNECTED

The Disability-based Connected Facilities and Programmes for Prevention of Violence against Women and Children (DIS-CONNECTED) project focuses on women and children with intellectual and psychosocial disabilities who are victims of violence in facilities and programmes designed to serve them. The project will create a multi-disciplinary cooperation and response protocol with law enforcement, service providers and victim support workers to enable prevention, early identification, and protection against violence that women and children with psychosocial and/or intellectual disabilities face. Specifically, the project objectives are to:

- Improve reporting of violence through enhancing the knowledge base and improving monitoring relating to violence against women and children with mental disabilities in facilities and programmes that serve them;
- Build the capacity of independent professionals to prevent, detect and facilitate reporting of and redress for violence against women and children with mental disabilities;
- Enhance on-going cross-disciplinary reporting and response mechanisms through practical protocols;
- Improve access to services through the development of practical protocols and accessible online geo-location maps to signpost where victims should go to obtain the support they need;

The project is being implemented in Bulgaria, Hungary, Lithuania, Portugal and Slovakia from March 2023 to February 2025.

The findings of the monitoring visits carried out in the target countries

Research in the project countries has shown that there are various gaps in the social care system, criminal justice system and victim support system related to the prevention and reporting of violence against women and children with intellectual and psychosocial disabilities and supporting victims. Women and children with disabilities living in Bulgaria, Hungary, Lithuania, Portugal and Slovakia often do not recognise violence committed against them due to a lack of access to education on rights and violence. Many professionals who work with persons with disabilities also lack adequate training and tools to address violence. Gaps in the criminal justice system and victim support system include a lack of reasonable and procedural accommodations for victims with disabilities and difficulties with access to information and resources. On a societal level, stigma surrounding disability and gender-based violence also contribute to a lack of awareness and violence cases remaining uncovered.

Based on the analysis of the data, several recommendations have been formulated in the National Briefing Papers pertaining to these issues. First, disaggregated data collection related to child and women victims of violence with disabilities in the justice system would be crucial to have a better understanding of the issue. Education and training related to violence prevention for professionals working with people with disabilities as well as to people with disabilities would be essential to enable them to recognise and address cases of abuse. Awareness-raising on violence against women and children with disabilities for the general public is also needed.

Regarding the justice system and victim support system, there is a need for more training, better cooperation among actors and establishing clear protocols. Professionals across the criminal justice system and in victim support system should have more knowledge on working with people with people with disabilities. Enhanced cooperation among authorities and organisations, having clear protocols on handling violence cases as well as clear referral procedures would also be important to better support victims and avoid secondary victimisation.

Finally, improved monitoring is a key component in working towards reducing violence against women and children with disabilities. Establishing effective monitoring services in institutions and community-based services could enhance both preventing and addressing violence. Regular and ad hoc monitoring visits, with the participation of persons, especially women, with disabilities and independent non-governmental organisations, guided by the UN Convention on the Rights of Persons with Disabilities (CRPD) framework would largely contribute to uncover abuse.

Aims of the Monitoring Methodology

As noted above, people with intellectual and psychosocial disabilities are often subject to poor-quality care and violations of their human rights.[1] This is especially the case for those segregated from society as the result of their placement in institutions that include, but are not limited to, social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based centres, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels, leprosy colonies and other congregated settings.[2] Women and children can be especially at risk[3] of violence and abuse.

While States must fulfil their obligations to implement the right of people with disabilities to live in the community, it is still critical to assess the observance of human rights in these institutions, as well as in community-based services. The UN Committee on the Rights of Persons with Disabilities stressed in the *Guidelines on deinstitutionalization, including in emergencies* that "definitions of community-based support services, including in-home and other support services, and personal assistance should prevent the emergence of new segregated services, such as group housing – including small group homes – sheltered workshops, institutions for the provision of respite care, transit homes, day-care centres, or coercive measures such as community treatment orders, which are not community-based services."[4] A comprehensive monitoring of facilities can help to identify human rights violations and to promote the users' autonomy, dignity and right to self-determination.

[1] World Health Organization (2012). Quality Rights Tool Kit, p. 1. available at: https://www.who.int/publications/i/item/9789241548410, last accessed 10 September 2024.
[2] CRPD Committee (2022). Guidelines on Deinstitutionalization, Including in Emergencies. CRPD/C/5, para 15. available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/5, last accessed 10 September 2024.
[3] Please see the National Reports on Bulgaria, Hungary, Lithuania, Portugal and Slovakia from the DIS-CONNECTED project for more information. The National Papers are available here: https://validity.ngo/projects-2/dis-connected/national-reports/, last accessed 10 September 2024.
[4] CRPD Committee (n 7), para 28.

This monitoring methodology aims at the detection and reporting of domestic violence and violence in facilities and programmes that focus on persons with intellectual and psychosocial disabilities. It contains the relevant legal norms and standards, practical guidance on risk factors and monitoring methods, and a break down on the main principles and steps of human rights monitoring. The methodology supports the training of multi-disciplinary monitoring teams to conduct monitoring of services and programmes and should be used together with the Monitoring handbook.

Our monitoring methodology is intended to be used by monitoring teams created within the DIS-CONNECTED project; to carry out monitoring visits aimed to prevent, early identify and address violence against women and children with disabilities. However, the methodology can be of benefit to any non-governmental organisation who wish to carry out monitoring, as well as to national human rights institutions.

Methodology

The methodology is based on the United Nations Convention on the Rights of Persons with Disabilities, the United Nations Convention on the Rights of the Child, the United Nations Convention on the Elimination of All Forms of Discrimination Against Women, United Nations Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, and builds on the Validity Foundation's and consortium partners' expertise and experience in human rights monitoring in psychiatric and social care institutions. This includes exposing abuses against children with disabilities[5] and investigating access to justice for children with intellectual and psychosocial disabilities.[6]

The monitoring methodology was also inspired by the content of the Ithaka Toolkit for monitoring Human Rights and General Health Care in mental health and social care institutions (2010),[7] the CHARM toolkit[8] and the World Health Organization (WHO) Quality Rights Tool Kit for assessing and improving quality and human rights in mental health and social care facilities (2012).[9]

[5] MDAC, GIP, LIGA, ACT (2017). The CHARM Toolkit - The Child Human Rights Abuse Removal Monitoring Toolkit. available at: https://www.mdac.org/en/charm-toolkit, last accessed 10 September 2024.
[6] Training materials and other deliverables from the Innovating European Lawyers to Advance the Rights of Children with Disabilities project are available at: https://www.mdac.org/en/innovating-lawyers, last accessed 10 September 2024.
[7] The ITHACA Project Group (2010). The Ithaka Toolkit for Monitoring Human Rights and General Health Care in Mental Health and Social Care Institutions. Available at: http://www.ithacastudy.eu/toolkits/english/2.4%20Ithaca%20Toolkit%20English.pdf, last accessed 10 September 2024.
[8] MDAC, GIP, LIGA, ACT (n 5).
[9] WHO (n 1).

LEGAL NORMS AND STANDARDS

This chapter lists the legal norms and standards pertaining to women and child victims of abuse in social care and psychiatric institutions, in health and childcare institutions and in different forms of non-residential services. It is crucial for professionals working in these settings to be aware of and adhere to these standards to protect the rights and well-being of vulnerable individuals.

International human rights framework

International treaties (universal)

- Convention on the Rights of the Child (CRC): Emphasises the protection of children from all forms of physical or mental violence, injury, or abuse, neglect or negligent treatment, maltreatment, or exploitation, including sexual abuse. Articles most relevant to children with disabilities and protection from violence:
    - Article 2: Right to non-discrimination
    - Article 12: Right to be heard
    - Article 19: Right to protection from violence. States must take appropriate measures to protect the child from all forms of violence, abuse and neglect
    - Article 23: Rights of children with disabilities to become independent and participate in the community. Special care free of charge, access to education, training, healthcare, rehabilitation and preparation for employment and recreation.
- Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW): Represents the most important international treaty on women's rights. Stresses the importance of protecting women from violence, including those in institutional settings.
- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT): Desires to make effective the struggle against torture and other cruel, inhuman or degrading treatment or punishment throughout the world. The following articles are the most relevant when it comes to violence against women and children with disabilities:
    - Article 1 on the definition of torture
    - Article 13 on the right to complain
    - Article 14 on the right to redress and reparations
    - Article 16 on the definition of acts of cruel, inhuman or degrading treatment or punishment.
- Convention on the Rights of Persons with Disabilities: Highlights the rights of persons with disabilities to live free from abuse, and the need for appropriate measures to prevent all forms of exploitation, violence, and abuse. The following provisions concern specifically women and girls with disabilities:

    - Paragraph q in the preamble of the CRPD recognises that women and girls with disabilities are often at greater risk of violence, abuse, neglect, or exploitation.
    - Article 3 in the CRPD includes "equality between men and women" as one of the underlying principles to be upheld throughout the CRPD.

- Article 6 in the CRPD calls upon state parties to recognise that women and girls with disabilities experience multiple discrimination. It requires countries ratifying the CRPD to work to ensure that women with disabilities can fully enjoy all human rights and freedoms.
- Section 5 in Article 16 in the CRPD on Freedom from Exploitation, Violence, and Abuse requires state parties to create legislation and policies to identify, investigate, and prosecute violence against people with disabilities. It also indicates that these should include women- and child-focused legislation and policies.
- Paragraph b in Section 2 in Article 28 in the CRPD on Adequate Standard of Living and Social Protection requires that people with disabilities, particularly women and girls with disabilities, have access to social protection and poverty reduction programs.

General recommendations and general comments of UN treaty bodies

- General Recommendation No. 18 on disabled women (1991). Committee on the Elimination of Discrimination against Women (CEDAW Committee): The CEDAW does not contain text specifically addressing women with disabilities. However, the CEDAW Committee asks state parties to CEDAW to provide information on disabled women in their periodic reports. The Committee also asks CEDAW state parties to report on "measures they have taken to ensure that disabled women have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life."
- General Recommendation No. 19 on violence against women (1992). CEDAW Committee: Requires undertaking all necessary measures to eliminate discrimination against women and eliminate violence against women, including the adoption of specific legislation on all forms of violence against women, criminal penalties for violence perpetrators, civil remedies, preventive and protective measures. For over 25 years, the practice of state parties has endorsed the Committee's interpretation. The opinio juris and state practice suggest that the prohibition of gender-based violence against women has evolved into a principle of customary international law. General recommendation No. 19 has been a key catalyst for this process.
- General Comment No. 9 on the rights of children with disabilities (2006). Committee on the Rights of the Child, CRC/C/GC/9. Recognises that children with disabilities face discrimination in various aspects of their lives and development and examines how this is linked to violence.
- General Comment No. 13 on the right of the child to freedom from all forms of violence (2011). Committee on the Rights of the Child, CRC/C/GC/13. Addresses the right of children to freedom from all forms of violence – which refers to children with disabilities.
- General Comment No. 3 on Article 6 (2016) on women and girls with disabilities (2016). Committee on the Rights of Persons with Disabilities, CRPD/C/GC/3: Article 6 should guide States parties to comply with their Convention-related responsibilities to promote, protect

and fulfil the human rights of women and girls with disabilities, from a human rights-based approach and a development perspective.

- General Recommendation No. 35 on gender-based violence against women, updating general recommendation No. 19 (2017). CEDAW Committee, CEDAW/C/9C/35: Includes a recommendation for states to provide education and training for members of the judiciary, lawyers and law enforcement officers, including forensic medical personnel, legislators and health-care professionals and all education, social and welfare personnel, including those working with women in institutions, such as residential care homes, asylum centres and prisons, to equip them to adequately prevent and address gender-based violence against women.[10]

Reports

- Report of the Special Rapporteur on violence against women: Advancement of women (2012), A/67/227: Aims to deepen the findings of the OHCHR study (A/HRC/20/5 and Corr.1) and further examine the manifestations, causes and consequences of violence against women with disabilities. In addition, the report briefly examines relevant international and regional legal frameworks and provides recommendations. Regarding institutional violence, the Special Rapporteur stated the following:

  38. In institutional settings, women with disabilities are subjected to numerous forms of violence, including the forced intake of psychotropic drugs or other forced psychiatric treatment. Furthermore, forced institutionalization itself constitutes a form of violence. People with mental health conditions and intellectual disabilities are sometimes subject to arbitrary detention in long-stay institutions with no right of appeal, thereby robbing them of their legal capacity.[18]

  39. Women in institutions who need support services are usually more vulnerable. Vulnerability, both in institutions and in community settings, can range from the risk of isolation, boredom and lack of stimulation, to the risk of physical and sexual abuse. Evidence suggests that people with disabilities are at higher risk of abuse for various reasons, including dependence on a large number of caregivers and also because of barriers to communication.[19] One study found that the majority (68 per cent) of psychiatric outpatients in a hospital had experienced major physical and/or sexual assaults therein, a higher frequency than in the general population.[20]

- Report of the Special Rapporteur on the rights of persons with disabilities: Sexual and reproductive health and rights of girls and young women with disabilities, 2017, A/72/133, 14 July 2017: Examines the challenges experienced by girls and young women with disabilities in relation to their sexual and reproductive health and rights, and provides

[10] Other relevant general comments include: CRPD Committee (2017). General comment (2017) No. 5 on living independently and being included in the community. CRPD/C/GC/5; CRPD Committee (2018). General comment 2018) No. 6 on equality and non-discrimination. CRPD/C/GC/6; CRC Committee (2006). General comment No. 8(2006) on the right of child to protection from corporal punishment and other cruel or degrading forms of punishment. CRC/C/GC/8; CAT Committee (2012). General comment No.3(2012) on the implementation of article 14 by States parties. CAT/C/GC/3.

guidance to States on how to ensure legal and policy frameworks that support their autonomy and address the structural factors that expose them to violence, abuse and other harmful practices.

- Report of the Special Rapporteur on violence against women, its causes and consequences: A framework for legislation on rape (model rape law), 2021, A/HRC/47/26/Add.1. Provides states and other stakeholders with a tool for implementing international standards on rape, as established under international human rights law, international humanitarian law and international criminal law, including as interpreted in the jurisprudence of relevant tribunals and soft law produced by expert mechanisms. These standards are presented in the report of the Special Rapporteur on violence against women on rape as a human rights violation and a manifestation of gender-based violence against women (A/HRC/47/26) and are applicable both in times of peace and during conflict. The document refers to women with a disability specifically in a few provisions, including:

  Art. 12 (b) (i): *A child victim or witness of crime shall be treated in a caring and sensitive manner that is respectful of his or her dignity throughout the legal proceedings, taking into account his or her personal situation and immediate and special needs, age, gender, disabilities if any and level of maturity.*
  Art. 20 (30) (f) (iii): *in the case of victims with physical, psychological, mental or intellectual impairment or disabilities, obtaining the assistance of a special educator, psychologist or other person familiar with appropriate communication techniques for example braille, sign language or other electronic and information technology accessible to people with specific needs, before interviewing or recording the statement of the victim;*
  Art. 20 (34): *All victims must be supported to access justice through timely, appropriate and gender-sensitive and disability-sensitive medical examinations, which are conducted with the voluntary, genuine and informed consent of the victim. Victims should also have access to therapeutic and psycho-social care to aid their healing. They should also be supported to access criminal justice processes if they wish to do so.*
  Art. 20 (40) (g): *Administrative and judicial data on rape cases' victims and perpetrators, disaggregated by sex, age and type of violence as well as the relationship of the perpetrator to the victim, geographical location and any other factors deemed relevant, such as race/ethnicity/nationality status/immigration status/caste/sexual orientation/disability/ and gender identity.*[11]

Other sources

- Guidelines on deinstitutionalization, including in emergencies (2022), Committee on the Rights of Persons with Disabilities, 10 October 2022, CRPD/C/5: These guidelines

[11] Other relevant reports include: Juan E. Méndez (2013). Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. A/HRC/22/53, esp. para 48; Manfred Nowak (2008). Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. A/63/175, esp. paras 60, 68; Juan E. Méndez (2015). Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. A/HRC/28/68, esp. para 33.

complement the Committee's general comment No. 5 (2017) and its guidelines on the right to liberty and security of persons with disabilities (art. 14). They are intended to guide and support States parties, in their efforts to realise the right of persons with disabilities to live independently and be included in the community, and to be the basis for planning deinstitutionalisation processes and prevention of institutionalisation.

- Declaration on the Elimination of Violence against Women (1993), United Nations General Assembly: Specifies actions to be undertaken by the states in order to eliminate domestic violence, which include appropriate criminal legislation, development of national action plans, provision of services and resources for women victims of violence, training and gender sensitisation of public servants, as well as allocation of resources in the government budgets to combat violence against women.
- The Beijing Declaration and Platform for Action (1995): In the area of domestic violence, recommends as priority issue to review and revise legislation and take other necessary measures, including the establishment of appropriate mechanisms in order to ensure that all women enjoy protection from domestic violence which should be treated as criminal offence sanctioned by the law. It refers to women with disabilities in various provisions. The document remains the most comprehensive global policy framework and blueprint for action and is a current source of guidance and inspiration to realise gender equality and the human rights of women and girls.
- Resolution 2003/45 on the elimination of violence against women, United Nations Commission on Human Rights: Encourages governments to introduce: "affirmative duty to promote and protect the human rights of women and girls and must exercise due diligence to prevent, investigate and punish acts of all forms of violence against women and girls".
- Global Plan of Action to strengthen the role of the health system within a national multisectoral response to address interpersonal violence, in particular against women and girls, and against children (2016), World Health Organisation: A technical document informed by evidence, best practices and existing WHO technical guidance. It offers a set of practical actions that Member States may take to strengthen health system and intersectoral actions to prevent and respond to interpersonal violence in general, and against women and girls, and against children, in particular. The plan also outlines Actions that the WHO Secretariat is expected to carry out in support of member states.
- Resolution 2475 (2019), United Nations Security Council, S/RES/2475 (2019): Protects persons with disabilities in conflict. The first stand-alone resolution on the protection of persons with disabilities, emphasising the obligation on parties to a conflict to ensure that persons with disabilities enjoy equal access to basic services, access to justice, effective remedies, and, as appropriate, reparation. It recognises that forced institutionalisation is a form of violence that deprives women and girls of liberty on the basis of disability and stresses the importance of ensuring the full, effective and meaningful participation and inclusion of all women and girls with disabilities in decision-making processes and leadership roles by involving and supporting organisations of and led by persons with disabilities.

- The 2030 Agenda, through Sustainable Development Goal No 5, seeks to put an end to all forms of discrimination against women and girls and eliminate all forms of violence against women and girls in the public and private spheres, including trafficking and sexual exploitation.

Regional human rights instruments

COUNCIL OF EUROPE

International treaties

- European Convention on Human Rights (ECHR): Article 3 prohibits torture and inhuman or degrading treatment or punishment. Article 8 protects the right to private and family life and gives people of marriageable age the right to marry. Article 14 forbids discrimination on any grounds in relation to any of the other rights in the Convention. This includes discrimination on the grounds of sex or gender. Article 5 of Protocol 7 to the Convention states that spouses should have equal rights in marriage. Protocol 12 to the Convention extends the prohibition of discrimination in Article 14 to cases not engaged by other rights in the Convention.
- The Council of Europe Convention on preventing and combating violence against women and domestic violence (Istanbul Convention): The most significant and comprehensive legally binding text addressing violence against women. Focuses on preventing and combating violence against women and domestic violence. Recognises gender-based violence against women as a violation of human rights and a form of discrimination. States should regularly run awareness-raising campaigns, train professionals in close contact with victims, include within teaching materials issues such as gender equality and non-violent conflict resolution in interpersonal relationships, set up treatment programmes for perpetrators of domestic violence and for sex offenders, work closely with NGOs, and involve the media and the private sector in eradicating gender stereotypes and promoting mutual respect.
- The Council of Europe Convention on the Protection of Children against Sexual Exploitation and Sexual Abuse (Lanzarote Convention): Covers sexual abuse within a child's family and in the "circle of trust" as well as acts carried out for commercial or profit-making purposes. Tackles all possible kinds of sexual offences against children.
- The European Social Charter (revised): Includes the right of persons with disabilities – irrespective of their age and the nature and origin of their disabilities – to independence, social integration and participation in community life (Article 15), and the right of the child to be protected against negligence, violence and exploitation (Article 17).

Recommendations

- Recommendation 1582 (2002) on domestic violence against women, Council of Europe Parliamentary Assembly: Calls on the member states to recognise that they have an obligation to prevent, investigate and punish all acts of domestic violence and to provide

protection to its victims. sets out a series of measures to end all forms of violence against women. These measures include legislative and policy measures to prevent and investigate violence against women, to assist victims, work with perpetrators, increase awareness, education and training, and collect relevant data. Implementation of this Recommendation is regularly monitored and member states are provided with information on progress achieved and any existing gaps.

- Recommendation 1905 (2010), Council of Europe Parliamentary Assembly: Suggests the necessity to protect children who witness domestic violence, referring to its Resolution 1714 (2010) on children who witness domestic violence.
- Recommendation 2227 (2022) Deinstitutionalisation of persons with disabilities, Council of Europe Parliamentary Assembly.
- Recommendation No. R (90) 2 on social measures concerning violence within the family, Council of Europe Committee of Ministers. Recommends specific measures in the area of information, early detection of violence, reporting violence, giving assistance and therapy (emergency telephone lines, crisis services and counselling centres), measures for children, measures for women, measures for the perpetrators of violence, education measures (e.g. creating preventive programmes for children in schools), etc.
- Recommendation Rec(2002)5 on the protection of women against violence (2002), Council of Europe Committee of Ministers: Suggests that member states take measures against violence against women in the areas of media, criminal law, civil law, judicial proceedings, intervention programmes for the perpetrators of violence, measures with regard to sexual violence, sexual harassment, violence withing a family, genital mutilation, violence in conflict and post-conflict situations, failure to respect freedom of choice with regard to reproduction, killings in the name of honour and early marriages. In relation to measures concerning violence in institutional environments, the member states are recommended to:

  77. penalise all forms of physical, sexual and psychological violence perpetrated or condoned by the state or its officials, wherever it occurs and in particular in prisons or detention centres, psychiatric institutions, etc;

  78. penalise all forms of physical, sexual and psychological violence perpetrated or condoned in situations in which the responsibility of the state or of a third party may be invoked, for example in boarding schools, retirement homes and other establishments.
- Recommendation REC(2004)10 concerning the protection of the human rights and dignity of persons with mental disorder and its Explanatory Memorandum (2004), Council of Europe Committee of Ministers: Aims to enhance the protection of persons with mental disorder, in particular those who are subject to involuntary placement or involuntary treatment.
- Recommendation Rec(2005)5 of the Committee of Ministers to member states on the rights of children living in residential institutions, 16 March 2005.
- Recommendation CM/Rec(2010)2 of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities, 3 February 2010.

- Recommendation CM/Rec(2009)10 of the Committee of Ministers to member states on integrated national strategies for the protection of children from violence, 18 November 2009.
- Recommendation CM/Rec(2011)12 of the Committee of Ministers to member states on children's rights and social services friendly to children and families, 16 November 2011.
- Recommendation CM/Rec(2012)2 of the Committee of Ministers to member States on the participation of children and young people under the age of 18, 28 March 2012.
- Recommendation CM/Rec(2012)6 of the Committee of Ministers to member States on the protection and promotion of the rights of women and girls with disabilities, 13 June 2012.
- Recommendation CM/Rec(2013)2 of the Committee of Ministers to member States on ensuring full inclusion of children and young persons with disabilities into society, 16 October 2013.

Other sources

- Opinion of the European Economic and Social Committee on the situation of women with disabilities, 2018/C 367/04: This opinion calls on the EU, jointly with all its Member States, to implement the CRPD; (2), the recommendations that the EU received from the CRPD Committee with regard to women and girls with disabilities in 2015 and the UN Committee's General Comment No 3 on Article 6 of the CRPD.
- Guidelines of the Committee of Ministers of the Council of Europe on child friendly justice, 17 November 2010.
- Resolution ResAP(2005)1 on safeguarding adults and children with disabilities against abuse, 2 February 2005.
- Resolution 2431 (2022) Deinstitutionalisation of persons with disabilities (2022), Council of Europe Parliamentary Assembly.
- CommDH/IssuePaper (2012)3, The right of people with disabilities to live independently and be included in the community (2012), Council of Europe, Commissioner for Human Rights.
- Deinstitutionalisation of persons with disabilities (2021), Council of Europe Parliamentary Assembly (Committee on Social Affairs, Health and Sustainable Development)[12]

EUROPEAN UNION

- The Charter of Fundamental Rights of the European Union: equality between men and women (Article 23), right to protection of children (Article 24), right to respect of physical and mental integrity (Article 3), right of persons with disabilities to benefit from measures to ensure their integration and participation in the life of the community (Article 26).
- Directive of the European Parliament and of the Council on combating violence against women and domestic violence: A recently approved directive is the first comprehensive legal instrument at EU level to tackle violence against women. The Directive criminalises

[12] Available at: https://assembly.coe.int/LifeRay/SOC/Pdf/DocsAndDecs/2021/AS-SOC-2021-46-EN.pdf, last accessed 10 September 2024.

physical violence, as well as psychological, economic and sexual violence against women across the EU, both offline and online. Female genital mutilation as well as forced marriage will be criminalised as stand-alone crimes. Moreover, the most widespread forms of cyber-violence will be criminalised. It provides for measures to prevent all types of violence against women, including domestic violence and sets new standards for victims' protection, support, and access to justice, for example, by obliging Member States to establish helplines and rape crisis centres to support victims. It will require Member States to ensure safe, gender-sensitive and easier reporting of crimes of violence against women and domestic violence - including an option to report online. It refers to women with disabilities in various provisions.

- The Victims' Rights Directive (Directive 2012/29/EU) establishes minimum standards for the protection of all victims of crime, including victims of gender-based violence. It requires Member States to ensure accessible communication with victims, taking into consideration any disabilities.
- The Equal Treatment Directives (Directive 2006/54/EC; Directive 2010/41/EU and Directive 2004/113/EC) prohibit harassment on the grounds of sex and sexual harassment as a form of sex discrimination in the context of employment and the offer or supply of goods or services.
- The Directive on combating and preventing trafficking in human beings (Directive 2011/36/EU) recognises the gendered nature of this crime (Article 1). Sexual abuse and sexual exploitation of children and child pornography is addressed in Directive 2011/93/EU.
- The European Commission's 'A Union of Equality: Gender Equality Strategy 2020-2025' recognises that women with health issues and with disabilities are more likely to experience various forms of violence and commits the Commission to developing and funding measures to tackle abuse, violence, forced sterilisation and forced abortion.
- The European Institute for Gender Equality (EIGE) has developed 13 indicators on intimate partner violence (IPV) to guide the data collection efforts of the police and justice sectors. The indicators developed by EIGE help to assess the progress made at the national level to reduce IPV and domestic violence and enhance the comparability of data in alignment with the minimum requirements of the EU's victims' rights directive and the Council of Europe's Istanbul Convention. This report provides guidance for national data providers that will participate in EIGE's data collection exercise.[13]
- Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009): Report was drafted by a group of independent experts convened by EU

[13] European Institute for Gender Equality (2023) Methodological Guidance: Administrative data collection on violence against women and domestic violence. Available at: https://eige.europa.eu/publications-resources/publications/methodological-guidance-administrative-data-collection-violence-against-women-and-domestic-violence-0, last accessed 10 September 2024.

Commissioner Vladimír Špidla in February 2009 to address the issues of institutional care reform in their complexity.[14]

[14] European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities (2009). Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care. Available at: https://ec.europa.eu/social/BlobServlet?docId=3992&langId=en, last accessed 10 September 2024.

PRINCIPLES OF HUMAN RIGHTS MONITORING

Human rights monitoring is guided by essential principles that ensure the safety, integrity, and effectiveness of the process. This section will summarise some of these principles, including minimising harm, fostering ongoing dialogue, maintaining independence, collecting reliable information, and securely managing data.

Principle 1: Do no harm

Monitors must take all necessary precautions to protect interviewees from retaliation or punishment for speaking with a monitor. Monitors should be careful not to reveal personally identifiable information during discussions or in the report. Thus, in addition to not mentioning a person's name or initials, it may be best not to mention personal information about them, even if they give their consent. As a result, it is critical to conduct multiple interviews so that authorities cannot determine who said what. Monitors should ask interviewees if they believe they are at risk and leave their contact information so that if any punishments are imposed as a result of a monitoring visit, the monitors can respond.[15]

Principle 2: Ongoing dialogue for reform

Human rights monitoring implies regular or ongoing monitoring in which there are repeated visits and regular and systematic follow-up to ensure improvements in human rights. Thus, while maintaining independence, the communication with the authorities responsible for the assessed fields/ institutions should be conceptualised as a long-term and ongoing, constructive dialogue focused on improving the human rights situation in these facilities while advocating for meaningful integration of service-users in the community.

Principle 3: Independence and credibility

It is vital that the people involved in managing, organising and carrying out human rights monitoring be independent of the government and the facility monitored. [16]

A credible team is a team trained in carrying out monitoring visits and who is aware of the standards against which these facilities will be monitored. When selecting the members for a monitoring team, it is advised to build a multi-disciplinary team that would consist of users or former users of services, health care practitioners with relevant experience and someone with a background in human rights.

Principle 4: Collect reliable information

Monitors must not rely solely on one person's opinion, but rather seek information from a variety of sources. Corroborating evidence is especially important in this monitoring field because people with intellectual and psychosocial disabilities face a strong stigma regarding the credibility of their

[15] The ITHACA Project Group (no 7).
[16] Ibid., p. 25-26.

statements, including from representatives of authorities charged with investigating allegations of ill-treatment and malpraxis in facilities.[17]

Principle 5: Store and share information securely

To protect confidentiality, monitors should ensure that the information collected, as well as any records and notes made during a visit, are kept in a secure location. Consider encrypting your files when sharing this information with other team members and sending passwords by phone.[18]

This is not a taxative list of the principles of human rights monitoring; other principles have been identified by other monitoring tools, including the Ithaca Toolkit,[19] the CHARM Toolkit,[20] the OHCHR Manual on Human Rights Monitoring.[21] Monitors are invited to be familiar with these principles.

[17] Ibid., p. 26.
[18] Ibid., p. 27.
[19] Ibid., p. 25-27.
[20] MDAC, GIP, LIGA, ACT (n 5)., p 55-61.
[21] United Nations Office of the High Commissioner for Human Rights (2011). Manual on Human Rights Monitoring. Chapter 02 on Basic Principles of Human Rights Monitoring. Available at: https://www.ohchr.org/sites/default/files/Documents/Publications/Chapter02-MHRM.pdf, last accessed 13 September 2024.

METHODS OF HUMAN RIGHTS MONITORING

Interviews, observations, and documentation review are the three most common methods for gathering information during the monitoring exercise. This section will provide a brief overview of these techniques and discuss how to record the data gathered. (See also pages 32 to 41 of the Training Handbook & Monitoring Toolkit.)

Method 1: Interviewing (See also Chapter 1 of the Monitoring Toolkit)

Location

Much of what is discussed will be personal and sensitive, potentially putting at risk the interviewee, so confidentiality is critical. Monitors should conduct interviews in a private and comfortable environment. This is not always possible, but every effort should be made to keep others out of sight and hearing range. Some service users may request to have a trusted person (but not a staff member) accompany them during the interview, which should be accepted.

Anonymity and confidentiality

Any information contained in the monitoring report that can be linked to a specific person may result in retribution against the named individual. As a result, interviewers are only permitted to discuss interview content with other members of the monitoring team.

The authors of this monitoring methodology recommend that monitors refrain from naming a user at risk of any intimidation or pressure. It can be useful to discuss the service users' perceptions of potential risks and whether they believe there is anything monitors can do to reduce those risks.[22]

Selecting interviewees

The monitoring team should be guided in selecting people to interview by the range of service users and staff as well as the sample size determined during the visit preparation (See also Step 5 for more information on determining which and how many people to interview from each facility.) To ensure that the process is impartial, the monitoring team, rather than the facility's staff, must choose the service users and staff to interview.

If it is decided to interview family members (or friends or carers), the monitoring team may choose which family members to interview or be guided in their selection by service users, and they must decide whether to interview family members during the visit to the facility or outside of the visit.

Staff, service users, and family members have the right to decline interviews, and the monitoring team must respect their decisions. Monitors must address the individual directly and obtain their permission to engage in a discussion.[23]

Selecting users to interview

During the visit, several users frequently rush up to the monitors to get their attention. While speaking with them, monitors should look also for people who are quiet, sit in a corner, and are not

[22] The ITHACA Project Group (no 7)., p. 28.
[23] WHO (n 1)., p.33.

part of the group. There are many reasons why someone is quiet or does not feel comfortable in a group setting.[24]

Please keep in mind that interviewees who live in institutions may be nervous about having strangers ask them questions about their lives. Furthermore, certain medications can impair people's ability to concentrate for extended periods of time.[25]

Sometimes, in case of adults whose legal capacity has been deprived or restricted, staff might say that monitors need the permission of the legal guardians of the patients/residents/users before the monitors can talk to them. Often, this is simply a way for staff to stop the monitors from talking to users. Denying the interview on these grounds violates the CRPD, but it may still be considered legal under the state's national legislation. The teams must discuss this aspect during the visit preparation stage. In other instances, monitors may have statutory powers to talk to any person in custody and can use their legal powers to override the attempt by staff to block the monitors' attempts to speak to residents.[26] If monitors are not allowed to talk to users under guardianship, this should be explicitly mentioned in the monitoring report along with the reason for refusing to conduct interviews.

Selecting staff to interview

Monitors should enter a facility with a collaborative mindset, keeping in mind that staff members are likely to be passionate about their work and strive to do their best. Monitors should request information from management and employees on a variety of topics. The management will be able to provide statistical and general information about the facility. They will provide an overview of the main problems as they see them, as well as major incidents and how they were resolved. At the same time, they should be able to provide policy answers to questions such as how the facility handles allegations of ill-treatment, how the facility handles someone who wishes to file a complaint, and so on.[27]

Finance staff may be able to provide information about the facility's budget, including the percentage spent on common categories such as staff salaries, therapies (if available), rehabilitation, food, and operating costs such as heating and water. They may also be able to provide information about the facility's financial constraints.

While the more senior medical staff will be able to provide information about recruitment of healthcare staff, about their training, about shifts, about supplies of medications and how clinical staff deal with issues such as challenging behaviour, the more junior one may be more open to share with you their anxieties about how the facility is managed. Monitors could inquire about their users' overall health, including screening and treatment for somatic conditions. They will be able to describe the quantity and quality of medications available, as well as shed light on legal issues that may arise in these types of facilities. Consider interviewing psychologists, social workers,

[24] For example, children and women with disabilities who appear overly withdrawn or lethargic might be experiencing forced medication or emotional abuse.
[25] The ITHACA Project Group (n 7)., p. 29.
[26] Ibid., p. 32.
[27] Ibid., p. 28.

occupational therapists, and speech and language therapists, as they may have valuable information to share with you. Volunteers can also offer important insights.

Auxiliary and security personnel are typically called on to restrain patients, and monitors can ask that they demonstrate what happens when someone becomes violent, as well as which patients/residents/users may leave the facility, when and how.[28]

During the interview

Providing accommodations

Every effort must be made to overcome any barriers in communication between the interviewer and the interviewee. For example, if the interviewee and the interviewer speak different languages or the interviewee has a communication impairment (e.g. difficulty in speech or hearing), appropriate language, including plain language or easy-to-understand language or sign language (independent) interpreters should be brought in. For some people, it may be helpful if there is someone with them who knows them, has spent time with them over a long period, and with whom they have developed a trusting relationship. For others, it may be easier for them to communicate with a stranger or in a more anonymous manner.

Depending on the identified needs, the interviewer will provide the appropriate type of accommodation. (See also "Step 5: Prepare the visits" below for more information on what types of accommodations should be considered during the preparation stage.)

What to tell interviewees

Before beginning an interview, the interviewers should introduce themselves, explain the reason for the interview, and answer any questions the interviewee may have. Interviewers should also ask questions to learn more about the interviewees (for example, where they are from and how long they have been at the facility). This introduction establishes rapport between the interviewee and interviewer, putting people at ease.

Ice-breaker questions for children with disabilities may include:

- What was the breakfast/lunch today?
- With whom do you like to play?
- What is your favourite game?

Ice-breaker questions for women with disabilities may include:

- What do you like to do when you have free time?
- Who are your best friends here?
- What is your favourite drink?

It may also be useful to discuss any concerns the interviewees may have about the potential consequences of their participation in the interview, as well as the steps taken to protect their anonymity and confidentiality.

[28] Ibid., p. 29.

Interviewees might need a break during the interview; monitors should be attentive to individual needs.

It is recommended that monitors encourage staff and service users to discuss personal experiences in their own words when giving testimony, as this is likely to produce more insightful information. While gathering information about an event or circumstance, monitors should refrain from asking leading questions.[29]

Generally, in the case of incidents or ongoing problems, the following questions can be helpful to get more information:

- *What happened?*
- *To whom did it happen?*
- *When did it happen?*[30]
- *How often did/does this happen?*
- *How were/are other people affected by it?*
- *How did/does it happen?*[31]
- *Why did/does it happen?*
- *What was the reaction of the staff?*
- *What has been done to prevent it happening again?*

If a user is explaining something that happened, some useful questions to ask for more detail could be:

- *What happened then?*
- *Could you describe what it was it like?*
- *Can you tell me a bit more about...?*
- *How did it make you feel?*
- *I have heard other people say […] What do you think about this?*
- *What were, or are, the worst parts of all this?*
- *How would you like things to be done differently?*[32]

These are all "open" questions with a wide range of potential responses. Compared to "closed" questions, these are typically far more effective. The interviewer should be very proactive in communication, seeking ways to reach an effective communication. At the same time, the interviewer should be careful about signs that the person is trying to please him or her, or the personnel, or is afraid of them. (See also "Step 6: Carry out the visits" below for further advice on conducting interviews.)

Gender-sensitive and trauma-informed interviewing

First and foremost, the monitoring team should include female members preferably doctors and psychologists, including who have knowledge of child psychology to ensure that interviews with girls are conducted in a child and gender-sensitive manner. If it is possible, there should also be

[29] Ibid., p. 30.

[30] Some people may have a problem with the concept of time. If this is the case, to ensure more precise information, it is good to name an event or time of the day that is clear and easy to identify (for example Christmas or lunchtime) and ask whether it happened before or after.

[31] In some cases, it can help persons with disabilities to illustrate this by drawing on paper.

[32] The ITHACA Project Group (n 7)., p. 30.

members of the team with experience of dealing with post-traumatic stress disorder and other trauma experienced by women who have experienced violence, including especially sexual violence. However, monitoring teams should be attentive so that the monitoring visit does not re-traumatise female experts by experience of the team. Female members of the monitoring team from ethnic and racial minorities, indigenous peoples, and foreign nationals will be better able to identify and discuss the specific challenges and vulnerable situations that women in these groups face in the facilities to be visited.

Members of the monitoring team should have at least a basic knowledge of how to deal with sexual violence and other sensitive gender-related issues. The monitoring team must be able to ask the right questions using gender-sensitive language.[33] **(See also "Step 2: Build the monitoring team" below for more details about setting up the monitoring team.)**

During the interview, the monitoring team members should take into consideration these four principles of trauma- and violence-informed interviewing:[34]

1. *Understand trauma and violence, and their impacts on people's lives and behaviours*
   Violence can occur in various forms and can have traumatic long-term effects on someone's life. Trauma is a response to violence, either violence that occurred in the past or ongoing violence. Monitoring team members should avoid blaming and judging people for their reactions to experiences of violence as these may stem from trauma. Instead, pausing and reflecting when someone has an unexpected reaction, listening and validating the experiences they share are helpful.[35]

2. *Create emotionally and physically safe environments*
   To create an environment that interviewees feel comfortable in, interviewers should communicate in a non-judgemental way that enables the interviewee to feel understood and accepted. Providing information and expectations regarding the interview is also important.[36]

3. *Foster opportunities for choice, collaboration, and connection*
   Communicating in an open, non-judgmental way can foster connection and encourage interviewees to share their experiences and feelings. Interviewers should listen carefully to the interviewees and check if they have understood everything correctly.[37]

4. *Provide a strengths-based and capacity-building approach to support coping and resilience*

[33] Penal Reform International (2015), Women in Detention: a guide to gender-sensitive monitoring, p.10. available at: https://www.apt.ch/knowledge-hub/publications/women-detention-guide-gender-sensitive-monitoring, last accessed 11 September 2024.

[34] GBV Learning Network (2020), Issue 32 - Trauma- and Violence-Informed Interview Strategies in Work with Survivors of Gender-Based Violence. available at: https://gbvlearningnetwork.ca/our-work/issuebased_newsletters/issue-32/index.html, last accessed 11 September 2024.

[35] Public Health Agency of Canada (2018) Trauma- and Violence-Informed Approaches: Policy and Practice, Government of Canada. available at: https://www.canada.ca/en/public-health/services/publications/health-risks-safety/trauma-violence-informed-approaches-policy-practice.html#s7-1, last accessed 11 September 2024.

[36] Ibid.

[37] Ibid.

Finally, interviewers can help validate interviewees' experiences and help them understand that their responses, to violence for instance, are normal. Reflecting on how structural conditions shape people's lives can also be a supportive approach.[38]

Dealing with people diagnosed with delusions

Monitors should attentively listen to users diagnosed with delusions even if staff believes that they have fixed false beliefs. This situation and attitude make these people more exposed to human rights violations.

Dealing with intrusive staff

The head of the monitoring team should explain at the outset of the visit that interviews with individuals, including service-users, are a crucial part of the monitoring process and that they must take place in private, that is, away from staff members' view. The head of the monitoring group should take note of the director's concerns and deal with them directly at that point if there are any.

If the director denies permission, the person who gave the go-ahead for the visits should be contacted and asked to explain why the interviews must be conducted in private. Alternatively, in some cases, it might be sufficient to inform the director that their refusal to cooperate will have to be noted in the report. Staff members must also be reminded of these details each time they put up obstacles in the way of conducting private interviews.[39]

Ending the interview

Interviewers should end the interview by thanking service users for their time. They should be informed of how to contact the monitoring team if they need to provide additional information after the visit, report any new problems or abuses, or express any concerns about repercussions following the interview. Interviewers should also inform interviewees about the next steps in the visit and that they will be notified of the results once the report is completed.[40]

Keeping safe

The head of the monitoring team must make sure that all members of the team are well during the visit. If anyone has any issues or is not feeling well, the team leader must take immediate action.

Method 2: Observation

Observation entails using one's senses to perceive everything a monitor sees, hears, smells, touches, and tastes during the visit. It entails visiting all premises and facilities and being able to meticulously inspect and record detail in a wide range of rooms. When observing, the monitor's firsthand experience provides the evidence. Detailed and objective recording is required so that the observer's experiences can be accepted as credible rather than dismissed as unreliable. (See also Chapter 2 of the Training Handbook & Monitoring Toolkit.)

Staff frequently offer monitors an official tour of the facility. While this is useful, the tour is likely to be superficial and will not show monitors the 'worst' areas of the facility. As a result, monitors

[38] Ibid.
[39] The ITHACA Project Group (n 7)., p. 32.
[40] WHO (n 1)., p. 32

should consider what they are seeing and what is not being shown. Asking service users where they keep those who "do not behave" could be a good strategy for getting into areas of the facility that monitors have not seen.

Another thing to look out for on an official tour is how service users interact with the staff member who is showing them around. There may appear to be a comfortable relationship, but there may also be no contact or avoidance. Similarly, the attitude and behaviour of other employees can be telling: for example, do staff members knock on bedroom doors before entering? Do they address service users politely?[41] (See also "Step 6: Carry out the visits" below for more information on observation techniques.)

Method 3: Reviewing documentation

Monitoring teams can use a variety of documents to support their reports. Some may be freely available online, while others may require formal requests to obtain them. Some of this information could include:

- Statistical data on the number of people detained under mental health legislation, those living in mental health facilities or social care institutions, and those under guardianship.
- Policies, standards, guidelines, and other official directives (such as staff development, health and safety, suicide prevention, and restraints policies). These documents are a valuable resource for information on matters pertaining to service quality, facility conditions, and human rights situation. When there is no policy in place for a particular area, it is frequently a sign that the applicable requirements are not being fulfilled. That being said, there is no guarantee that a facility will comply with adopted policies that respect human rights and quality standards.
- Administrative records, such as records of admission and discharge, the age and gender of those residing in the institution, but also the number and types of employees. These documents contain important information about human rights concerns. For example, it might imply that many persons are being admitted and treated against their will, indicating a systemic denial of the legal capacity of service users.
- Specific event records (for example, complaints, appeals against involuntary admission and treatment, theft, abuse, and deaths). These can reveal problems, violations, or even patterns of abuse at the facility that should be investigated further during the monitoring visit. A lack of complaints should also be documented, as it could indicate that there is no complaint mechanism or that it is inaccessible to service users.
- Personal records or files of service users, such as nursing notes. These documents are confidential, so the facility may be rightly hesitant to show them to monitors. In this case, monitors could ask the staff to let patients/residents access their own medical records.[42] Monitors should be allowed to request the user's consent to access their personal documents. If consent is given by the user and the facility denies access, this should be noted in the monitoring report. The denial of access to personal files can be legal under domestic law. If the facility uses this argument, the legal basis for the denial of access to personal/medical/ files should be also noted in the monitoring report.

[41] Ibid., p. 33.
[42] Ibid., p. 34.

- Policies, plans, contracts, consent sheets, information booklets etc, given to users upon arrival.[43]

Monitors may request information prior to the visit from the facility to be visited or from their supervisory body. This will help them get organised and know roughly what to expect from the visit. (See also Chapter 3 of the Training Handbook & Monitoring Toolkit.)

Recording information during the visit

Note-taking

During monitoring visits, taking notes is the main way to document information. Monitors should always ask the user whether notes can be taken. If not, monitors should write down some notes after the interview. Monitors should also ask whether notes can be taken by using a laptop if they want to take notes on a laptop. Some people would not like monitors taking notes by using a laptop but a notepad and a pen.

Notes aid in reconstructing the visit and producing precise reports. Different monitors take notes in different ways, so it is important to find a method that works for you. Taking notes should not interfere with interviewees' ability to listen or cause them discomfort. A smooth conversation can be ensured by using various techniques, such as summarising information after observing a situation. Additionally, team talks where one person leads, and the other takes notes may be preferred by monitors.

Visual and audio recordings

Photographs, video, and audio recordings can be used to back up statements and help the audience understand a situation. The privacy and confidentiality of users should be protected when considering visual and audio recordings. If individual service users do not want their photographs taken, do not take them. Even if monitors have the service user's permission to photograph or film, it would be useful also to ask permission from the staff. This helps to avoid confrontations and antagonism.

It is also worth noting that during the planning phase of a monitoring visit, monitors must decide whether they are comfortable showing people's faces and identifying characteristics. Showing a person's face is often more powerful because it captures a human being's facial expressions, however, it should be decided carefully whether the image could be used in public. Taking pictures of people's backs or displaying their hands may fix this issue, while also showing that there are real people involved.[44]

[43] Ibid.
[44] Ibid.

TEN STEPS OF HUMAN RIGHTS MONITORING

This section provides a thorough, step-by-step guide for monitoring human rights in facilities that provide mental health and social care services to women and children with disabilities in accordance with established monitoring practices. The guidance outlines key questions for the core team to consider as they plan and execute each step. The primary goal of this section is to explain the human rights monitoring process and provide practical assistance to both the core team and monitors throughout the monitoring cycle.[45]

Step 1: Establish a management team and assess objectives

The first step in conducting multi-disciplinary monitoring is to form a core team of people who will be in charge of overseeing the entire monitoring cycle. Unlike the monitoring team, whose mission is typically limited to monitoring-related activities and report writing, the core management team will be in charge of managing the entire monitoring exercise and, more importantly, setting and measuring its outcome and impact level objectives.[46]

The management team should determine both the overall goals of the monitoring exercise and the scope of each monitoring visit. When deciding on the former selection, the management team should consider the most serious issues, how much monitoring can be done, and what is likely to make a difference in terms of findings, target audience, and follow-up activities (after the reports are published). Furthermore, the following considerations must be made: the country's political, economic, and social context, the benefit of involving external parties in the monitoring exercise, the target audience, the monitoring timeframe, and the available budget.[47]

These are some of the generical outcomes that might be sought from the monitoring exercise:

- *Advocacy and campaigning*. Governments and policymakers are likely to respond to evidence based advocacy.
- *Awareness-raising*. One important way of doing this is via the media: print, television, radio and online.
- *Capacity-building*. Utilising credible evidence on the human rights deficiencies in mental health and social care systems. Raising an organisation's profile and enable it to make informed decisions about strategic issues on which it should focus.[48]
- *Litigation*. A report can demonstrate an issue and support an argument.

Objective/s	Type of facility	Measured how?	Agreed by whom?	Realistic how?	By when?

[45] This section builds on section 5 of the ITHACA Toolkit and chapter 3 of the Monitoring Handbook of the CHARM Toolkit. Cf. The ITHACA Project Group (n 13); MDAC, GIP, LIGA, ACT (n 7).
[46] Please check this link for more information of outcome vs impact level objectives: https://councilfordisabledchildren.org.uk/sites/default/files/uploads/files/Outcomes%20explainer-%20professionals.pdf.
[47] WHO (n 1)., p. 37.
[48] Ibid., p. 24.

Step 2: Build the monitoring team

Selection of the monitoring team members should be made by the management group. A multidisciplinary team comprising at least three individuals is advised for the monitoring team: an individual with prior experience as a service user, a medical professional, and a human rights/legal professional. In order to provide additional valuable knowledge and experience to a monitoring visit, it may be appropriate, depending on the type of facility visited, to include social workers, for example.[49]

A key principle in forming a monitoring team is that the members must be independent of the government and the facilities being evaluated. Thus, members of the management team can serve on a monitoring team as long as they are independent of the actors mentioned above and have no conflict of interest in conducting the actual monitoring.

The gender, ethnic group, race, disability and cultural balance of the monitoring team should be considered in selecting members, as well as values shared, which should be in line with the principles specified in the CRPD and of the other International Human Rights Instruments.

In the case of a follow-up visit or a repeated monitoring visit to the same facility, the monitoring team should ideally consist of the same individuals who visited before. This could help build trust with the persons with disabilities placed at the service.

Determine the different functions of the members

The management team may find it helpful to list members of the monitoring team and discuss who will be responsible for different aspects of the visit, including:

- coordinating the meetings of the team; visits to facilities and follow-up work
- observation of conditions in facilities
- review of documentation.
- conducting interviews (See also the "Gender sensitive and trauma-informed interviewing" section in the Methodology chapter above).
- drafting the monitoring reports, including collating inputs from all members
- addressing questions, concerns or complaints after a facility visit

The table below can serve as a tool for systemising the information about the candidates for the monitoring team, including their skills, expertise and background. After the table is completed, the management team may wish to review whether the monitoring team lacks any particular skill or expertise. If so, the former may want to bring in experts to fill any skills gaps.

[49] Article 33(3) of the CRPD says that any domestic monitoring of the implementation of the CRPD must involve persons with disabilities and their representative organisations.

Objective of the visit no. 1:								
Activity	Required skill/expertise		Candidate				Expert's background	Available Skill/expertise
		Name	Disab.	Gen	Age	Other[50]		

Members of the monitoring team should not be restricted to specific roles; rather, their various strengths should guide decisions on the allocation of roles and responsibilities, while being prepared to engage in a variety of activities throughout the visit.[51]

Step 3: Train the monitoring team

It may be necessary to conduct trainings to ensure that all members of the monitoring team have the same level of comprehension and readiness for carrying out human rights monitoring visits. Individuals from the management team may deliver these. Another option is to have some of the training conducted by outside instructors who possess the necessary experience.

The monitoring team should be familiar with CRPD, which outlines the rights of people with disabilities, and should have at least a basic knowledge of the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political, relevant EU legal framework, as well as a number of (non-binding) documents that provide useful guidance on the rights of people with disabilities. At the same time, they should be also familiar with relevant national policies, plans and laws related to mental health, disability and with anti-discrimination legislation. (See also the "Legal norms and standards" chapter above.)

It may also be necessary to become familiar with reports from national and international human rights monitoring bodies, such as the Equality Body, European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), UN Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (SPT), National Preventive Mechanism (NPM), and Ombudsperson, as well as articles and reports from non-governmental and other organisations regarding the rights of people with disabilities and the conditions in the monitored facilities.

The monitoring team should also be instructed on the goals, principles, and methods of human rights monitoring at that point. They should receive training in observation, documentation, and trauma-informed interviewing techniques. They should also receive instructions on how to handle challenging situations that may arise during the visit. (See also pages 7 to 16 of the Training Handbook & Monitoring Toolkit for the recommended instructions in training outline.)

[50] Ethnic, racial, religious minorities; indigenous peoples or foreign nationals - depending on the national context.
[51] WHO (n 1).

Step 4: Establish the authority of the team to conduct the monitoring visit

Having the authority to conduct the monitoring visit enables the members of the monitoring team to work independently, free from outside influence, and without the fear of the consequences for themselves or those who share information with them, regardless of the visit's conclusions. Furthermore, it may grant the monitoring team full access to all areas of any facility so that it can visit and observe it without restriction and interview any relevant individuals while protecting their anonymity and confidentiality.

This authority may be conferred by the country's relevant authority (e.g. Ministry of Social Protection).

Step 5: Prepare the visits

Gather background information

Before the visit, the monitoring team needs to obtain and ensure they have an understanding of legal information, such as legislation, ministerial decrees and other sources of law, as well as mental health and social care policies. The team should analyse these domestic provisions against the international legal instruments[52] to find out the extent to which national laws comply with the relevant international human rights standards. A thorough understanding of the relevant laws and policies will increase the accuracy, and therefore the credibility and likely impact, of the monitoring report.[53]

Monitors may also speak with survivors of institutions, with a focus on people with intellectual and psychosocial disabilities and relevant organisations, to gain additional insights about the issues that will be monitored.

Determine which and how many people from each facility to interview

Interviews should be conducted with a diverse range of people associated with the facility, including service users of various genders, ages, diagnoses, and ethnic origins; people who have recently been admitted as well as those who have been there for some time; users who are present voluntarily as well as those who are there without their consent.[54]

Similarly, different categories of staff should be interviewed, including the head of the facility, assistant nurses, registered nurses, social workers, psychologists, psychiatrists and other health professionals. Staff who have been at the facility for some time should be interviewed as well as those who are new to the facility. (See also Chapter 1, Section "Method 1: Interviewing, Selecting Staff to Interview" above for more information.)

The number of people interviewed depends on the number of service users and staff associated with the facility, the size of the facility and the number of units it comprises and will be determined by the teams in the context of each facility.

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[52] United Nations General Assembly (2007). UN Convention on the Rights of Persons with Disabilities. A/RES/61/106; United Nations General Assembly (1966). International Covenant on Economic, Social and Cultural Rights; United Nations General Assembly (1966). International Covenant on Civil and Political Rights, and other relevant EU legal measures.

[53] The ITHACA Project Group (n 7)., p. 40.

[54] WHO (n 1)., p.20.

The guiding principle is to gather enough information through documentation review, observation, and interviews to provide an accurate picture of the facility's conditions. Once these combined sources have provided a clear picture of the establishment, it may be unnecessary to conduct additional lengthy interviews. This may be particularly true for large residential institutions. It should also be noted that the sample of interviewees must be large enough to ensure their anonymity. The more people interviewed, the more difficult it is to attribute specific responses to specific individuals, such as service users, family members, and staff.

When conceptualising their interviewing work, the management team should consider structural factors such as age, gender, and disability, as these can influence the degree of disclosure.[55] For example, people who have experienced disability and have conducted interviews may be more effective in conducting interviews with service users because they have a better understanding of some of the issues and can gain the users' trust. At the same time, female interviewers should be involved when conducting interviews with women.

When preparing for interviews with people with disabilities, monitors should consider that many of them may require additional support measures to participate meaningfully in discussions. Thus, during preparation, the following circumstances should be considered, and plans made to provide eventual accessibility, accommodations and support:

- Barriers to participation: including environmental, attitudinal, information
- Personal circumstances: including age, gender, health, trusted person, living circumstances
- Communication abilities and difficulties: speaking, reading, writing, understanding
- Risks and threats: previous victimisation, vulnerability to repeat victimisation, risk of secondary victimisation
- Relationship with the potential aggressors: personal relationship, dependency, guardianship[56]

Finally, in order to preserve the emotional well-being and productivity of the monitoring team, the management team should encourage the selected members of the monitoring teams to take compassion fatigue (also known as secondary traumatic stress) and job burnout self-evaluation tests before being assigned for a specific visit.[57]

Prepare the relevant handouts

The monitoring team may also create a flyer to distribute to staff, service users, and children's families, outlining the purpose of the visit, the monitoring team's mandate, the monitoring process, what happens after the visit, and contact information for the management team, NPM, and ombudsperson. The information should also be available in easy-to-read format.

Seek oral consent

[55] Manderson, L., Bennett, E., & Andajani-Sutjahjo, S. (2006). The social dynamics of the interview: age, class, and gender. *Qualitative health research*, *16*(10), 1317–1334. https://doi.org/10.1177/1049732306294512.

[56] Validity Foundation et al (2020). Voices for Justice Toolchest for professionals. available at: https://validity.ngo/wp-content/uploads/2023/01/Voices-for-Justice-TOOLCHEST-for-professionals-_EN.pdf, last accessed 11 September 2024.

[57] Bride, B. E., Radey, M., & Figley, C. R. (2007). Measuring compassion fatigue. *Clinical Social Work Journal, 35*(3), 155–163. https://doi.org/10.1007/s10615-007-0091-7.

Before conducting interviews, interviewees must provide their oral consent. Without this, members of the monitoring team cannot proceed with the interviews.

Protecting the confidentiality and anonymity of the people being interviewed is crucial to ensure that no negative repercussions result from the monitoring visit. All potential notes, tape and video recordings, photographs, and other documentation that may reveal interviewees' identities must be kept in a secure location that is only accessible to members of the team.

Gaining access

The management team must also plan access to facilities and may need to seek approval from the relevant government body, authority or the facility itself before conducting the monitoring. That body must recognise the monitoring team's authority to conduct the monitoring visit and should notify facilities that may be visited. (See also "Step 4: Establish the authority of the team to conduct the monitoring visit" above.) When negotiating access, monitors should consider promising the facility an advance copy of the report to correct any factual errors. Monitors should retain copies of all official letters sent and received in case they are needed later. Monitors should take copies of permission letters on all monitoring visits.[58]

Alternatively, access to the facility can be ensured by collaborating on the visit with the ombudsperson institution or the national preventive mechanism established by a State under the UN Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT), which has the authority to visit institutions and other places of detention unannounced.

Select a person to be in charge

Assign one person to head the monitoring team. Sometimes difficult decisions must be made, and having agreed-upon leadership in these situations is extremely beneficial.[59]

Step 6: Carry out the visits

A typical monitoring visit will most likely involve the following, but not necessarily in this order:

- Internal briefing
- Introduction interview with the director or other senior management.
- Tour of the facility
- Targeted and in-depth observation in a small number of departments/wards/units
- Interviews with the service users, (family members or friends or carers if present) and staff
- Review of documents and policies
- The feedback after the monitoring visit
- Internal debriefing

Several of these steps will be described below.

Internal briefing

[58] The ITHACA Project Group (n 7)., p. 45.
[59] Ibid., p. 43.

Before each visit, the head of the team should conduct a thorough briefing session for all monitoring team members. This should cover the basic facts of the facility, the duration of the monitoring visit, the role of each of the monitoring team members, and what to do if there is a problem.

Introduction interview with the director or other senior management

On arrival in the facility, the monitoring team should meet with the director of the facility and be shown into their office. The head of the monitoring team will explain the purpose of the monitoring visit and will outline what they will be doing and what they hope to achieve.

A similar introduction should be made to facility staff, and service users.

Staff may feel uneasy about the monitoring visit, fearing that their work is being monitored and judged. Service users may also be wary of the monitoring and fear repercussions if they take part in interviews. Therefore, members of the monitoring team should be attentive to this.

The monitoring team must not raise unrealistic expectations about what the monitoring will achieve.

Tour of the facility

Monitors should then go on a quick tour of the facility covering all the departments/wards/units. Even if it is a big institution, the monitors should walk through the corridors getting a sense of the place. It will be much easier for the rest of the visit to gauge whether one particular unit/department is 'better' than others. Monitors can then choose in which units/departments they would like to spend more time.

Targeted and in-depth observation in a small number of departments/wards/units

In the case of inpatient services, for example, observations should be made in acute and chronic units, the sleeping quarters in both male and female wards, seclusion rooms, occupational therapy rooms, the kitchen, eating area, toilets and bathrooms.

Observation should not be restricted to an examination of physical conditions; it should also include what happens at the facility. For example, when visiting inpatient and outpatient services, the monitoring team should observe the interactions between staff and service users in order to determine whether the users are being treated with dignity and respect and whether their rights and their legal capacity are respected.

Tips for observation

The WHO Quality Rights tool kit proposes the following tips for observation, which might be highly relevant also for the monitoring visits carried out within this project. It proposes that the observation to be made with all five sense, as follows:

See - Carefully observe the physical conditions and assess whether they are acceptable. For example, are the washing amenities and toilets clean? Do service users' sleeping quarters offer enough privacy? Is there overcrowding? In both inpatient and outpatient facilities, observe the interactions and relationships between staff and service users. Are service users spoken to and treated with dignity and respect?

Smell - Be aware of the different smells in inpatient facilities. For example, do the toilets smell? Bad smells may indicate that the toilets are not working or are not cleaned regularly and are thus unhygienic and possibly hazardous.

Feel - Touch the bedding to determine whether it is of adequate quality and appropriate for the climate. Feel for yourself whether the ambient temperature in different parts of the facility is comfortable or too hot or too cold. Turn on the taps to determine whether there is running hot water. It is not enough to ask whether there is adequate bedding, heaters or ventilators in the bedrooms or hot running water. You must check these for yourself.

Hear - Sounds in a facility, or sometimes their lack, can also be revealing. Are there shouts or screams from service users? If so, try to determine why and what is being done about them. Is the volume of music or a television inconsiderate of service users? Is there silence in the facility, and, if so, does this indicate a repressive atmosphere in which service users are reluctant to communicate with each other, visitors or members of staff?

Taste - Sometimes the food given to service users in facilities is not fit for consumption. Therefore, taste the food to judge whether it tastes good and is edible.

Interviews with service users, (family members or friends or carers) and staff

Interviews with service users, family members, and facility staff, as well as listening to their perspectives, are critical components of the monitoring visit. There are several issues to consider when conducting the interview. (See also "Method 1: Interviewing" above for more information.)

Interviewing tips

The WHO Quality Rights tool kit proposes the following tips for carrying out interviews:

Interviewers should conduct interviews in a manner that is respectful and courteous. Interviewees should not be made to feel that they are being cross-examined but rather that they are providing valuable input for the monitoring visit.

The perspectives of all those being interviewed are important. Very often, the views of service users are considered invalid or are overlooked. Interviews should be conducted in a manner that acknowledges and respects the views and perspectives of service users.

Allow for silence to give the interviewee time to think, and do not interrupt. Silence may be needed for longer than feels usual or comfortable.

Avoid interruptions. Allow people to speak without interrupting them. If you have a question about what they are saying, wait until they have finished their sentence.

Avoid excessive note-taking. Note-taking can be distracting for interviewees. It is important to listen to responses. One possibility is to have two people at interviews: one asking questions and listening to the responses and the other taking notes.

Short summaries, repeating what you have heard in your own words, may be a useful technique to indicate that you are listening and to check that you have understood what the person is saying correctly.

Avoid leading interviewees in their answers. Interviewers often tend to lead interviewees to the answer they are expecting to hear. It is important to be aware of this tendency and make efforts to avoid it.

Use open-ended questions. Open-ended questions (e.g. “How would you describe the physical state of the property?”) allow interviewees to share information they consider important. Avoid closed questions (e.g. “Do you think the physical state of the facility is bad?”) as far as possible, as these can prevent interviewees from expressing their views in their own way.

Be flexible. Interviewees’ answers to one question might also provide information relevant to a question planned for later in the interview. Do not stop them by saying that you plan to ask that question later on, but allow them to answer the question at hand fully.

Try to ascertain whether issues highlighted by the interviewees are unique events or practices or whether they are commonplace and common practice in the facility. For example, if someone says that a member of staff spoke to them disrespectfully, try to ascertain whether this happened only once with one member of staff or whether it is a common occurrence, with one or several staff.

Volume, speed, tone. Be aware of the volume of your voice and also your tone and speed. You should not speak too loudly, too quietly or too quickly. Allow the interviewee to set the pace of the interview.

Practice, practice, practice. Conducting interviews is a real skill. Learning interview techniques takes practice. It is therefore important to practice them, for example with other monitors before your visit to the facility.

It is critical that the interview process does not cause harm to the interviewee. As a result, the interviewee's well-being must always be prioritised. (See also "Method 3: Reviewing documentation" for a description of the tasks associated with this activity.)

The feedback after the monitoring visit

Following the monitoring visit, the director may request feedback on the findings. It is recommended that feedback on anything be directed only to the director. It is rarely appropriate for the monitoring team to invite someone subordinate to the director to attend the meeting, especially if that person is the target of any criticism the monitoring team wishes to level. It is critical to emphasise that monitors will not identify the individuals who spoke with the monitoring delegation. It is also critical to exercise extreme caution when saying anything that could reveal who said what.[60]

Reporting cases of abuse

Monitoring team members may become aware during interviews, observe or upon review of service user complaints that one or several service users are being exposed to abuse or neglect that puts their health and well-being at immediate risk for harm. Before the monitoring visit, therefore, the monitoring team should decide how such situations will be handled, perhaps by speaking with the head of the facility or another relevant authority, so that the situation can be addressed quickly.

If there are allegations of mistreatment and an interviewee still has marks and they agree for monitors to inspect them, monitors should try to record as much detail as possible. This should, if possible, be done by a medical member of the monitoring team. Monitors may want to take a photograph, noting the site, size, shape, colour and type of the injury. Monitors can ask if there was any medical assessment or treatment given, and can then try to find documentation of this and/or speak to the doctor who was involved.

The agreement of the service users concerned might have to be sought before the abuse is reported. Typically, the monitoring team should tell the director that they intend to do this and give reasons.

When there are specific national guidelines or legal provisions on the reporting of abuse, these must be followed. The monitoring team should identify legal or social channels and the names of legal representatives or advocates who can assist victims of abuse. In addition, monitoring team members might decide to give service users a telephone number at which they can be contacted should the users wish to report any incidents of abuse or neglect after the visit.

Internal debriefing and self-care

Human rights monitoring is exhausting and can be emotionally draining. It is vital that the monitoring team talks openly about how they are feeling and talking through the difficult issues, preferably immediately after leaving the facility. If there is a user of mental health services on the monitoring team, it might be difficult to 're-live' experiences by visiting an institution or a non-residential facility. All members of the monitoring team might need support. An external person

[60] Ibid., p. 45.

might be involved for the monitoring team to talk to. Also, it may mean keeping in touch with each other after the monitoring visits by making the occasional phone call.[61]

Step 7: Write the report

Shortly after the visit, the monitoring and management team will hold a debriefing session to discuss their findings. This can help identify the key issues that the report will address, the type of recommendations that should be made, and the nature of the follow-up. Discussions may reveal issues with the law and/or its implementation. Instead of presenting a list of individual problems, the teams should look for patterns and systemic issues. This analysis can serve as the basis for the report and its recommendations.

The monitoring team can use the following structure to document the findings in a facility in their monitoring report.

- executive summary (+ recommendations)
- method used for the monitoring
- results of the monitoring visit
- discussion and
- conclusions and recommendations.
- appendices to provide further technical information, in case they are relevant

There are several ways to write a monitoring report. Some monitoring teams collaborate on writing, while others assign one person to write a draft that is then reviewed by the rest of the team. Whatever strategy is used, the writing must be completed quickly, as the longer the report takes to write and produce, the greater the risk that memories will fade, and the report will become inaccurate as circumstances change. It is recommended that the group reconvene when the text is nearing completion to make any necessary changes and formally adopt the text.[62]

It is typical to discover during the analysis phase that more data, interviews, or site visits are needed. This kind of follow-up can be helpful in proving that the monitoring's conclusions are accurate and current.

If monitors are unsure about the credibility of a piece of information, it is best to leave it out, as discrediting one piece of evidence in a report can invalidate all of the findings. It is always worth remembering that all information can be verified. Information presented should be supported by facts. Make the information as accurate as possible.[63]

The report might include technical detail (for example, the wording of laws) and must include quotations to add credibility. The latter demonstrate direct contact with those affected by the problem and can bring dry text to life. Quotations are most effective when used to demonstrate a point or raise an issue.

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[61] Ibid., p. 46.

[62] WHO (n 1)., p. 20.

[63] The ITHACA Project Group (n 7)., p. 47.

Before publishing the draft report, monitors might want to send it to the facility for feedback on the facts.

Lastly, in the course of conducting independent monitoring, monitors may choose not to release certain information because, for instance, they may believe that the person who provided a particular piece of information is seriously at risk of punishment or retaliation if the information is made public.[64]

Step 8: Disseminate the report

Assessments of human rights violations in mental health, child care and social care facilities can serve several purposes, and the results can be used in many different ways, including informing policy, planning, and law reform; understanding human rights violations and advocating for change; raising awareness about these issues among the relevant authorities and stakeholders; developing and implementing violence prevention plans within the monitored facilities and beyond; and capacity-building in human rights.

The report must be distributed to the appropriate authorities, organisations, and people as soon as it is published. The management team must gather a list of recipients and obtain their contact information in order to accomplish this. It is a good idea to include a covering letter with the report that highlights important points to persuade the recipient to read it.

Stakeholders to whom reports may be sent include the following:

- Governmental authorities include ministers and other high-ranking government officials as well as policymakers in ministries and quasi-governmental organisations, as well as the personnel of the monitored facilities.
- Members of parliament, particularly those who hold relevant committee positions or have demonstrated a prior interest in issues related to mental health, disability, women's rights, child rights or human rights.
- Organisations of and for people with psychosocial disabilities and intellectual disabilities, women's organisations and child rights organisations which may use the monitoring data in their own campaigns to raise awareness and advocate for change.
- National Human Rights Institutions
- Academics and university departments, especially those relating to human rights or social and health care.[65]

Step 9: Evaluate the process

Doing an evaluation is the penultimate step in the monitoring process. There are numerous approaches to this, but in general, it entails getting the perspectives of various individuals regarding the degree to which the monitoring goals were met.

- How successful was the monitoring?
- What was the level of monitoring efficiency?

[64] Ibid., p. 48.
[65] Ibid.

- What could be done differently in the upcoming cycle of monitoring?

Again, depending on the intended audience and the outcome of the monitoring, it is worth considering these points in terms of the project's impact, methodology, report production, distribution and publicity, project management, and logistics.[66]

Step 10: Plan future visits

The necessity of human rights monitoring as a continuous and regular process has been emphasised throughout our Monitoring Methodology. In addition to preventing torture and other cruel, inhuman, or degrading treatment or punishment, routine monitoring helps to record the advancement—or lack thereof—of human rights over time.

[66] Ibid., p. 49.