

## USE IT!

You can use the Disability and Healthcare checklist in many ways, depending on your profession and expertise. Please have a look at the ideas below.

### ✓ Policy Maker

Make sure you include these recommendations in your political programmes and that programmes are inclusive and lead to improvements.

### ✓ Citizen with a Disability

You are a source of knowledge and you can give an incredible contribution to society, follow our suggestions and become an active citizen, starting in your community.

### ✓ Disabled People's Organisation

Communicate these messages to your stakeholders and make sure you keep working hard to let the needs of people with disabilities be known and promoted in accessing all kind of services.

**READ MORE**

[www.ifglobal.org](http://www.ifglobal.org)

Contact us



🏠 16 rue des Alexiens  
B- 1000 Brussels

☎ +32 (0)2 502 04 13

✉ [info@ifglobal.org](mailto:info@ifglobal.org)

## About us

The "Disability and Healthcare Checklist" is the result of a workshop "It's our Year, give us a voice. Active Citizenship through the equal access to healthcare" organized by the International Federation for Spina Bifida and Hydrocephalus with the contribution of:

**European Union of the Deaf**  
**European Disability Forum**  
**Mental Health Europe**  
**Inclusion Europe**  
**Autism Europe**  
**The European Year of Citizens Alliance**



The workshop was held in the European Parliament on 15 October 2013 under the patronage of MEP Diane Dodds.

## Disability and Healthcare *checklist*

**Towards accessible healthcare**  
for persons with disabilities

What does being an active citizen mean to a person with disability? How important is it to have access to proper healthcare? Follow our Disability and Healthcare Checklist and you will discover it!



## RIGHTS AND INCLUSION

- ✔ People with disabilities have the right to life and the **right to the highest attainable standard of healthcare**. Equal rights to accessible healthcare services are important, but equal does not mean the same.
- ✔ One of the problems in getting access to healthcare for people with many kinds of disabilities is that they often are not taken seriously in all sorts of complaints. Much of their pain and disorderly behaviour is attributed to their disability. A good **check-up on specific complaints** should be routinely made, because people do not ask for it themselves.
- ✔ Health professional and non-professional health staff who potentially deliver services to people with disabilities should receive appropriate **training** on how to listen to, talk with, and treat people with disabilities.
- ✔ Health professionals need an **on-going education** and up-to-date knowledge to recognise potentially life-threatening conditions and provide immediate treatment.
- ✔ People with complex needs and challenging behaviour need a **contact point in hospitals**, where they can be treated adequately. The medical staff in those contact points should have competence in specific issues like psychiatric and neurological issues, and should have experience in dealing and communicating with patients with complex needs and challenging behaviour. They should provide first aid, transfer to other departments without delay, and cooperate with staff from other departments.
- ✔ Health service providers should make **reasonable accommodations** in the provision of services to meet the range of impairment- and disability-related needs of people with disabilities.
- ✔ In hospital settings **sign language interpreters** should be provided and using a third party should be allowed if a direct communication with the patient is not possible. Alternative and augmentative means of communication should also be available for people with learning disabilities and/or autism.
- ✔ It is of crucial importance that people with intellectual disabilities have **personal support** especially in healthcare surroundings. A personal assistance is needed, whether family, friend or a support worker.
- ✔ **Universal standards** for the treatment of specific disabilities should be defined by national health authorities in cooperation with the World Health Organisation and implemented in healthcare settings.
- ✔ Developing a "**Health Passport for All**" that includes a person's health history would prevent misdiagnosis and could be used by people with communication barriers to help to communicate with doctors.
- ✔ Health systems should make provisions to offer **health checks** for individuals who have a higher risk of certain health problems or who may not self-refer.
- ✔ National health services should remain **affordable** and institutions taking decisions about health services need to have a dialogue with people with disabilities and not only with private companies.
- ✔ Hospital settings should **involve people with disabilities** and use their experience, point of view and knowledge to improve services, preferably through employment, but otherwise as volunteers.
- ✔ If an accessible healthcare for people with disabilities is not assured, physical injuries and even **deaths** are the grave personal consequences for the individual and the family. An independent authority should automatically investigate the death of any person with a disability while being in healthcare.
- ✔ Health services should be **accessible and available to all** even in rural areas.

## CHECKLIST

### MAINSTREAMING

- ✔ Disability is a part of life and people with disabilities have the same rights as any other human being. This message should be included in the **school curricula** from kindergarten to higher education.
- ✔ The European Commission should **review the situation of persons with disabilities** in the time of the crisis with regard to access to healthcare.
- ✔ One of the biggest obstacles for a good healthcare is being institutionalized. People are being neglected and abused in some institutions and although people in the community can be neglected and abused as well, there is an **institutional tendency to dehumanize people with disabilities** and to deny regular independent healthcare.
- ✔ Existing EU and national **legislations should be reviewed** to avoid discrimination of people with disabilities when accessing healthcare services.
- ✔ Politicians should **look outside EU borders**. There are many good practices, beyond Europe, including developing countries that could help European countries.
- ✔ Reports, legislation and consultations, such as questionnaires to collect information from people with disabilities and Disabled People's Organisations, need to be written in **clear and understandable language**. This is good for everyone, but in addition easy-to-read materials, video information, and education, training and specific personal support are necessary to make information accessible to everyone.
- ✔ Associations representing people with disabilities need to work together with **statistics institutes** such as EUROSTAT, since disability data collection is strongly needed for research and policy making.
- ✔ **Research on health and disability** should be promoted, as well as resource centres and networks on health and disability should be developed.
- ✔ Disabled People's Organizations need to contribute to the **UNCRPD Monitoring Reports on the Art. 25 and 26** by bringing concrete stories from the ground.

### COMMUNICATION

- ✔ People with disabilities should be consulted and get **actively involved** in hospital settings, political parties or any other place where their point of view and knowledge could be imperative for the inclusion of people with disabilities.
- ✔ Relatives of disabled people should, with due regard for the privacy and wishes of the disabled person, be given appropriate information and be able to **contribute to supporting the recovery** of the person with a disability.
- ✔ Asking for something is not enough to make the voice of associations representing people with disabilities heard by politicians. **More solidarity is needed** among associations to work together on clear recommendations to policy makers.
- ✔ Awareness raising campaigns have to become **global campaigns using social media**.
- ✔ Online information, including websites of public institutions need to be **accessible** to people with disabilities.
- ✔ **Guidelines for a healthy lifestyle** should be inclusive and tailored to the person's specific disability, as well as to the life cycle.
- ✔ The European Commission should develop and adapt its own **Disability Communication Strategy** to create accessible information for people with disabilities. Using complex and specialized language should be avoided.

IF's mission is to improve the quality of life of people with Spina Bifida and Hydrocephalus worldwide!

IFGLOBAL