



Co-funded by the
Erasmus+ Programme
of the European Union



A guide

for working with young people

with Down syndrome



The present guide is a result of the information created and collected by the participants present at the training course within the
"DOWN - Without barriers!"
Project 2019-3-RO01-KA105-077815
Project funded by the Erasmus+ Programme of the European Union

Project partners:

Direcția de Asistență Socială și Medicală (Cluj-Napoca, Romania)

Asociația AGA Down Sindrom Cluj (Cluj-Napoca, Romania)

Asociația Babilon Travel (Cluj-Napoca, Romania)

Türkiye Down Sendromu Derneği (Turkey)

Associazione Italiana Persone Down Onlus (Italy)

The Municipality of Fyli (Greece)

The European Commission support for the production of this publication does not constitute an endorsement of the contents which reflects the views only of the authors, and the National Agency and Commission cannot be held responsible for any use which may be made of the information contained therein

**WHAT IS
DOWN
SYNDROME
?**

DOWN SYNDROME IS A CONDITION

1. Down syndrome is a condition in which a person has an extra chromosome. Chromosomes are small “packages” of genes in the body. They determine how a baby’s body forms and functions as it grows during pregnancy and after birth. Typically, a baby is born with 46 chromosomes. Babies with Down syndrome have an extra copy of one of these chromosomes, chromosome 21. A medical term for having an extra copy of a chromosome is ‘trisomy.’ Down syndrome is also referred to as Trisomy 21. This extra copy changes how the baby’s body and brain develop, which can cause both mental and physical challenges for the baby.

2. Even though people with Down syndrome might act and look similar, each person has different abilities. People with Down syndrome usually have an IQ (a measure of intelligence) in the mildly-to-moderately low range and are slower to speak than other children. Some common physical features of Down syndrome include:

- A flattened face, especially the bridge of the nose
- Almond-shaped eyes that slant up
- A short neck
- Small ears
- A tongue that tends to stick out of the mouth
- Tiny white spots on the iris (colored part) of the eye
- Small hands and feet
- A single line across the palm of the hand (palmar crease)
- Small pinky fingers that sometimes curve toward the thumb
- Poor muscle tone or loose joints
- Shorter in height as children and adults

WHAT WE HAVE LEARNED!

- Be aware of myths and reject them.
- Down syndrome is a genetic condition.
- Down syndrome is not a disease that needs to be treated.
- There isn't any known cause of it.
- While the number of chromosomes in a typical human body is 46, it is 47 in individuals with Down syndrome because of the three 21st chromosomes.
- They are like us.
- They are different from us like we all are different from each other.
- They are different from each other in many ways.
- They have some common physical features.
- They have emotions.
- They are unique. They have their own strengths and weakness.
- Early intervention is important.
- Start physiotherapy when they are 1 month old, special education when they are 6 months old and speech language therapy when they are 10 months old.
- They have both good and bad habits like we have.
- Lifelong trainings are important.
- Aim is independent life and participation.
- Don't do things for them but be facilitator for them to choose and decide by themselves.



BUILDING COMMUNICATION SKILLS

Describing communication features of a person with Down syndrome

- Vocabulary is not very rich. Use simple words
- They insist to receive an answer very quickly
- We should ask yes/no questions
- They use gestures. They hug or hold your hand
- They speak about reality, not fantasy
- We should always give feedback
- Their speech may not be clear always. We need time to understand
- Use word and body language together
- We should use short sentences
- Don't use metaphors
- Be patient
- Give time to receive and answer

Why do they have that features?

- They have cognitive delays
- People always anticipate answers
- It depends on having mild or severe development delays
- They have an extra chromosome and muscle conditions
- We give support more than they need
- Parents speak instead of them



Communication examples

She asked you something, but you didn't understand what she said

- I can ask another person who understands better
- Can you repeat again?

You said something, but he didn't give any response

- Give them two choices after having an answer than change the place of the choices and ask again
- You try to understand if he can't or don't want to respond
- I wait until he processes my question
- It could be about environment if there is so much stimulation
- Make shorter sentences

You gave him four jobs to do. He said ok but he finished only one of them

- Four jobs are too much
- Use a checklist
- Maybe he doesn't want to do it
- Explain the reason and how to do it
- Have a 5 minutes break and wait for a second turn
- Use their motivations, they need to find their motivations themselves
- Jobs should be given one by one

You asked something but her response is not meaningful

- Rephrase the question
- Use simple words and ask again
- Maybe she doesn't want to give an answer
- Repeat what you understand and ask again
- Give some time and ask again later





WHAT WE HAVE LEARNED!

1. Their speech may not be clear or fluent. It's because their muscle development is weak;
2. Give yourself time to understand their dialect;
3. When you do not understand them, do not pass it off by saying ok. Do not hesitate to ask them to repeat;
4. Ask other questions to understand what they want and meant;
5. Use short sentences;
6. Use daily words and expressions;
7. Avoid metaphors;
8. Speak slower;
9. Give enough time to understand and give response to you. Be patient;
10. There are no silly questions and answers. All dialogs are meaningful in a context. But sometimes that context is just not clear for us. Help them focus on the topic or you follow their leadership and let the conversation flow;
11. Warn them kindly, if they are out of topic and ask again;
12. Be sure that he/she understands what you want or say;
13. Split duties into small pieces;
14. Use cards, pictures, body language, apps etc. if they can't talk. Don't forget not talking doesn't always mean not understanding;
15. Treat the person according to his/her age;
16. Be careful about boundaries. Don't violate both emotional and physical boundaries.;
17. Make it and keep it clear and simple.

WORKING WITH YOUNG PEOPLE



WITH DOWN SYNDROME AND INTELLECTUAL
DISABILITIES



You may feel insecure about interacting with people with Down syndrome or other intellectual disabilities. This may cause some extreme reactions which are not desirable while working with people with Down syndrome or intellectual disabilities like avoiding them or being overly funny and making fun with them. The aim of that part is to give you some tips that foster you to have a good relationship with people with intellectual disabilities.

OUR TARGET IS INCLUSION, PARTICIPATION AND AUTONOMY. WHY?

These objectives are related to the central themes of the United Nations Convention on the Rights of Persons with Disabilities

For growth, self-confidence, self-awareness, developing social skills, making own decisions and choices and gain new competencies

- 1. You should be able to discover what you can do and what you want.**
- 2. You should be in the real life not in isolated, overprotective environments.**
- 3. You must be challenged.**

What should we do when we work with young people with Down syndrome

- Saying no is okay to a person with DS. In that way they also learn how to do it in a right way
- Always explain what and why you want to do something
- Respect their choices
- Give them time to answer
- Teach them by showing first
- We can practice before a meeting if they need to know more about how to attend
- Use simple sentences
- When they try to touch you without permission, you can say no
- Let them exercise
- Challenging times are good for create a communication
- If you don't understand somebody's speech spend more time with them if possible
- Ask them if they need help
- Start from simple
- We should give notice to them what will happen next
- Behave according to their age
- Be patient
- Accept they express themselves and give them the opportunity to speak autonomously
- Make easy reading documents

LET'S
TALK IT
OUT

What shouldn't we do when we work with young people with Down syndrome

- Don't do their job for them
- Don't talk with parents in the first interaction
- Don't treat them like children
- Don't correct their mistakes for them. Let them learn from their mistakes!
- Don't imagine they always can understand what you were saying
- Don't be bossy
- Don't panic



WHAT WE HAVE LEARNED!

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- Talk as you normally speak, use your normal voice;
- Use daily words;
- Explain terms that you need to use;
- Use illustrations that are not too childish when dealing with adults;
- Use examples from everyday life;
- Make a chat in the square;
- Prepare a clear structure of a meeting and share it before;
- Ask their opinion;
- Changes are generally no problem if you give enough time to adapt;
- Make decision together;
- Keep your own body limits in the contact. If you do not want a hug, that's okay!
- Discuss with the parents how they want to be involved in the information;
- Motivate shy ones;
- Let them be a part of sessions;
- Listen carefully without asking leading questions;
- Beware of 'undervaluation'. People with disabilities are often capable of much more than you initially estimate. If someone can close their own coat, do not take over;
- Do not speak in a childish tone;
- Do not ignore them, both during a lesson, on the street, in communication and information provision;
- Avoid overstimulation;
- Do not think that everything will go well by itself;
- Don't focus only on talkative ones;
- Ask leading questions;
- Do not talk about them, but with them.

Conditions for learning



The conditions for effective learning are the same for all people, but for people with a disability, a number of things are extra important. Especially if you want long-term returns.

Development Oriented Guidance

Development-oriented guidance is about promoting autonomy in concrete development opportunities, or strengthening the skills for everyday life, including social-emotional possibilities.

Task of the supervisor is making reality accessible to people with a disability based on the response of the participant. There is a great emphasis on looking at how the participant and environment interact.

It is necessary to focus the concrete observation in a situation on: why do you use this material for this participant, why does this suit him or her, and what could be a next change as development stimulation? This is an essential point for the guidance itself.

People with intellectual disability can develop when they have opportunity to;

- Increase self-awareness
- Increase independence
- Develop Social Skills.

People's own choices are the starting point of their guidance. By making own choices, intrinsic motivation is created. Intrinsic motivation leads to better learning outcomes.

It is important to make the transition from a system-based approach to a person-oriented approach. Customization often requires more creativity.

Personal connection and being of value is important for every person. In the training, therefore, much attention is paid to personal exchange. Participants are motivated to use their experience in the training. A person grows when feels that she/he doesn't just receive the care and guidance but can also give it to others.

What are the key points for effective learning?

- Encouraged the participant use her own qualities and solutions to develop his own style.
- There is usually no straight line to the goal to be achieved because the goal of the facilitator/trainer may not be the goal of the participant.
- Provide alternative communication methods so that everyone can participate.
- Prepare different type of activities for the same output so that they learn in different ways.
- Create opportunities to use what they've learned in different environments and cooperate with the network around the participant.
- Learning environment must also have a positive effect on the participant, for example a low-stimulus environment if concentration is required, but also recognisability in the arrangement of tables and chairs.
- Talk with participants to learn what they need for learning.
- Offer activities infeasible steps. The steps must be sufficiently challenging so that the participant can grow.
- Know participants. What the participant already knows and can and where the development lies.
- Adapt and diversify games, materials, subject according to participants' skills and competencies.
- The relationship with the participant is based on reciprocity, learning from each other.
- In every activity, a bridge is created to other contexts, situations. The skills are immediately translated into practice.
- The participant is encouraged to take the initiative and reflect on his own actions.
- Encourage active participation to teaching process. Peer to Peer teaching is a strong tool for learning.
- Help to separate main and minor issues.
- Repeat endlessly, be patient and learn tricks or give tools to remember difficult things.
- First and most important rule! Let participants as a part of teaching process!
- Build good relationship with participants. There must be equality and mutual trust.
- Use positive approach. It helps the participant with his self-confidence, especially when it is aimed at the personality, learning objective and learning style of the participant.
- Be calm and show confidence both in verbal and non-verbal communication.
- Trust participants will have a meaningful result for themselves.
- Ensure a safe environment where mistakes can be made.
- Prepare plain documents and materials (daily language, clear design, short sentences, clear photographs).
- Give enough time to participants to understand documents and materials.
- If you do not understand me, I have not explained it correctly, is the thinking method of the facilitator/trainer.

Published by:



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Project 2019-3-RO01-KA105-077815

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2022