# Do not write for us without us

Involving people with intellectual disabilities in the writing of texts that are easy to read and understand









Partners of the project "Pathways to adult education for people with intellectual disabilities" wrote another 3 brochures:



To download them: www.life-long-learning.eu

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## Why there is a need for easy-to-read documents

- People with intellectual disabilities are just like everyone else. They can do a lot in life if they get the right support.
- People with intellectual disabilities can find it harder to understand things and to learn new things.

This is why it is important for people with intellectual disabilities to have information that is as clear and as easy to understand as possible.

 Like everyone else, people with intellectual disabilities have a right to good information.

This is written in the Convention of the United Nations which is about the rights of disabled people. In its article 9, this Convention says that people with disabilities have to receive accessible information.

Good information helps people find out what they need to know. It helps them to make their own choices and decisions.

- If people with intellectual disabilities do not get good information, they will be left out.
   They will not be able to join in with things happening around them.
   And they will have to wait for other people to make choices and decisions for them.
- To make good information means making information easy to read and understand.
   To do this well, you have to follow standards.

You can find out more about easy-to-read standards from another booklet we have written.

The booklet is called "Information for all – European Standards for making information easy to read and understand".

# Why it is important to involve people with intellectual disabilities

People with intellectual disabilities know best what is good for them. They know best what they need to understand information.

No easy-to-read text should ever be written without people with intellectual disabilities taking part at some point.

# Why this brochure is written in easy-to-read

In order to know when they can be involved, people with intellectual disabilities need to know what are the different steps in the writing of a brochure.

Often, people with intellectual disabilities themselves do not know when or how they could be involved in the writing of a brochure.

Therefore, we decided to write this brochure in easy-to-read format. So people with intellectual disabilities understand which role they can have in the writing of an easy-to-read document.

# Some advice to professionals before they start working with people with intellectual disabilities

- 1. Make sure people with intellectual disabilities are clear about
  - what they are doing,
  - what their role is,
  - o and how the whole process will work
- 2. Be prepared to work at a slower pace than usual.

You need to take this into account when planning how long the work will take.

Writing or testing material is hard work
for people with intellectual disabilities.
When people with intellectual disabilities do this often,
they become experts in this work.
And expert work should be paid whenever possible.
So try to include financing

for the work of people with intellectual disabilities in your budget.

# Producing easy-to-read material

We will consider 2 different situations

- 1. When you decide to write your own text directly in easy-to-read about a specific topic.
- 2. When you translate a difficult text into easy-to-read.

# 1. Writing your own text directly in easy-to-read

#### a. Choosing the topic

It is important that people with intellectual disabilities are involved in the decision related to the content of the material. In order to do this, you can:

- ask people with intellectual disabilities about their needs in terms of information
- include people with intellectual disabilities in boards or committees which choose what should be published in easy-to-read
- inform them in general about what is going on and see what they are interested in.

### b. Before you start writing

When you decide to write your own text directly in easy-to-read, the best option is to involve people with intellectual disabilities directly from the start.

This means that you sit down together with them and talk about the text. You can talk about these points:

- the topic,
- what is important to say on this topic,
- how the text should be presented.

This is important in order to produce easy-to-read material that is relevant and useful for people with intellectual disabilities.

## c. Writing a first draft

From this discussion,

you should agree together who writes the first draft.

- A person with intellectual disabilities alone?
- You with a person with intellectual disabilities?
- You alone?

Indeed, the topic you choose can sometimes be quite hard or unknown to the people you are working with. For example the question of legal capacity. In this case, people with intellectual disabilities could decide to be involved only when a first draft of the easy-to-read document has been written.

Your choice of who will write the first draft depends on

- the difficulty of the topic
- your experience and the experience of people with intellectual disabilities
- time and budget limits
- the relationship you have together.

#### d. After the first draft

Once a first draft has been written, it must be proof-read by people with intellectual disabilities. Check the point about "Testing your document" for more information.

## 2. Translating a difficult text into easy-to-read

In this situation, 2 ways of working are possible.

- You produce the first easy-to-read translation alone.
   Then you ask people with intellectual disabilities to proofread it.
   Check the point about "Testing your document" for more information.
- 2. You work with people with intellectual disabilities directly from the start. This means that you sit down with them and read the difficult text. You see what they understand and explain the rest. Then you (and they) write an easy-to-read version.

This way of working probably takes much more time than the first one. But it makes people with intellectual disabilities much more participative.

## **Testing your document**

People with intellectual disabilities know best by themselves what is good for them.

They are experts in deciding if a document is easy-to-read or not.

Therefore it is important to give the text to people with intellectual disabilities, asking them to check the text.

We call this "proofreading".

#### Concretely, you can:

- Ask people to highlight any confusing words or phrases when they are reading your document.
- Ask if they need additional information to understand the text.
- Ask them to make comments in writing or verbally.

They can also write down questions about your document, when they are reading it.

#### A few tips about the proofreading:

- You should test your easy-to-read document with both individuals and a group.
- It is important to test it also with people with intellectual disabilities who have not been involved in creating the document.
- Likewise, it is important to test your document on people who have a different range of ability and experience.
- Proofreading can be something quite difficult to do.
   Some people with intellectual disabilities are used to this job, some are not.

The best is always to test your document both

- o on people who have done this before
- o and on people who have never done this kind of thing.
- When evaluating your document with people with intellectual disabilities, do not ask questions to which people can simply answer "yes" or "no".
   Do not ask things like "Is it easy to understand?".

Rather, ask questions that will show whether people have understood.

For example: "What is this document about?"

"What did you understand" or "What did you not understand"?

- Tell people they should check
  - o the accessibility,
  - o the content,
  - and the layout.
- Show people new drafts of the document and test it more than once.
- Warn people with intellectual disabilities
  that not necessarily all their comments will be taken into account.
  Explain why this could happen.
  For example:
  Sometimes names of people or organisations are not easy-to-read.
  But we cannot change these names to make it more accessible.
- The term "proof-reader" refers to people being able to read.
   However, to check if the content is easy to understand, documents can also be read by supporters to people who cannot read.
   This will also be a good test to see if the text is easy to understand or not.

# Finalising your document

- If possible, make sure that you make changes after the comments.
- Mention the role played by people with intellectual disabilities.
   You could write on the back of the cover page
   "The proofreading of this easy-to-read brochure has been done by XXX".

The leading organisation of the project was Inclusion Europe. 9 other partners were also involved:

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# **Inclusion Europe**

The European association of people with intellectual disabilities and their families.

Inclusion Europe is a non-profit organisation.

We campaign for the rights and interests of people with intellectual disabilities and their families.

Our members are national organisations from 36 countries.

People with intellectual disabilities are citizens of their country. They have an equal right to be included in society, whatever the level of their disability. They want rights, not favours. People with intellectual disabilities have many gifts and abilities. They also have special needs.

Inclusion Europe focuses on three main policy areas:

They need a choice of services to support their needs.

- Human Rights for people with intellectual disabilities
- Inclusion in society
- Non-discrimination

Inclusion Europe co-ordinates activities in many European countries, including projects, conferences, working groups and exchange meetings. It responds to European political proposals and provides information about the needs of people with intellectual disabilities. Inclusion Europe advises the European Commission and members of the European Parliament on disability issues.



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