

# Guide on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and how national Alzheimer's associations can participate in the review process



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# 1. Foreword

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) came into effect on 3 May 2008.

As an international human rights instrument, it was heralded as a landmark convention which transformed paternalistic approaches which aimed to protect people with disabilities, to a paradigm of empowerment and autonomy, holding people with disabilities as equal citizens, with the same rights and entitlements as anyone else. Under the definition of disability set out in the UNCRPD, dementia was recognised as a disability, placing obligations on governments to ensure that people living with dementia were supported and to ensure that policy and legislation aligned to the articles of the Convention and upheld their rights.

The UNCRPD has undoubtedly been the catalyst for wide-ranging legal and policy changes across Europe, both at a national and EU level. Yet 15 years later, its implementation remains variable. In many countries, dementia is still not recognised as a disability. As such, the rights of people with dementia as set out in the UNCRPD are not universally recognised or fulfilled.

Since the Convention came into effect, only one of Alzheimer Europe's national member organisations (the Alzheimer's Society – UK) has engaged in the UNCRPD review process, highlighting how the rights of people with dementia, under the Convention, were not being met by the policies and actions of the government. In doing so, when the UNCRPD Committee issued its recommendations



to the UK government, some dementia-specific actions were included amongst these.

As such, we believe that there is a significant opportunity for our members to bolster their excellent campaigning and advocacy work by engaging in the UNCRPD review process. Although the process cannot itself force governments to change

policies or legislation, by drawing attention to gaps in implementation of the Convention, it provides the opportunity for concerns and evidence to be presented to an independent and external actor; this can be a useful strand of advocacy and campaigning activities, especially if the concerns are acknowledged by the Committee in its final report.

It is Alzheimer Europe's hope that the development of this guide will enhance European Alzheimer's associations understanding of the purpose and relevance of the UNCRPD process for their advocacy and campaigning activities in relation to dementia and will provide a useful and practical guide which enables them to take part in the review process in future.

**Jean Georges**

Executive Director  
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## 2. The United Nations Convention on the Rights of Persons with Disabilities

### 2.1 A brief overview of the Convention and the Optional Protocol

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its Optional Protocol were adopted on 13 December 2006 at the United Nations Headquarters in New York, USA, and were opened for signature on 30 March 2007. The Convention entered into force on 3 May 2008.

The development and adoption of the Convention is a key instrument of the United Nations in its efforts to change the societal and legal context relating to persons with disabilities, moving away from medical and paternalistic models of disability, which have historically not recognised the agency and autonomy of individuals living with a disability. The Convention seeks to embed the conditions where the rights of persons with disabilities are upheld, recognising their agency to claim their rights and make decisions for themselves, based on free and informed consent.

The UNCRPD is an international human rights instrument with an explicit social development dimension, reaffirming that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms on an equal basis with others. Through its 50 Articles, it sets out how these rights apply to persons with disabilities across all areas of social, economic, cultural, civil and political life, as well as identifying where adaptations must be made to facilitate the exercise of rights.

The Optional Protocol is an additional agreement to the UNCRPD. Across 18 additional articles, it establishes an individual complaints mechanism for disabled people who allege that their rights under the Convention have been denied. It enables individuals or groups, who claim to have had their rights breached under the UNCRPD, to make a complaint to the Committee which oversees its implementation.

It is important to note that these methods of engagement are only available for individuals or organisations living in countries which have ratified the Optional Protocol. The list of countries which have ratified the UNCRPD and the Optional Protocol is available on the [website of the Office of the United Nations High Commissioner for Human Rights \(OHCHR\)](#). We explore these processes in detail in section five of this guide.

### 2.2 Why the Convention matters for persons living with dementia

Article 1 of the UNCRPD states:

*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

As such, people with dementia are recognised as having a disability, meaning that they should be afforded the same rights and protections outlined in the Convention. It can therefore serve as a useful foundation on which to articulate the rights of people with dementia, holding governments to account in relation to the services and support which they provide and the measures they take to ensure that people with dementia can be fully included in society.

Additionally, the review process by the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) and other mechanisms provide a useful measure to monitor the situation of persons with disabilities in your country and to highlight where governments must improve. In the following sections, we will explain how these work in practice, as well as how national Alzheimer's associations can contribute to the review processes within their countries, making this a part of their advocacy activities.

## ARTICLES OF THE UNCRPD

<b>Article 1:</b> Purpose	<b>Article 26:</b> Habilitation and rehabilitation
<b>Article 2:</b> Definitions	<b>Article 27:</b> Work and employment
<b>Article 3:</b> General principles	<b>Article 28 :</b> Adequate standard of living and social protection
<b>Article 4:</b> General obligations	<b>Article 29:</b> Participation in political and public life
<b>Article 5:</b> Equality and non-discrimination	<b>Article 30:</b> Participation in cultural life, recreation, leisure and sport
<b>Article 6:</b> Women with disabilities	<b>Article 31:</b> Statistics and data collection
<b>Article 7:</b> Children with disabilities	<b>Article 32:</b> International cooperation
<b>Article 8:</b> Awareness-raising	<b>Article 33:</b> National implementation and monitoring
<b>Article 9:</b> Accessibility	<b>Article 34:</b> Committee on the Rights of Persons with Disabilities
<b>Article 10:</b> Right to life	<b>Article 35:</b> Reports by States Parties
<b>Article 11:</b> Situations of risk and humanitarian emergencies	<b>Article 36:</b> Consideration of reports
<b>Article 12:</b> Equal recognition before the law	<b>Article 37:</b> Cooperation between States Parties and the Committee
<b>Article 13:</b> Access to justice	<b>Article 38:</b> Relationship of the Committee with other bodies
<b>Article 14:</b> Liberty and security of person	<b>Article 39:</b> Report of the Committee
<b>Article 15:</b> Freedom of torture or cruel, inhuman or degrading treatment or punishment	<b>Article 40:</b> Conference of States Parties
<b>Article 16:</b> Freedom from exploitation, violence and abuse	<b>Article 41:</b> Depositary
<b>Article 17:</b> Protecting the integrity of the person	<b>Article 42:</b> Signature
<b>Article 18:</b> Liberty of movement and nationality	<b>Article 43:</b> Consent to be bound
<b>Article 19:</b> Living independently and being included in the community	<b>Article 44:</b> Regional integration organizations
<b>Article 20:</b> Personal mobility	<b>Article 45:</b> Entry into force
<b>Article 21:</b> Freedom of expression and opinion, and access to information	<b>Article 46:</b> Reservations
<b>Article 22:</b> Respect for privacy	<b>Article 47:</b> Amendments
<b>Article 23:</b> Respect for home and the family	<b>Article 48:</b> Denunciation
<b>Article 24:</b> Education	<b>Article 49:</b> Accessible format
<b>Article 25:</b> Health	<b>Article 50:</b> Authentic texts

## 3. The Review process for the UNCRPD

### 3.1 The United Nations Committee on the Rights of Persons with Disabilities

The United Nations Committee on the Rights of Persons with Disabilities monitors the implementation of the UNCRPD by the countries that have become State Parties (i.e. that have ratified the Convention).

As set out in Article 34 of the UNCRPD, the Committee comprises 18 independent members who are elected by States Parties. Members are elected for a term of four years (renewable once, if re-nominated) by States Parties from among their nationals, with consideration given to ensure equitable geographical distribution, relevant legal experience and gender-balanced representation. Members are independent and serve in a personal capacity and not as representatives of the State Party which nominated them.

The Committee holds two sessions per year in Geneva, Switzerland. At these sessions, the Committee:

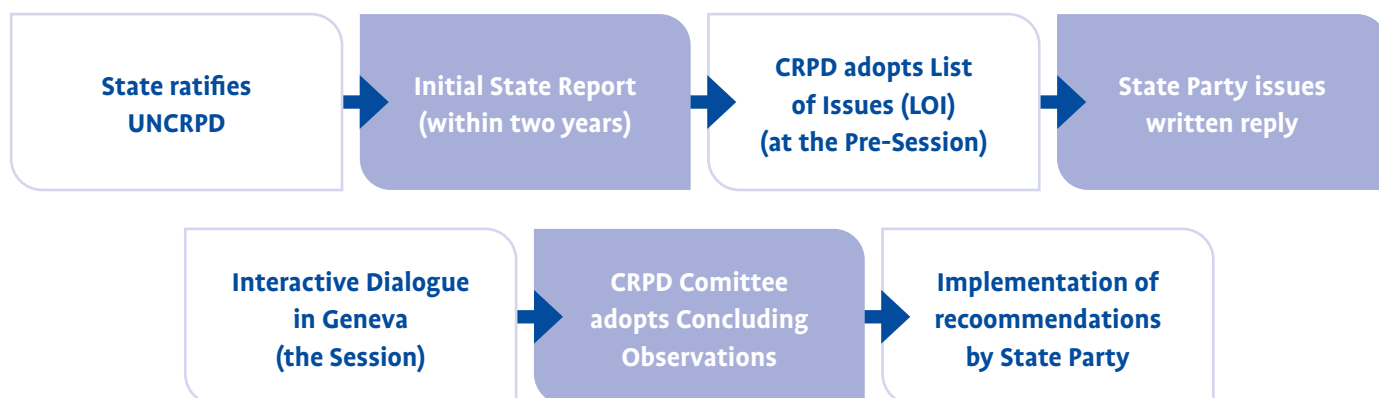
- Reviews the implementation of the Convention by the countries who ratified the Convention and adopts concluding observations
- Examines individual complaints and conducts inquiries concerning violations of disability rights
- Discusses the interpretation of articles of the Convention and adopts General Comments to guide countries in ensuring the rights of persons with disabilities.

### 3.2 How the UNCRPD review process works

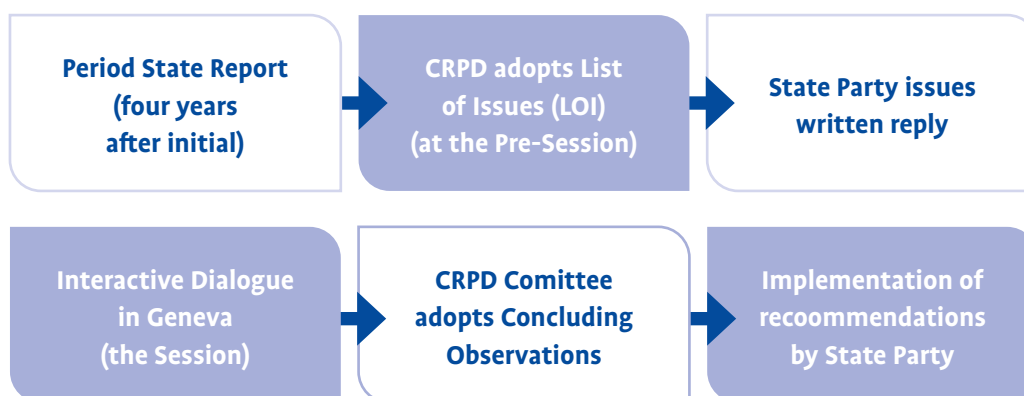
Under Article 35 of the UNCRPD, each State Party to the Convention must submit regular reports to the Committee on the measures it has taken to implement the UNCRPD. These reports form the basis for the Committee's review of progress made in implementing the Convention. The process can be summarised as follows:

- Within two years of ratifying the Convention, State Parties must submit a report to the Committee on how it has implemented the Convention, addressing all articles of the Convention.
- The Committee reviews this initial report before developing and issuing questions to the State Party (referred to as the List of Issues), seeking further information on any matters relating to the report, to which the State Party must respond. These questions will be developed and adopted during the Pre-Session Working Group.
- Following this, an interactive dialogue session is organised between the Committee and representatives from the State Parties, during which the Committee can ask questions on the implementation of the CRPD to which the State Party replies orally.
- The Committee then adopts its Concluding Observations, which set out the Committee's findings in relation to the State Party's adherence to the Convention, as well as non-binding recommendations on actions for the State Party.
- After four years, the State Party must submit a new report to the Committee. If the State Party has accepted the simplified reporting procedure, the Committee will initiate the proceedings by adopting questions for the list of issues prior to reporting, with the government's response being considered as the State Report.

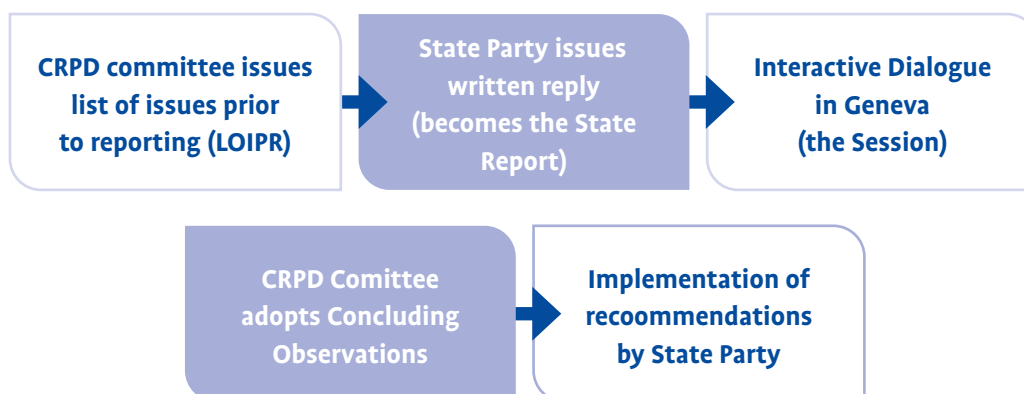
## Initial State Party Report



## Periodic Report (without simplified reporting procedure)



## Periodic Report (with simplified reporting procedure)



### 3.3 Why it is important for Alzheimer associations to involve themselves in the process

There are a number of reasons why Alzheimer's associations should involve themselves in the review process. As dementia is recognised as a disability under the Convention, the policies and practices, including services and supports which relate to, or affect, a person living with the condition, should be in line with the Convention.

The Committee is reliant upon receiving information from a broad range of stakeholders in order to formulate its List of Issues/Concluding Observations, and in particular from representative organisations of persons with disabilities. Guidelines for the reporting process require State Parties to facilitate the involvement of persons with disabilities, civil society organisations and National Human Rights Institutions (NHRIs) in the preparation of their periodic reports.

As such, there is likely to be additional context, knowledge and information which the Alzheimer's association can provide through their own submissions and engagement, which would give the Committee a fuller understanding

of the extent to which the Articles of the Convention are being implemented in a country, as well as the impact on the lives of persons with Alzheimer. Whilst other disability and civil society organisations will engage in the process, they may not focus on issues which specifically relate to dementia. For example, where countries do not recognise dementia as a disability (e.g. for the purpose of social protection, healthcare etc.), this is an issue which could be highlighted to the Committee as a failure to adhere to the Convention.

In addition to drawing the attention of the Committee to potential violations of the Convention, Alzheimer's associations can use the review of their country, especially during the Concluding Observations, as part of their advocacy work, to highlight the need for action in a certain area. Whilst the recommendations within the Concluding Observations are non-binding, it can be used as a way to encourage governments to take action or to highlight inaction in an area. Having these issues recognised by a UN Treaty Body gives significant weight to the matter and can be extremely helpful for an association as part of its advocacy work and to hold its government accountable to implement the CRPD and make it a reality for persons with dementia.

## 4. How national organisations can become involved in the review process

### 4.1 Opportunities for involvement in the review process

There are multiple opportunities for civil society organisations to be involved in the review process, both through the submission of information, as well as engaging the Committee in person or videoconferencing.

If your organisation does not have the capacity to be involved in all stages of the review process or is unable to undertake these actions itself, it may be possible to collaborate with other civil society organisations, including disability organisations, who will likely have knowledge and experience of engaging in the process.

To understand how best to contribute to the review process, it is essential to understand at what stage of the process your country has reached. The following resources can help:

- The Office of the United Nations High Commissioner for Human Rights (OHCHR) [hosts a website showing the current timeline for all UN Treaties](#), including the UNCRPD, searchable by Year, Region, Country, Treaty and Document Type.
- [The OHCHR website](#) also contains a dedicated page showing the dates and forthcoming pre-sessions and sessions of the Committee.
- The European Disability Forum and the International Disability Alliance can also provide support in developing inputs to the CRPD Committee and/or providing training on the topic.

The following is a brief description of the three ways in which your organisation may contribute to the review process.

#### Initial state report/Periodic report

When preparing their Initial State Report/Periodic Report, governments should engage with persons with disabilities, civil society organisations and National Human Rights Institutions (NHRIs). As such, look for consultations or events that your government may be holding and use these opportunities to contribute the perspective of people living with dementia. Alternatively, if you have contacts in any government ministries, you should seek to engage with the relevant person or directorate with responsibility for the development of the report.

It is likely that civil society organisations, including disability organisations, will seek to engage in any consultation process operated by the government. Therefore, if you do not wish to engage directly with the process or do not have the capacity to do so, you may wish to contact other organisations to explore the potential to collaborate or contribute to their response.

#### Alternative/Shadow reports

Whether or not you have contributed to the report developed by the government, you may also wish to prepare and submit an Alternative/Shadow Report to the Committee. These reports allow civil society organisations to highlight the challenges experienced by people with disabilities and how their rights, as defined in the Convention, are not being met. This report would be an opportunity for you to specifically highlight how the rights of persons with dementia are or are not being met by government, and to propose recommendations on ways to improve the situation.

The Committee recommends that civil society organisations submit their report at a relevant stage of the procedure, noting that reports should be submitted:

- Before or after the State Party submits its Periodic Report (before the pre-session)
- Before the adoption of the list of issues (before the pre-session)
- After the state party has submitted its replies to the List of Issues and before the constructive dialogue (before the session)
- Before the Committee adopts the List of Issues within the framework of its simplified reporting procedure, also known as the List of Issues Prior to Reporting (before the pre-session).

In section 4.2, we have suggested that submissions be aligned to the pre-sessions and sessions, aligning them with the meetings of the Committee.

It is likely that an organisation of persons with disabilities in your country will develop their own Alternative/Shadow Reports. These organisations will also have experience drafting these reports and may be able to offer support or answer questions, to inform the development of your own report. Alternatively, if you do not have the capacity to develop your own reports, there may be the opportunity to collaborate or contribute to the development of their report.

#### Private meetings/briefings with the Committee

It is possible to request to attend one of the private meetings/briefings held by the Committee, either in person in Geneva, Switzerland, or via video-conference.

During the pre-session in Geneva, you can take part in a private meeting/briefing with the Committee to provide detailed information on the situation of persons with disabilities in your country. These meetings last generally meeting last 1-1.5 hours and take place before the adoption of the list of issues. In this meeting, no government representatives are present.

You must prepare a statement on the main issues and will be asked clarifications/additional information by the Committee members. During the pre-session, a smaller number of Committee members are present (usually six to nine). During the full session in Geneva, a private meeting will be held, similar to the one taking place at the pre-session, where you can raise issues of importance with the

Committee, which provides the opportunity to feed into the concluding observations. Additionally, civil society organisations are also permitted to attend the interactive session as an observer, however, they are not permitted to speak during these sessions.

## 4.2 Preparing an alternative report and practical details

As noted in the previous subsection, there are multiple opportunities for civil society organisations to provide written contributions to the work of the Committee. These can be aligned to the pre-session working group session and the main session of the Committee:

- For a report submitted in **advance of the pre-sessional working group** (either in relation to the State Party Report, the List of Issues or List of Issues Prior to Reporting) you can submit:
  - » A detailed report covering all relevant articles of the Convention; or
  - » A shorter report summarising the main issues.
- Either version submitted at this stage can include suggested questions for the List of Issues/List of Issues Prior to Reporting, and also include proposed recommendations for the Concluding Observations.
- You can also decide to send your answers to the List of Issues, or include this in your report in advance of the interactive dialogue.
- For reports submitted **in advance of the interactive dialogue/session**, in relation to the Concluding Observations, you should submit a detailed report covering all of the relevant articles under the UNCRPD. This report can include suggested recommendations for the concluding observations.

It is possible to revise your alternative/shadow report and add more information between the pre-session and the interactive dialogue. You may wish to do this, for example, if there is additional information you wish to convey (e.g. in response to a matter raised in the State Party Report, which you did not address in your initial contribution). Alternatively, reports can be submitted independently of each other.

Whilst the reports may differ slightly depending on the stage of the procedure, the substance and format of the reports, should broadly be consistent. Below, we highlight some of the key points from the Committee's own guidance.

### Key information to include in the report

Reports should generally follow the following structure:

- An overview of the organisation, its activities and mission statement, as well as the role of persons with disabilities in the organisation, including in the development of the submitted report. The Committee also wishes to know how the report was developed, which organisations were consulted etc.
- An executive summary of no more than one page.
- Reference to specific articles of the Convention and the extent to which governments are adhering to these, as well as the gaps in implementation of the specific article.
- Proposed questions or recommendations (depending on the stage of submission).

For the substantive sections of your report, it is advised that you address each specific article of the Convention in turn, even where certain policy or legislative matters may fall under multiple articles.

The focus for your reports should be on how the State Party (through policies, legislation and other administrative decisions) affected the way in which the rights of persons with dementia are or are not upheld, in relation to the specific article.

Depending on which stage of the process in which you are engaging, you may wish to address points raised in the State Party Report or in the government's response to the List of Issues/List of Issues Prior to Reporting. This could include additional information or context that you feel is missing from the government's response or to bring attention to a specific issue which affects persons with dementia (e.g. if the government highlights a policy as evidence of its compliance with a UNCRPD article, but people with dementia are ineligible, this additional context is important for the Committee to know).

### Length

There are word limits limited imposed for all submissions to the Committee. For alternative reports to the State Party Report, the word limit is 10,700 words. For all other submissions the limit is 5,350. The description of the organisation and the executive summary do not contribute to the word limits.

### Language

The Committee works in the five UN languages, therefore, reports can be submitted in English, French, Chinese, Russian or Spanish. However, it should be noted that the Committee does not translate any of the submissions received from civil society organisations – therefore we recommend submitting reports in English.

### Deadlines

The deadlines for the submissions depend on the stage of review and whether the country has agreed to the simplified reporting procedure. Submission should be made as follows:

- No later than three weeks before the opening of the pre-session/session
  - » Submissions can still be submitted up to one day before the session, however, due to time constraints, these submissions are not guaranteed to be considered by the members of the Committee
- For the development of the LOIPR, submissions may be submitted up to four months prior to the beginning of the session in which the List of Issues will be adopted.

The current status of a country in relation to the stage of review can be checked on the [OHCHR website which shows current timelines for all UN Treaties, including the UNCRPD](#).

### Format

The Committee asks for written submissions should be provided in accessible digital or electronic formats, for example, Microsoft Word or Rich Text Format. Hard copies should not be sent to the Committee.

### 4.3 Examples of a dementia-specific submission

Alzheimer Europe is only aware of one of its member organisations having submitted an alternative report to the Committee during a review process. We have included a brief overview of the key points covered by the submission, as an illustration of how issues relating to dementia can be addressed in the context of the Convention.

#### **Alzheimer's Society response to State Party Report in 2017**

The Alzheimer's Society, working with a number of other organisations, developed and submitted an alternative report in 2017, following the submission of the UK Government's Periodic State Report (prepared by the UK Independent Mechanism (UKIM)).

The report noted that people with dementia face significant challenges in realising their rights under the UNCRPD, as a result of stigma, prejudice and lack of understanding about the condition as well as discrimination on multiple grounds including age and gender.

Additionally, they highlighted that dementia was a 'hidden' or 'invisible' disability, with dementia still viewed through the medical model of disability, rather than the social model, meaning that stereotypes exist about dementia, overlooking people's actual experience. These themes were discussed with specific reference to Articles 19, 25, 27 and 28.

The alternative report also highlighted that people with dementia face challenges when accessing support services which enable them to continue living independently within their communities, resulting in obstacles to realising their rights under Article 12 and 14.5. It further highlighted the existence of a paternalistic and risk-averse culture in public services and wider society which frequently fails to respect people's ability to make their own decisions.

The report set out a range of suggested recommendations to include in the Concluding Observations, with a strong focus on measures needed to challenge negative views of dementia, as well the need for all sections of society to better understand dementia to ensure people living with the condition are able to access the support they need.

The full Alternative Report is available on the [Alzheimer's Society's website](#).

#### **Response of the Committee**

When issuing their recommendations as part of the Concluding Observations, the Committee included a specific reference to dementia, and a slightly broader reference to neurological and cognitive conditions, reflecting some of the issues raised in the alternative report.

Specifically, in relation to Article 8 (Awareness Raising), the report stated:

*22. The Committee is concerned at the persistence of negative attitudes, stereotypes and prejudice against persons with disabilities, particularly persons with intellectual and/or psychosocial disabilities and persons with neurological and cognitive conditions such as dementia and Alzheimer's, and about their social protection entitlements*

*23. The Committee recommends that the State party, in close collaboration with organizations of persons with disabilities, strengthen its awareness-raising campaigns aimed at eliminating negative stereotypes and prejudice towards persons with disabilities, particularly persons with intellectual and/or psychosocial disabilities and persons with neurological and cognitive conditions such as dementia and Alzheimer's. To that end, the State party should include mass media strategies and campaigns, with different target audience groups, based on the human rights model of disability.*

In addition, in relation to Article 25 (Health), the report stated:

*55. The Committee recommends that the State party, in close collaboration with representative organizations of persons with disabilities:*

*Develop a targeted, measurable and financed plan of action aiming at eliminating barriers in access to health care and services, and monitor and measure its progress, especially in relation to persons with intellectual and/or psychosocial disabilities and those with neurological and cognitive conditions.*

The full Concluding Observations of the Committee, in relation to the UK, are available on the [UN Treaty Body Database](#).

## 4.4 Preparing for private meetings / briefings

At both the pre-session and session of the Committee, country-specific private meetings are held with civil society organisations, providing the opportunity to provide further information to the Committee prior to their adoption of their List of Issues or Concluding Observations. Additionally, it provides the Committee the opportunity to follow up with specific questions on the situation in your country.

Participation in these meetings can be done in person in Geneva or via video-conference, with interpretation into the five languages of the UN. However, it should be noted that in-person attendance is not supported financially by the Committee. To participate in these private meetings with the Committee, you must send a [request to the Secretariat](#) (usually at the same time that you send your alternative report) before the deadline set for each session (in general one month before the start of the session).

Exact deadlines for submissions to the pre-sessions and sessions can be found on the [announcement on the Committee website](#). Under each webpage of the pre-session or session, an “Information note for Stakeholders” will be published some months in advance, which will provide details on:

- The dates and times of the private briefings.
- Who should be contacted to request participation.
- The deadline for requesting participation.

If accepted, further information will be sent to you by the Secretariat. You will be asked to prepare an oral statement and to submit it in writing to the Secretariat of the Committee in advance of the meeting. The statement should be concise and inform the Committee on the major issues in your country in relation to the implementation of the Convention. You may also wish to emphasise specific questions/recommendations which you would like included in the List of Issues/Concluding Observations.

Organisations wishing to attend and present at the private meetings must register for accreditation to the session. Information on how to do this will be provided in the “Information note for stakeholders” and should be communicated by the Secretariat.

The private meetings/briefings will generally proceed as follows:

- Presentations will be made by organisations of persons with disabilities, independent monitoring frameworks, equality bodies, national human rights institutions and other civil society organisations.
  - » The length of time available to speak will vary depending on the number of organisations who have registered to participate, however, individual organisations will usually have around 5 minutes to present.
- Questions will be asked by Committee members to representatives of the presenting organisations.
- Responses will be provided by representatives of the presenting organisations.

If there is time remaining after the replies, the Committee members are invited to ask follow up questions, and the representatives are given the floor to answer once again).

As with the written submissions, disability organisations are likely to participate in these proceedings. It is advisable, even if you intend to participate yourself, to engage with these organisations in order to coordinate messages or themes you will raise during the meeting. These organisations may also be able to provide additional information or advice about the sessions.

## 5. Complaints: Individual communications and inquiries

### 5.1 What are individual communications and inquiries?

In addition to the review procedure, it is possible for the Committee to examine alleged violations of the rights of persons with disabilities which are submitted to it directly by an individual or organisation. However, this can only be done in countries which have ratified the Convention **and** its Optional Protocol.

Depending on the information sent to the committee and the background to the complain the Committee will either:

- Adopt a view, potentially including recommendations, on individual complaints (referred to as “individual communications”), when the rights of a person with disabilities have been violated; or,
- Launch an investigation (called an “inquiry”) where it is believed that there are grave or systematic violations of the rights of persons with disabilities in the country. The Committee may visit the country as part of its inquiry.

There are slight differences between the criteria for an individual communication and an inquiry, as follows:

#### INDIVIDUAL COMMUNICATION

Complaint concerning one or several persons with disabilities

Only after having exhausted domestic remedies (i.e. through the courts)

Identification of the victim(s) (cannot be anonymous)

#### INQUIRY

Complaint concerning grave or systematic violation affecting a large number/group of persons with disabilities

Domestic remedy does not have to have been sought prior

Complainant(s) can remain confidential

In both instances, the government concerned has six months in which to respond recommendations and findings of the Committee.

As with the Concluding Observations and General Comments, these findings and recommendations are non-binding, however, they send a strong message to countries that violated the rights of persons with disabilities.

### 5.2 How to support individual communications and inquiries

Organisations of persons with disabilities can submit information to the Committee either as an individual communication or to provide information for inquiry. To do so, individuals or organisations must submit the following information:

- Information concerning the author(s) of the communication
- Information concerning the alleged victim(s)
- Information on the State Party concerned
- Subject matter of the communication
- Nature of the alleged violation(s)
- Steps taken to exhaust domestic remedies
- Other international procedures
- Specific requests/remedies.

#### Individual communications

As the cost of pursuing actions through court can be substantial, it is a course of action which will not be feasible, both for individuals and civil society associations. As this is a prerequisite for individual communications, submitting an individual communication to the Committee is unlikely to be an option which is open to most associations and individuals. However, if you do submit an individual communication on behalf of an individual, you must demonstrate that you have the authority to do so e.g. by having written consent from the person. Associations can still play an active role in ensuring that people with

dementia are fully aware of their options should they feel their rights under the Convention have been breached. As much of the information about the process is only available in the UN's working languages, the association may wish to have information or resources about this particular approach translated into your country's national language(s).

Further information on Individual Communications is available on the [Treaty Bodies website](#).

### Inquiries

Alzheimer's associations frequently support individuals with matters relating to health, social services, social protection and other aspects covered by the Convention, providing advice, information and guidance to individuals living with the condition. As such, your organisation is likely to be well positioned to identify emerging themes and trends, especially where supports and services are not upholding the rights of persons with dementia. Depending on the frequency and severity of the breaches of rights, your organisation may decide that there is merit in asking the Committee to launch an inquiry into the policies, legislation and/or actions of a government.

Whilst this reporting methods does not require having exhausted the domestic means of challenge, e.g. having taken the matter through the courts, organisations should still seek to engage with governments and lobby for change in the first instance. Requesting an inquiry from the Committee should only be considered where the government refuses to engage and the systemic breaches of rights continue.

According to the Committee's guidance for submissions, requests for inquiries should include:

- Identification of your organisation, including your mission statement, as well as the role of persons with disabilities in your organisation
- An outline of the grave and systematic violations of rights in the Convention
- Credible and reliable information on which the submission is grounded
- Recommendations to the Committee about how to remedy the violation of rights
- Suggestions for other references and additional information regarding the matter of inquiry that may contribute to the procedure

The Committee has [guidelines for Civil Society Organisations](#).

## 5.3 Examples of Committee Inquiries with relevance for people with dementia

To illustrate how the Committee has conducted inquiries in the past, we have provided a brief summary of two of the three inquiries held by the Committee to date, specifically those which have the greatest relevance for people living with dementia.

### United Kingdom (2014)

In 2014, an inquiry was launched focusing on the impact of legislation, policies and measures adopted by the UK Government relating to social protection, work and employment (dating from 2010). The CRPD Committee determined that the reform of the welfare system resulted in a reduction of benefits, which were assessed using a medical model. Additionally, the reform affected housing and community-based services, which affected the rights of persons with disabilities.

The Committee concluded that there were grave and systematic violations of the rights of persons with disabilities in relations to articles 19, 27 and 28 of the CRPD.

### Hungary (2017)

In 2017, the Committee examined evidence submitted that suggested that people with disabilities were systematically deprived of their right to equal recognition before the law, that institutionalisation was being expanded and that persons with disabilities were subject to guardianship orders. The Committee carried out a confidential inquiry, including a country visit in 2019, finding that the number of people with disabilities living under a guardianship order or inside institutions was increasing, whilst community-based services and support were found to be underdeveloped and insufficient. People with intellectual and psychosocial disabilities were found to be particularly affected by these actions.

The Committee concluded that there were grave and systematic violations of the rights of persons with disabilities in relations to articles 4, 5, 12 and 19.

The documents relating to the inquiries are available on the [UN Treaty Body Database](#).

## 6. General Comments

### 6.1 What are General Comments?

The Committee has on occasion issued General Comments, which provide detailed explanations relation to its own interpretation and implementation of a specific Article or Articles in the Convention. To date, the Committee has adopted eight General Comments on various articles of the Convention.

It is important to note that these General Comments are not legally binding, but rather represent the Committee's interpretation of the Convention and indicate how, for the purposes of Monitoring and Reporting, the Conventions should be interpreted and applied.

DATE ADOPTED	GENERAL COMMENT	TOPIC
09 September 2022	<a href="#">General comment No. 8 (Advance unedited version)</a>	<b>Article 27:</b> Work and employment
21 September 2018	<a href="#">General comment No. 7</a>	<b>Article 4.3 and 33.3:</b> Participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention
09 March 2018	<a href="#">General comment No. 6</a>	<b>Article 5:</b> Equality and non-discrimination
31 August 2017	<a href="#">General comment No. 5</a>	<b>Article 19:</b> Right to independent living
26 August 2016	<a href="#">General comment No. 4</a>	<b>Article 24:</b> Right to inclusive education
26 August 2016	<a href="#">General comment No. 3</a>	<b>Article 6:</b> Women and girls with disabilities
11 April 2014	<a href="#">General comment No. 2</a>	<b>Article 9:</b> Accessibility
11 April 2014	<a href="#">General comment No. 1</a>	<b>Article 12:</b> Equal recognition before the law

### 6.2 How to contribute to General Comments

Civil society organisations are periodically invited to make written submissions and participate in Days of General Discussion on the topic of the General Comments, which helps inform the Committee in relation to implementation affecting persons with disabilities.

For instance, before the adoption of General Comment No 6, the Committee organised a [Day of General Discussion](#)

[on the right of persons with disabilities to equality and non-discrimination](#) to which organisations were invited to send written submissions and make oral interventions.

The requirements for written submissions and interventions vary, therefore it is advisable to check the [Committee website](#) for information on new general comments and instructions on contributions.

## 7. General Discussion Days

From time to time, the Committee will host days of general discussion (DGDs), which aim to develop understanding of the content and implications of the Convention as they relate to specific articles or topics, as well as to inform the development of other relevant documents such as General Comments. Representatives of Governments, representative organisations of persons with disabilities and other civil society organisations, UN human rights mechanisms, UN bodies and specialised agencies, national

human rights institutions, as well as individual experts, are invited to take part in the DGDs in person, as well as by submitting evidence in advance. Associations may wish to engage in these days, particularly where there is an issue of particular importance to people with dementia, which your organisation believes should be considered when interpreting a specific Article. Further information on the DGDs and examples of those from the past can be found below.

YEAR	TOPIC
2023	Preparation of a General Comment on persons with disabilities in situations of risk and humanitarian emergencies
2021	The right of persons with disabilities to work and employment
2018	The consultation and involvement of persons with disabilities in decision-making and monitoring processes
2017	Equality and non-discrimination
2016	The right to live independently and be included in the community
2015	The right to education for persons with disabilities
2013	Women and girls with disabilities

Further information on the DGDs, when they will happen, how to register and how to submit information in advance, will be posted by the Secretariat on the [website of the Committee](#).

## 8. Appendix 1 – Glossary of Terms

This guide uses a number of the terms which are used in relation to the UNCRPD and the reporting process, which reflects the terms used by the Convention and the Committee. Below are some explanations of some key terms:

**Alternative/shadow report:** A report prepared by civil society organisations on the implementation of the Convention in their country, which may provide additional information and context to the State Party Report, which is submitted by the country being reviewed.

**Concluding observations (COs):** The official conclusions of the Committee, which indicate whether a State has respected or violated the rights of persons with disabilities, which will usually include specific recommendations for actions the country should undertake in order to ensure compliance with the Convention.

**General Comment:** A document which clarifies the Committee's interpretation of an Article (or Articles) of the UNCRPD, explaining their content and how they should be implemented and reported on by State Parties.

**Individual communication:** Also known as complaints, these submissions, from or on behalf of a person or group of persons, highlight a violation of the Convention by a State Party. However, the Committee can only do so where the State party has ratified the Optional Protocol.

**Inquiry:** An investigation by the Committee to determine whether a State Party has violated the rights of persons with disabilities, only undertaken after receipt of a complaint(s) from individuals or organisations of grave or systematic violation of the rights of persons with disabilities. The Committee looks into the complaint(s) and may visit the country. However, the Committee can only do so where the State party has ratified the Optional Protocol.

**Interactive dialogue:** Meeting between the Committee and a State for its review. It is sometimes referred to as constructive dialogue.

**List of Issues (LOI):** Questions prepared by the Committee and sent to a State in advance of the session dedicated to the examination of the State Party's Periodic Report. The State must respond to these questions before the start of the session.

**List of Issues Prior to Reporting (LOIPR):** Questions developed and issued by the Committee, for States who have previously been reviewed and who have opted into the simplified reporting procedure (this commences the round of review).

**Optional Protocol:** An additional agreement to UNCRPD which establishes an individual complaints mechanism for disabled people who believe that their rights under the Convention have been denied.

**Pre-session/pre-sessional working group:** A group composed of at least five members of the Committee which has responsibility for the development of the List of Issues/List of Issues Prior to Reporting. This group meets twice per year.

**Simplified reporting procedure:** An optional reporting mechanism open to States which have previously been reviewed, whereby the Committee will develop and issue a "List of Issues Prior to Reporting" in advance of the scheduled periodic report of a country. The State's response to these questions is then considered as its State Party Report.

**State Parties (to the UNCRPD):** Countries or supranational organisations (such as the EU) which have signed, acceded to or ratified the UNCRPD.

Find a full glossary of technical terms on the [UN website](#).





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