



# IF INFORMATION PACKAGE ON THE UNCRPD AND THE REPORTING CYCLE



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS

# Introduction

One of the primary missions of the International Federation for Spina Bifida and Hydrocephalus (IF) is the advancement and full realisation of the human rights of individuals with Spina Bifida and/or Hydrocephalus (SBH) as per international human rights law. The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is the most important international treaty for the global SBH community.

IF has created this information package on the UNCRPD for its Member Associations and individuals with SBH and their families with the ambition to empower and inform.

**In this information package you will find information on:**

- **The UN Convention on the Rights of Persons with Disabilities**
- **Monitoring the implementation of the UNCRPD**
- **What does IF do for the global SBH community?**
- **How can you participate?**
- **Useful links**



# The UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) entered into force on the 3rd of May 2008. The UNCRPD outlines the rights of persons with disabilities and the obligations which governments have to uphold and protect those rights.

The UNCRPD was created after decades of work by the United Nations (UN) and disability rights activists who campaigned to transform the attitudes towards persons with disabilities and protect their right to make decisions for themselves and to be included as active members of society. This is achieved through active participation by persons with disabilities and their representative organisations in decision making processes which affect them.

## UN Convention on the Rights of Persons with Disabilities



UNITED NATIONS  
HUMAN RIGHTS  
OFFICE OF THE HIGH COMMISSIONER

# Key words and acronyms

## UN Convention on the Rights of Persons with Disabilities (UNCRPD)

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An international convention which outlines the rights of persons with disabilities and the duties that states/countries have to advance and protect those rights.

## Signatory of a convention

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This means that a state/country has signed a convention and has expressed its support and intent to examine it according to their own political systems and consider full ratification.

## State Party

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A state party to a treaty is a state/country that has ratified or acceded to an international convention. This means that they agree to take steps to bring their legislation and policies in line with the convention.

## Ratification of an international convention

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When a state/country ratifies an international human rights treaty it takes on an obligation to implement the rights outlined in that treaty and subject themselves to the monitoring process outlined in the convention. When a state has ratified a convention it becomes a state party to the convention.

## Conference of States Parties (COSP)

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This is made up of all the states which have signed the UNCRPD. Delegates from the state parties meet regularly at the UN headquarters in New York USA to discuss the implementation of the UNCRPD.

## Committee on the Rights of Persons with Disabilities (CRPD)

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A committee of 18 independent experts that monitor the implementation of the UNCRPD. They are elected by the States at the Conference of the State Parties for a 4 year term. They do not represent governments or state parties. The CRPD usually meets twice a year in Geneva, Switzerland.

# The EU and the UNCRPD



The EU has signed and ratified the UNCRPD and is the first international organisation to become a state party to a UN Convention. This is important because most international treaties only allow countries to sign and ratify them. By allowing the EU to sign and ratify the UNCRPD the UN and its Member States acknowledged the EUs unique role as a supranational international organisation in advancing and protecting human rights.

This means that the EU has obligations to advance the implementation of the UNCRPD and ensure that all of its activities and legislation comply with the convention. In 2021, the EU published a strategy which outlines how that is to be achieved. It is called 'Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030'.

In addition, all of the 27 Member States of the EU have signed and ratified the UNCRPD.

## How is it supposed to be implemented?

**Article 33 of the UNCRPD states that all state parties must set up national focal points which are tasked with implementing the convention. In addition, state parties must also set up an independent monitoring mechanism. Usually this role is fulfilled by an independent national human rights institution.**

**Article 33 obliges state parties to ensure that persons with disabilities and their representative organisations are fully involved in the monitoring process.**

# The EU and the UNCRPD

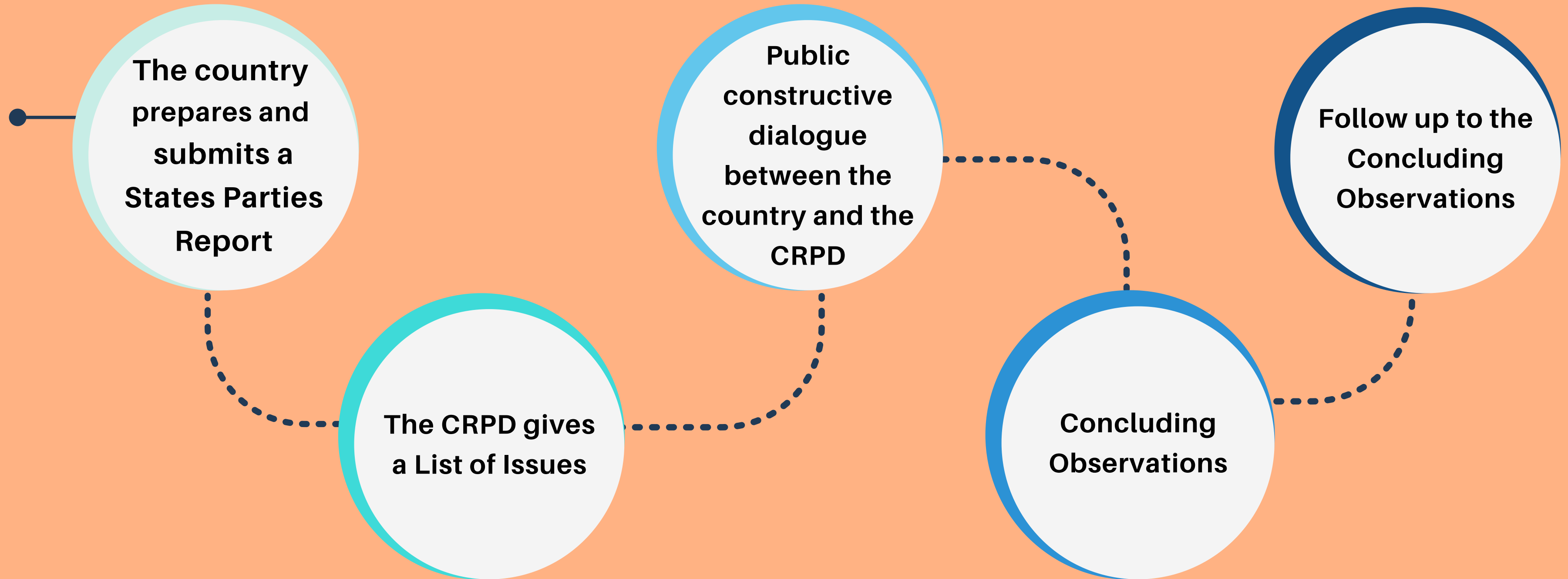


## **Optional Protocol to the Convention on the Rights of Persons with Disabilities:**

The Optional Protocol came into force at the same time as the UNCRPD but not all states parties to the UNCRPD have signed and/or ratified the Optional Protocol.

The Optional Protocol allows individuals or groups of individuals to submit complaints regarding violations of the UNCRPD directly to the CRPD. The optional protocol lays out the conditions and processes for how this should be done.

# Monitoring the implementation of the UNCRPD



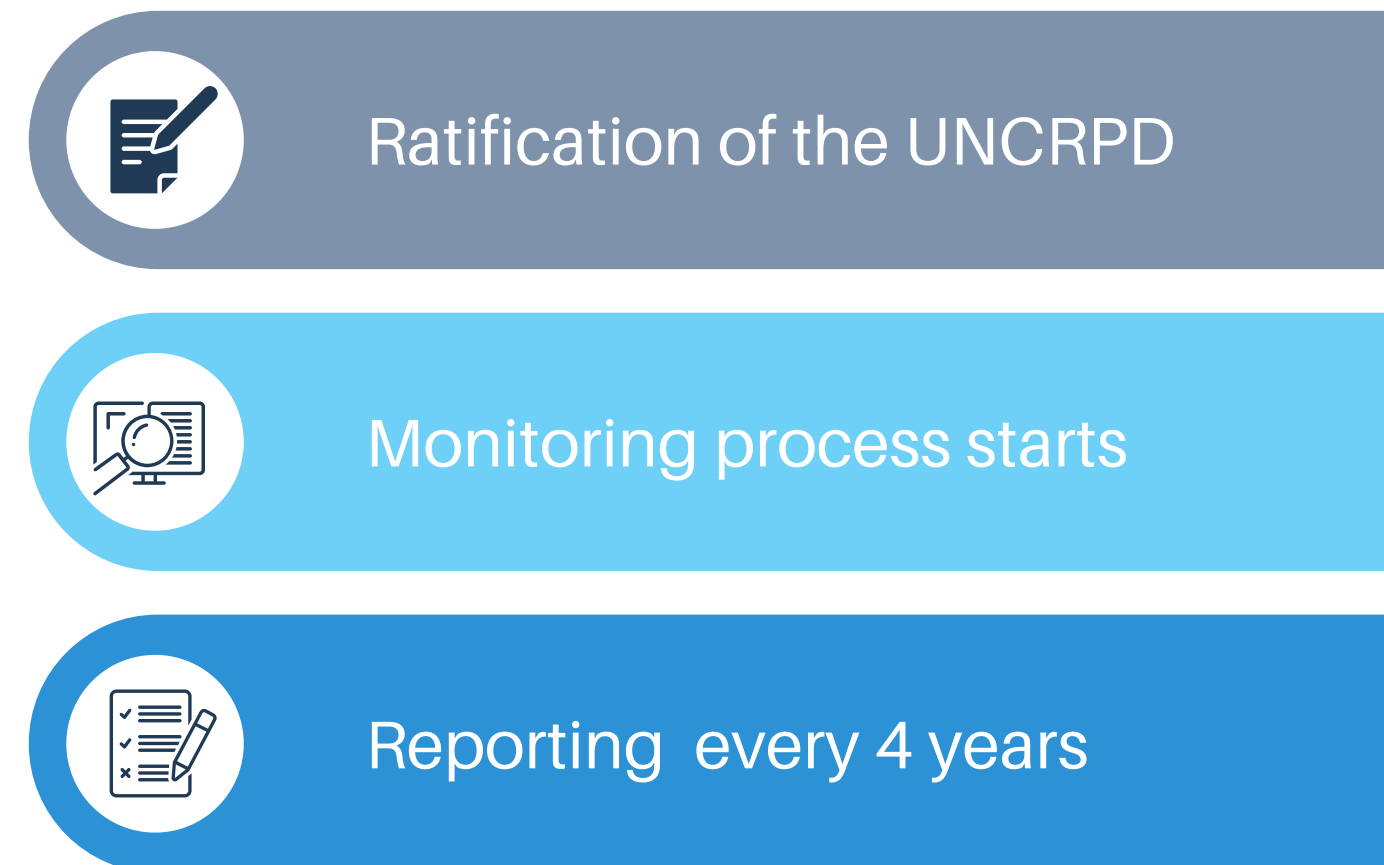


## How does it work on the national level?

All state parties have to take part in a monitoring process where they report to the CRPD on what the country has done to advance and protect the rights of persons with disabilities. This reporting cycle starts two years after a state party ratified the UNCRPD and then every four years.

This progress begins with the country submitting a States Parties Report where the country outlines what it has done to implement the UNCRPD. Countries often begin preparing for these reports well in advance of the deadline given. There are opportunities for civil society to participate in this process, either by providing input to their governments or raising awareness among policy makers and the general public of where the country has failed to fulfill its obligations under the UNCRPD.

Civil society including SBH associations and other organisations involved in disability rights also begin preparations for this monitoring process ahead of the deadline given by the CRPD.







## How does it work on the international level?

When a state party has submitted its report to the CRPD the committee will then examine it and create a document with their comments. These are called 'Lists of issues' or LOIs. This is followed by a constructive dialogue which is held when the CRPD meets twice a year. During this constructive dialogue civil society such as SBH associations are given the opportunity to make comments as well. This enables the CRPD to receive information from various sources and stakeholders and not just from the state party. The active involvement of persons with disabilities is very important for the work of the CRPD and the implementation of the UNCRPD.

From these discussions the CRPD writes the Concluding Observations where the CRPD takes all of this material together and outlines its opinion on how well (or not well) the state party has done in implementing the UNCRPD as well as recommendations for improvement.

Information on when countries are expected to report to the CRPD as well as access to documents from previous monitoring cycles such as the LOIs and Concluding Observations can be found online on the website of the CRPD.



## Shadow reports

Civil society can submit what is called an 'alternate report' or a 'shadow report' to the CRPD. These reports are submitted by civil society and provide a different perspective than what the country may be claiming in its own report.

For example, a state party may claim in its report that they have implemented new policies to improve access to healthcare and other essential services for persons with disabilities. However, if those policies have not been good enough and access to services is still bad civil society such as SBH associations and other disability rights organisations may seek to highlight that issue to the CRPD in a shadow report.

The CRPD provides guidelines on how these reports should look like and when submissions for these alternative reports are open. However, it is good to prepare ahead of time if you know that your country is going to be submitting a report to the CRPD soon. In addition, these shadow reports can be done collaboratively with several different civil society organisations by submitting a shadow report together.

The CRPD also has open calls for public consultations and/or comments. These are advertised on the CRPD website.



# What does IF do for the global SBH community?

IF represents the global SBH community and aims to advance and protect the rights of individuals with SBH and their families. IF achieves this through its policy and advocacy work as well as through awareness raising. IF actively works to increase its presence and visibility on the regional and international level, including in the EU's implementation of the UNCRPD and in relevant activities on the UN level.

IF monitors the work of the CRPD and reaches out to IF Members whenever a relevant opportunity for input or participation is identified. IF also prepares statements and inputs on behalf of IF Members to submit to the CRPD to ensure the voice of the SBH community is heard in the monitoring and implementation of the UNCRPD.

Supporting IF's Member Associations as well as individuals with SBH in their own policy and advocacy work is a vital part of IF's mission and work. IF organises a variety of opportunities for participation and training for its members each year. These are advertised and communicated to IF's Members on IF's social media accounts as well as through newsletters and emails.

If you have any questions, comments or ideas on the UNCRPD and disability rights advocacy please don't hesitate to contact the IF Team.

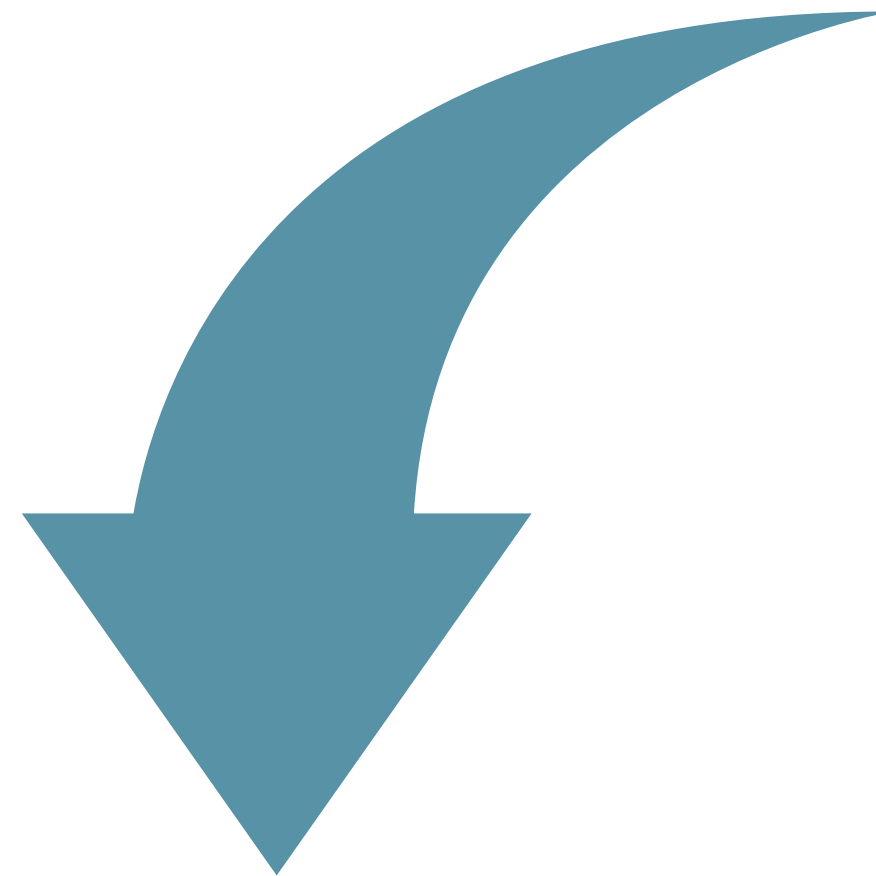


# How can you participate?

The creation of the UNCRPD is a testament of the power of disability rights activism. This international human rights treaty exists because of the collective work of individual activists, local and national disability rights movements and the international disability rights organisations which they created. There are a lot of different ways for organisations and individuals to be active in the implementation and monitoring of the UNCRPD.

## **In what way can national SBH Associations get involved?**

National SBH Associations play a key role in monitoring the implementation of the UNCRPD.



## ***Be active in IF activities, subscribe and follow IF's newsletters and social media accounts***

IF shares and creates social media toolkits for Members to use for awareness raising campaigns and, through its communication channels, keeps its Member Associations updated on relevant opportunities for input and participation. IF's policy and advocacy activities such as publications and statements can also be used by Member Associations for further dissemination and awareness raising of the rights of persons with disabilities on the national and local level. IF also asks Members for input when preparing statements, inputs or other activities relating to the UNCRPD and the CRPD.

## ***Familiarise yourself with the status of your country, has your country ratified the UNCRPD and the Optional Protocol and what has been done to implement them?***

Having as many countries signing and ratifying the UNCRPD and the Optional Protocol is vitally important to advance the rights of individuals with SBH. If your country has not done so, incorporating this demand into your associations advocacy and awareness work helps to spread the word and push for change. If your country has ratified the UNCRPD find what the state has done to implement the convention. What is the independent monitoring system in your country?

## ***Familiarise yourself with where in the reporting process your country is***

If your country has ratified the UNCRPD and the association wants to become active in the monitoring and implementation of the convention the first step is to understand where in the reporting process your country is in. Even if your country may not be due to report to the CRPD for a few years it is never too early to start preparations. States begin preparations for the reporting ahead of time and there might be opportunities for providing input, begin planning your own shadow report to the CRPD or inquire whether other civil society organisations in your country are planning to do so.

## ***Contribute to calls for input from the CRPD***

Opportunities to contribute to calls for input from the CRPD occur frequently and can be found on the website of the CRPD. These range from comments for a Day of General Discussion where the CRPD and Stakeholders explore concerns regarding specific articles or topics. Opportunities to speak at CRPD events such as the Day of General Discussion or during a Constructive Dialogue are also great opportunities to have the voice of your association heard. Information on what your organisation needs to do in order to participate in these activities as well as how to submit a shadow report can be found on the website of the CRPD. Your association can also have its voice heard by contributing to IF's statements and contributions to the CRPD.

### ***Incorporate the UNCRPD into policy and advocacy work***

Referencing specific articles of the UNCRPD in the policy and advocacy work of your association strengthens the legitimacy of your priorities and recommendations. This is because it emphasises that disability rights are a human right and not a privilege or a service which can be adjusted or removed. For example, if your SBH association campaigns on improving access to healthcare services then you can reference article 25 of the UNCRPD. Or if you wish to raise awareness of discrimination in education you can reference article 24 of the UNCRPD.

### ***Provide information and awareness to members and others on the UNCRPD and disability rights in your country and/or region***

It is important to raise awareness of the rights of persons with disabilities. For individuals with SBH and their families it is not only empowering but vital to understand one's rights both in context of the UNCRPD as well as national law. This helps to safeguard against discrimination and abuse. As well as understanding what to do and who to turn to when violations of rights are suspected. Awareness among the public, policy makers, service providers and other stakeholders is also important. National SBH associations can play an essential role in spreading awareness and information on the local, national and regional level.

# Every action counts, suggestions for individuals with SBH and their families.

## You can be a strong SBH advocate!

### ***Be active in your national SBH association and in IF activities***

Working together in a group can make a big difference and through your national association you can participate in IF activities such as advocacy training, workshops and IF advisory groups, such as the Youth Group.

### ***Familiarise yourself with where in the reporting process your country is***

Knowing where your country, or the EU for those who live in an EU Member State is in the reporting process can be very helpful. It can help you decide what activities you want to undertake and when.

### ***Know what your rights are under the UNCRPD***


Read the convention and explore what the national law is in your country. Knowing what your rights are and what to do when they have been violated is very important. Find your national independent human rights institution and familiarise yourself with what individuals and/or organisations can do when the rights of persons with disabilities have been violated.

### ***Organise or take part in campaigns to raise awareness in your country on the rights of persons with disabilities***

No action is too small or too big. Having as many voices raising awareness of the UNCRPD and the rights of persons with disabilities makes a difference. You can adjust your activities to your situation. You can participate in awareness campaigns for international days such as the World Spina Bifida and Hydrocephalus Day (WSBHD) or you can share your own personal story of disability rights issues in your community. Whether you share posts by other organisations or write your own you are participating in raising awareness of SBH and disability rights.



**IF is here to provide support to associations and individuals interested in advancing and protecting the rights of individuals with SBH. Please don't hesitate to reach out to IF and speak to the IF Team about your ideas, questions or request support for your projects.**

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- 👉 IF website: <https://www.ifglobal.org/>
  - 👉 IF Information package on the European Union: <https://www.ifglobal.org/publications/if-information-package-on-the-european-union/>
  - 👉 UN website for the UNCRPD: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
  - 👉 Website of the CRPD: <https://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx>
  - 👉 CRPD documents in plain language and Easy Read versions: <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/PlainAndERV.aspx>

If you have any questions regarding the UNCRPD, the monitoring cycle or opportunities for participation for yourself or your organisation, please don't hesitate to contact IF at [info@ifglobal.org](mailto:info@ifglobal.org)

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