

Inclusion of people with severe and profound intellectual disability



Inclusion Europe



Report

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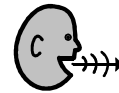
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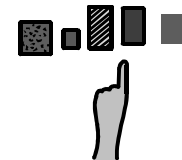
Introduction



There are many people with intellectual disability who are very much disabled. They cannot do many things by themselves. They very often cannot speak for themselves. They are called “people with severe and profound intellectual disability”.



But they have the same rights as other people. They also have their own opinions about simple things. For example what they want to eat or drink. Like any other persons they should have their own choices.



In some regards they need much more help. They also need more help to speak for themselves. Some cannot speak at all. We have to find other ways to understand their needs.

This brochure explains more about their needs. It wants to help organisations, self-advocates and parents to include them in their work. We must help them to participate in our lives. We must find ways to support them better.



Half of this brochure is written in easy language. I hope that we can help people with severe or profound intellectual disability to be included.



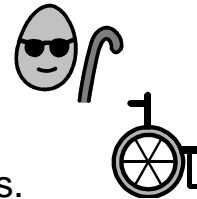
Françoise Jan, President of Inclusion Europe

What are their special needs?



People with severe disability are very vulnerable.

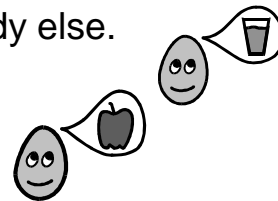
They often have more than one disability.
They can have intellectual disability
and need a wheelchair.



They cannot do many things by themselves.

They have many problems to relate to other people.

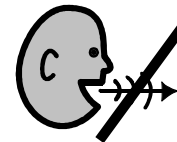
They have the same needs as everybody else.
They do not want to be hungry, thirsty
and want to feel safe.



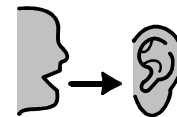
But they often cannot help themselves.

They also often cannot say what they want,
because they cannot speak.

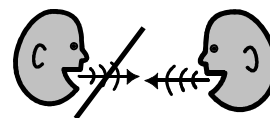
Their parents and supporters must learn
to listen to their signs.



People must talk to them,
even if they cannot respond in language.
They must be informed about everything
that concerns their lives.



Otherwise people with severe disability
may feel very bad and excluded.



People must understand
that people with severe disability are per-
sons.

They are not just bodies who need care!



The needs of people with severe and profound intellectual disability

People with severe and profound disability are the most vulnerable among disabled persons. Often they are persons with multiple disability, with a severe or profound intellectual disability associated to a motor and/or sensorial disability, causing a restriction of autonomy as well as of perception, expression and relating capacities. These restrictions cause complex needs and the danger of social exclusion from society.

For these persons, communication and relating to other persons are the most difficult questions and determine their quality of life. Their physical and mental well-being are connected, as the physical well-being is necessary to be open for relationships and learning. The physical well-being depends on the satisfaction of basic needs: hunger, thirst, sleep, and mental comfort. Persons with severe and profound disability often have difficulties to satisfy these needs themselves and often do not have the verbal language to express themselves. Thus they depend on the capacity of their contact persons to decipher their expressions by other means. A thorough and continuous observation is necessary to understand the minute signs of these persons. This can only be ensured by long-term contact persons like family members or staff who have received training in non-verbal communication methods.

Everyone has also the right to a mental well-being. People need to be respected, in particular in their privacy. Persons with severe and profound disability need to be listened to, to be informed of any change in their life, of any decision affecting their daily existence. They need to be recognized as persons.

Language is very important for social life. Even if a person is deprived of language, he or she needs to be included in all communication. If this does not happen, a psychosomatic reaction may occur, for instance that a person gets an ulcer or a depression if a change in his or her life has not been sufficiently explained. Behavioural difficulties may also be simply the reaction to a mental suffering that the contact persons have not noticed.

This difficult communication needs time and, consequently, a stable environment. This is one of the key factors for a person with complex dependency needs to be really recognized as a person and not reduced to a body that needs care.

Advocacy and self-advocacy



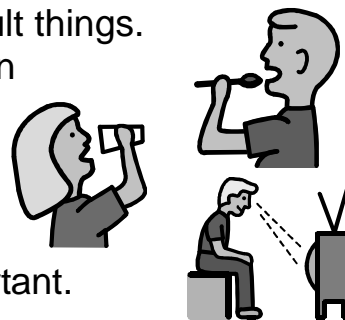
People with severe disability must have a say in everything that concerns their life. But they must also be able to understand it.



They often do not understand difficult things. For them, self-advocacy might mean to decide about simple things:

- What to eat and drink.
- What to watch on TV.
- Going out.

But these things are the most important.

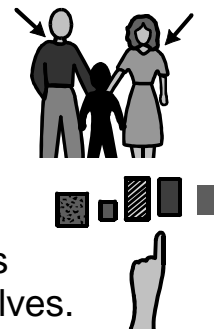


For difficult things they need other people to speak for them.

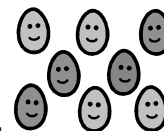
This can be parents, self-advocates or supporters.

Today, mainly parents speak for people with severe disability.

All these people should let disabled persons take as many decisions as possible themselves.



Self-advocates should learn how to speak for people with severe disability. Self-advocates should learn about their needs. Self-advocates should include people with severe disability in their movement.



Advocacy for and self-advocacy of people with severe disability

People with severe and profound intellectual disability require a re-thinking of the concept of self-advocacy. How and where can persons who have severe limitations to speak for themselves express their own needs and wishes? In this context, self-advocacy must focus on one very important principle: people with intellectual disability must have the possibility to be involved in all decisions that concern their lives, as far as they are able to understand the consequences.

For people with severe and profound intellectual disability this means that their scope for self-advocacy will often be limited to simple decisions about food and drink, watching TV, going out, choosing their support person, etc. The absence of verbal language and the difficulties of interpreting the signs sent by these persons can make it quite difficult to understand their wishes. However simple these decisions might seem, they are often the most important in the life of a person. Families, supporters and staff members very often assume a priori that a person with severe or profound disability cannot take any decision.

For persons with severe and profound disability, advocacy and support are very essential. Advocacy should never take away the largest possible autonomy and involvement of the person concerned, but take place only where necessary. Professionals working with people with severe and profound disability absolutely need to collaborate with the families.

Despite some promising models of good practice, self-advocacy still remains underdeveloped within this group of persons. Their representation by means of their families is today's most common and - undoubtedly - most adequate means. Families generally know the person best and can serve as intermediaries with the rest of the society.

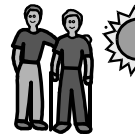
Nevertheless, in the future, and as the self-advocacy movement of persons with intellectual disability gets better organized, they have to learn how to better understand persons with severe and profound disability and their needs. They should aim to represent them at political level and to defend their interests. This is a necessary step to ensure that the participation achieved by people with intellectual disability does not turn into an additional discrimination among people with disability themselves.

Towards better inclusion!



We want to include people with severe disability in our activities.

First, we must make sure that they feel comfortable.

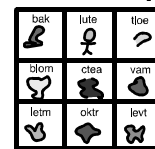


It is really difficult to talk with people with severe disability.

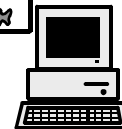
Often we will need help to understand what they want. Parents or other people who know the person with severe disability can help us.



We can communicate through movements or by watching the person's breathing. We can communicate with symbols and pictograms.

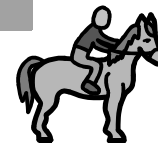
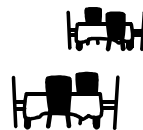


We can communicate by using a computer.



People with severe disability should be included in all everyday activities.

They should also go to a restaurant, to a swimming pool or horse riding.



They can also paint, dance or make music.

They need more time than others. But we all must include them in the life of society!



How to include people with severe and profound disability

For including people with severe and profound intellectual disability in activities, it is first and foremost very important that the basic needs of a person are satisfied. Medical problems should have been addressed and prostheses and technical aids should be well adapted. The position and posture of the body should be as comfortable as possible and should be regularly changed if necessary. In fact, people cannot take part in any activity if they are suffering.

Clothing and overall appearance should also be adequate, so as not to add to the feeling of strangeness and discomfort people often have in the presence of a person with severe or profound disability

However, the real challenge is communication. As mentioned before, efficient communication needs time to develop and, consequently, occasional relations always need the presence of an intermediary who is used to the person. Nevertheless, different methods have been developed to improve communication with persons with severe disability. Here are some of them:

- The “basic communication” developed by Winfried Mall draws on the thorough observation of muscle tone, respiration and movements. All of these are used to communicate with another person. This method also proposes an interpretation and relations grid.
- The “conductive” education of András Petö is a global educational method aimed to teach the child to live the daily life and to take responsibilities.
- There are numerous communication methods based on symbol systems and pictograms.
- Various communication tools have been developed facilitating the use of the computer.

The challenge is already in the participation of persons with severe and profound disability in everyday activities like washing, clothing or eating. Besides these basic activities, people with severe disability should be included in all kinds of leisure activities, like eating in a restaurant, visiting museums, going to a swimming pool or to the horse club. Various activities of artistic expression are also possible. The keyword is always the necessary time and attention, but these activities are indispensable to prevent social exclusion of this vulnerable group!

Good examples



In **Belgium**, people with severe disability go swimming in a public swimming pool.

The pool has all kinds of special aids.

They use the same pool as everybody else.



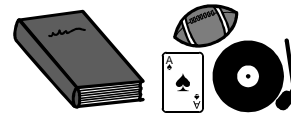
In **Belgium**, there is a discovery space.

People can feel, hear, smell, taste

and experience many different things.

In **England**, there is a book about leisure activities for people with severe disability.

It shows how people can be involved in all kinds of normal activities.



In **Sweden**, people with severe disability are members of an organisation called JAG.

JAG employs many personal assistants.

The disabled person decides when, where and how assistance is provided.

The disabled person has the help of a tutor to make these decisions.

Inclusion Europe will help all these people in different countries to talk to each other.

They can learn from each other and work together.

Examples of good practice

In Belgium, the Association of Parents and Professionals for Persons with Multiple Disabilities (AP3) initiated a swimming activity for persons with severe intellectual disability that takes place in a public swimming pool. The place is equipped with a nursing table, large cabin, transfer device, wheelchair for the shower, etc. The success allows the persons to be with others and the initiative received the Social Integration Prize of the European Day on 3 December 1998.

Again in Belgium, the association "Les Sens Ciel" opened a space of discovery during a walk full of varied sensorial discoveries: fragrances, shadows, lights, colour games, water mattress, resonance and bubble columns, giant sound instruments, "feeling" space (in the dark), etc.

In England, MENCAP developed an entire pack entitled "leisure for people with profound and multiple disabilities". This guide proposes a strategy for the development of leisure opportunities and gives very detailed information on various activities, from aromatherapy and sense gardens to cricket and rock climbing. This information is accompanied by diagrams and illustrations, as well as by a video tape.

In Sweden, the "JAG" association was founded in 1992 to defend the personal assistance and civil rights of persons with multiple disabilities. The members are the persons themselves. The word "JAG" means "I" or "me" in Swedish and it also stands for the initials of the Swedish words for equality, assistance, and integration. The member, with the help of a tutor and a supervisor, determines when, where and in what way the assistance should be provided. The supervisor may be a parent, a relative or a friend. He or she should know the assisted beneficiary very well and be able to communicate with him. JAG has presently 255 members and employs 2000 personal assistants, who give more than 1,3 million hours of assistance per year.

To conclude, it would be important to establish a European exchange network of all examples of good practice to concretely study the possibility of improving the life of persons with profound disabilities, especially by means of a larger participation in social life. Inclusion Europe will facilitate these contacts and exchanges by distributing this brochure and by putting interested people in contact with each other.

Inclusion Europe

The European Association of Societies
of Persons with Intellectual Disability
and their Families

Inclusion Europe speaks for people
with intellectual disability and their families.
Our members are organisations of
self-advocates and parents from
33 countries in Europe.

Inclusion Europe works with
the European Commission and
the European Parliament.
We tell them what our members want.

Inclusion Europe works in 3 main areas :

1. The fight against discrimination
2. Human Rights of people with
intellectual disability
3. Inclusion of all people in society

Inclusion Europe publishes reports,
newsletters and other documents.
We organise conferences
in many countries.
We work closely together with all
our members in Europe.



Inclusion Europe

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