



Our ability - developing innovative ways to support young people with disabilities and those working with them

OUR ABILITY

Participatory Research Toolkit

Erasmus+
Key Action KA220-YOU
Partnerships for cooperation
in the field of youth



**Co-funded by
the European Union**

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Imprint / Publishing information**Publisher:**

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Year of production:

2025

Licence:

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Introduction

This document presents the framework for participatory research developed and implemented during the initial phase of the project **Our Ability – Developing Innovative Ways to Support Young People with Disabilities and Those Working with Them**.

The main aim of the project is to gain a deeper understanding of the needs of young people with disabilities and to help organisations develop high-quality activities that respond to those needs. The project also seeks to explore the professional challenges faced by youth workers and other staff members working with young people with disabilities, with the aim of identifying ways to strengthen their well-being and professional support systems.

The participatory research approach places particular emphasis on the active involvement of participants, ensuring that the voices and perspectives of young people with disabilities, as well as those who support them, are meaningfully included in the research process. By gathering and analysing these perspectives, the research provides valuable insights that can inform the design of more inclusive and responsive youth work practices.

In addition, the project aims to introduce improved approaches to youth work and staff support programmes while strengthening cooperation and the international dimension of the partner organisations. The findings of the research are intended to support the development of innovative solutions that contribute to better inclusion, empowerment, and the well-being of young people with disabilities and of the professionals working with them.

The partnership involves organisations from five countries: **Fundacja Oczami Brata** (Poland), **Uniamoci APS** (Italy), **FAMDIF** (Spain), **Asociația Down Valea Jiului** (Romania), and **Tartu Vaimse Tervise Hooldekeskus** (Estonia).

The **Participatory Research Toolkit** has been developed to support organisations in collecting and analysing information on the experiences, needs, and perspectives of young people with disabilities. This document provides a comprehensive overview of the methodological framework, together with practical guidelines for designing and conducting research, including:

- purposes of the study;
- description of the participants of the research;
- general description of research activities;
- methodology,
- safety, consent and ethical considerations;
- instructions for the researchers and notes templates (in the annexes);
- participants characterization templates and consent templates (in the annexes).

1. Purpose of the study

The study is designed to provide a deeper understanding of **the needs of young people with disabilities**.

The research aims to gather the perspectives of young people with disabilities and the people who support them on the needs and aspects of empowerment that are currently most relevant to their lives. The knowledge generated through the study can help organisations better adapt their programmes and activities to the needs and priorities of young people.

The specific objectives of the participatory research are:

- To identify the needs of young people with disabilities by exploring their quality of life, including their levels of happiness and emotional well-being, autonomy, interests and preferences, access to resources and inclusion, as well as their everyday experiences.
- To qualitatively characterise the participants by highlighting their lived experiences, vulnerabilities, needs, and resources, while creating space to amplify their voices and ensure that their perspectives directly inform future actions and improvements.

The expected deliverables include:

- Reports produced by all partner organisations.
- An analysis of the current needs of young people with disabilities.

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2. Participants

The study involves three main groups of participants across five European countries:

1. **Young persons with disabilities (aged 16–30)**

A total of 60 participants from five European countries. Some are students in mainstream or special schools, while others are users of day centres or participants in occupational therapy workshops.

2. **Parents, guardians, and caregivers**

A total of 60 participants from five European countries who provide daily care, emotional support, and guidance to young people with disabilities.

3. **Support workers and professionals**

A total of 60 participants from five European countries, including staff from the partner organisations as well as external professionals. This group includes personal assistants, youth workers, trainers, teachers, and other specialists working with people with disabilities.

3. Research activities

The research follows a step-by-step approach, beginning with introductory "getting to know you" activities and continuing through the subsequent phases of the study.

The participatory research is conducted in three stages, described below.

Stage I – Persons with Disabilities

Research with young persons with disabilities is carried out using three methods.

1. **Photovoice.**

Wherever possible, this method should be implemented first. Photovoice should be organised as a group session, with two important considerations.

If it is anticipated that participants may feel too uncomfortable sharing personal experiences in the presence of others, it is recommended to organise smaller groups. In addition, the diverse levels of functioning among young persons with disabilities may make participation in a larger group discussion difficult or impossible. For this reason, it is recommended that Photovoice sessions be conducted with groups of three to six participants.

2. **Focus Groups or Individual Interviews.**

The second method involves interviews with 12 young persons with disabilities. It is recommended to organise two focus groups with a maximum of six participants in each session. However, where participants have specific needs or individual circumstances that make group participation difficult, researchers may conduct individual interviews instead. The questions and objectives remain the same for both focus groups and individual interviews.

Researchers are encouraged to select and adapt the research method according to the characteristics and needs of their participants. Due to the diverse levels of functioning among young persons with disabilities, some organisations may find it more appropriate to conduct individual interviews rather than focus groups. This flexibility ensures that all participants can comfortably share their perspectives and experiences.

3. **Life Stories.**

The third method involves developing life stories. Each organisation will select two typical, paradigmatic cases of young persons with disabilities and prepare a life story for each selected participant.

Stage II – Parents and Guardians

Research with parents and guardians of young persons with disabilities involves two focus group interviews with six participants each or, alternatively, one focus group with up to twelve participants in each participating organisation. If it is not possible to organise a focus group, individual interviews may be conducted with each parent or guardian.

The questions used in both focus groups and individual interviews remain the same. They are provided in the annexes to ensure consistency in the data collected across different organisations and research settings.

Stage III – Workers Supporting People with Disabilities

Research with this group involves two focus group interviews with six participants each in every partner organisation. Detailed guidance on organising focus group interviews is provided later in this toolkit.

4. Methods

This section describes the research methods and provides detailed guidelines for data collection, data analysis, and reporting in the qualitative study.

The study follows a qualitative approach, collecting and analysing non-numerical data to understand concepts, perceptions, and experiences. It is particularly well suited to generating in-depth insights into the needs, experiences, and challenges of participants, as well as to exploring complex social phenomena. Multiple methods are used to provide a more comprehensive understanding of the participants' needs and challenges.

As mentioned in Chapter 3, the methods used for data collection include:

- Visual and arts-based methods (Photovoice)
- Individual and group interviews (focus groups)
- Life stories (two paradigmatic life stories per country)

Qualitative, participatory, and arts-based methodologies are valuable because they help researchers understand how people experience and interpret social phenomena.

By emphasising participants' perspectives and using creative, non-intrusive methods, they create opportunities for participants to express their experiences, needs, and views in meaningful ways.

Moreover, the use of multiple research methods enables the phenomenon under study to be explored from different perspectives, contributing to a more comprehensive understanding of its complexity (Mason, 2006).

4.1 Conducting the research activities

In qualitative research, the role of the researcher is to gain insight into the thoughts and feelings of participants. This often involves exploring sensitive issues, but it also makes it possible to better understand the meanings that people attach to their experiences. For this reason, the profile, skills, and approach of the researcher are of great importance. This is not an easy task, as it requires inviting people to share personal and sometimes difficult experiences. The researcher is responsible for safeguarding both participants and their data, which means that appropriate ethical and data protection measures must be in place.

It is also recommended that the researcher should, wherever possible, have no prior hierarchical relationship with the participants and, where appropriate, may be someone from outside the organisation. Being an “insider” (a member of the organisation or group

being studied) or an “outsider” (someone from outside) has both advantages and disadvantages (Holmes, 2020). An outsider may face doubts about whether they can fully understand the experiences of participants, particularly within organisational settings. On the other hand, insiders may find it more difficult to maintain sufficient distance and neutrality, which can affect the credibility and trustworthiness of the research.

4.2 Involving participants as ‘co-researchers’

It is worth considering an approach that actively engages young people and representatives of other target groups as partners in the research process, rather than treating them solely as passive research participants (Smith, Monaghan & Broad, 2002). Co-research is a model in which young people and other participants collaborate with researchers, sharing responsibility and influence over the research process. This approach is grounded in the principles of participation, inclusion, and autonomy.

Involving participants as co-creators of the research process ensures that their perspectives are not only heard but also incorporated throughout all stages of the study. Such collaboration is widely recognised as leading to findings that are more meaningful, relevant, and better aligned with the real needs of the people being studied.

Engaging participants in the research process also brings a range of practical benefits. These include supporting the translation and interpretation of data - particularly important when working with participants with a migrant background and young persons with disabilities - as well as generating richer and more diverse research data.

4.3 Photovoice

Photovoice is a powerful qualitative research method that combines participant-generated photographs with accompanying narratives. Developed nearly three decades ago by Wang and Burris (1994, 1997) as a participatory public health research method, it has since evolved into an approach used worldwide across a wide range of academic disciplines and by practitioners working with communities to promote social change, advocacy, and social justice.

Photovoice is a participatory research and educational method in which participants use photography to document and reflect on their daily lives, needs, challenges, dreams, or available resources. The photographs are then discussed and interpreted collectively, often leading to new insights, ideas for change, or recommendations for action.

For participants, Photovoice provides a way to represent their experiences visually, enabling them to communicate personal knowledge and perspectives that may be difficult to express verbally. For researchers, the method facilitates dialogue, generates insights that may not emerge through interviews or focus groups alone, and combines visual and narrative forms of expression to provide a richer understanding of participants' experiences.

Further practical guidance and detailed instructions are provided in Annex 1.

4.4. Individual interviews

An individual interview is a one-to-one conversation between a researcher and a participant. It is designed to explore the participant's thoughts, feelings, and experiences in depth. A semi-structured format is recommended, guided by an interview framework that allows participants to steer the conversation towards the topics that are most meaningful to them.

In some cases, individual interviews are necessary because some participants may not be able to take part in group interviews, and one-to-one conversations are better suited to their needs and abilities.

The key strength of individual interviews is the depth of information they provide. As participants are interviewed individually, they often feel more comfortable sharing personal or sensitive information that they might hesitate to disclose in a group setting.

However, conducting individual interviews can be time-consuming and resource-intensive. Each interview requires considerable time and effort to plan, conduct, transcribe, and analyse.

Further practical guidance and instructions can be found in:

- Annex 2 with general instructions for conducting an interview and the template to record findings
- Annex 4 with purpose and questions for the interviews with young people with disabilities
- Annex 5 with purpose and questions for the interviews with parents and guardians of young people with disabilities
- Annex 6 with purpose and questions for the interviews with professionals about the needs of young people with disabilities.

4.5 Group Interviews (Focus Groups)

Group interviews, often referred to as focus groups, bring together a group of participants (typically 6–12 people) to discuss a specific topic under the guidance of a moderator. The aim of this method is not only to explore participants' individual perspectives but also to observe how they interact with one another, influence each other's views, and jointly construct meanings around the topics being discussed. In this type of research, group dynamics are just as important as the content of the discussion itself—one participant's comment may trigger memories, agreement, disagreement, or new ideas among other participants.

A semi-structured format is recommended, using an interview guide that allows participants to steer the discussion towards the topics that are most meaningful to them.

The main advantage of group interviews is that they enable researchers to collect a wide range of perspectives in a relatively short period of time. As participants respond to and build on one another's contributions, the discussion may reveal shared norms, values, and areas of agreement or disagreement that might not emerge during individual interviews. The group setting may also encourage greater openness, as participants often feel more comfortable sharing their experiences when they realise that others have had similar experiences.

At the same time, conducting group interviews presents a number of challenges. The presence of other participants may discourage individuals from openly sharing their experiences, leading them to provide socially desirable responses rather than fully expressing their genuine views and experiences. Maintaining confidentiality is also more difficult, as participants are aware of one another's identities and hear each other's contributions. In addition, analysing focus group data is more complex because researchers need to consider not only what is said but also how group dynamics influence the discussion.

Moreover, discussions may be dominated by more outspoken participants, while quieter or less confident individuals may contribute less. A certain degree of homogeneity within the group is generally beneficial, as it facilitates communication and encourages open discussion. If a group is too diverse in terms of participants' experiences, communication abilities, or social characteristics, participants may feel less comfortable expressing their views, and the discussion may become less productive (Bloor et al., 2001).

Further practical guidance and instructions can be found in:

- Annex 3 with general instructions for conducting a focus group and the template to record findings
- Annex 4 with purpose and questions for the interviews with young people with disabilities

- Annex 5 with purpose and questions for the interviews with parents and guardians of young people with disabilities
- Annex 6 with purpose and questions for the interviews with professionals about the needs of young people with disabilities

4.6. Life stories

The life stories prepared as part of this study will present two illustrative cases of the lived experiences of young persons with disabilities from each country, highlighting the factors and processes that influence their quality of life and their access to rights, opportunities, and resources that are generally available to other members of society. These stories must be collected and presented with full respect for participants' privacy and confidentiality.

A life history is a qualitative research method used to gather and present an individual's personal history, focusing on key turning points and significant life themes (Bertaux, 1981). Terms such as *life history*, *personal narrative*, *biography*, and *life story* all refer to the collection and interpretation of personal accounts in order to understand how individuals experience everyday life, what they consider important, and how they perceive past, present, and future events (Roberts, 2002).

Life histories are based on data collected during the research process, typically in the form of transcribed interviews or oral accounts provided by participants. These accounts are subsequently analysed, interpreted, and presented in a narrative form. A life history may focus on a specific theme or provide a broader overview of a participant's life and experiences.

Instructions for researchers and the reporting template are provided in Annex 7.

An example of a completed life story is included below to illustrate how this method can be applied in practice.

Growing Up with Cognitive Challenges – A Story of Struggle and Resilience

Tom describes his early school years as confusing and frustrating. Diagnosed with an intellectual disability at a young age, he often struggled to keep up with lessons and instructions that other children found easy. "I knew I wanted to do well, but I just couldn't follow along like the other kids," he recalls. His teachers sometimes became impatient, and he often felt embarrassed in front of his classmates.

Transitioning to primary school was a major turning point. Tom remembers being placed in a mainstream classroom with some support, but the pace of learning was overwhelming.

“I wanted to answer questions, but I couldn’t remember everything fast enough...sometimes I’d get really upset.” He also struggled socially, often being excluded from games or activities because peers didn’t understand his learning difficulties.

By Grade 4, Tom’s frustration led to behavioral challenges. He would sometimes act out in class, refusing to participate, throwing books, or arguing with teachers when he felt misunderstood. “I just wanted them to understand me,” he says. After discussions with his parents and the school, Tom’s learning program was adapted with smaller group sessions and individualized support, which helped reduce some of his anger and confusion.

Entering secondary school brought new challenges. Tom found it difficult to follow multiple subjects and keep up with homework, and he sometimes became withdrawn or anxious. Teachers’ low expectations affected his confidence. “One teacher told me I would never pass certain subjects...that made me feel like giving up.” Despite this, Tom gradually developed coping strategies with the help of a mentor and a learning support coordinator, attending after-school tutoring sessions and using visual aids to organise his work.

Tom’s social life remained a challenge. He experienced bullying and misunderstanding from peers, which at times led him to isolate himself. Yet he found support in a small group of friends and a special interest club, where he could express himself and contribute meaningfully. By the end of secondary school, Tom had developed a stronger sense of self, learned to advocate for his learning needs, and participated in community activities designed for young people with cognitive disabilities.

Tom’s story highlights the interplay between barriers, support systems, and personal resilience. While his intellectual disability presented ongoing challenges academically and socially, access to tailored support, understanding adults, and opportunities for meaningful engagement enabled him to grow in confidence, independence, and self-advocacy.

5. Ethics

Conducting research with participants (including participants with disabilities) requires particular attention to ethical safeguards, as some individuals may belong to vulnerable groups. To ensure compliance with national and institutional ethical standards, all partners should commit to the wellbeing, protection, and safety of participants. The study should follow the following core ethical principles:

1. **Minimizing risk:** Research activities should avoid causing harm or discomfort to participants.
2. **Informed consent:**
 - Ensure participants understand the purpose and relevance of the research.
 - Confirm that the research objectives are not harmful or prejudicial.
 - Consider the legal status and specific vulnerabilities of participants.
 - Keep comprehensive records of consent.
 - For minors or participants under legal guardianship, consent must also be obtained from responsible adults or appointed supervisors.
3. **Confidentiality and anonymity:** Participants' identities must be protected, and any personal information should not be included in research outputs without explicit consent. Compliance with national regulations and the EU General Data Protection Regulation (GDPR 2016/679) is mandatory. All publications or online dissemination must fully respect these data protection standards.
4. **Pseudonyms:** Participants should be offered the opportunity to choose a fictitious name for use in the study, ensuring they feel comfortable and respected throughout the research process.

Guidance for Ethical Practice and Informed Consent

Researchers are encouraged to adopt the following practices, especially when working with vulnerable participants:

1. Recognize and mitigate personal biases; avoid prejudices.
2. Provide clear, accessible information about the project and the objectives of the research, emphasizing that participation is safe and voluntary, that the research poses no foreseeable risk or prejudice to participants, and highlighting the importance of their contributions.
3. Use neutral, respectful language during interactions, allowing participants to express their opinions freely without judgment or signalling agreement/disagreement.

4. Encourage elaboration through prompts such as, “Can you tell me more about that?” or “Can you give an example?” to reinforce the value of their ideas.
5. Allow participants to ask questions and clarify their understanding.
6. Engage participants by explaining how their input can contribute to broader goals, while avoiding creating unrealistic expectations.
7. Respect and value all perspectives, experiences, skills, and life trajectories, ensuring participants feel that their point of view and contributions matter.
8. Prepare a plan for incidental findings—for example, notifying national authorities, NGOs, or relevant agencies if research uncovers situations affecting participants’ rights, safety, or wellbeing. Any information that may pose risks to others must also be reported appropriately.

Special Considerations

- Research should focus on the present (“here and now”) rather than asking participants to recount past events that could be distressing or sensitive.
- Consent can be obtained in stages: first, introduce project aims to the group and allow general questions; then provide written materials (e.g., project leaflets) for participants to review at their own pace.
- It is essential to remind participants that they can withdraw from the study at any time without providing a reason.

In Annex 8 you will find ready consent templates for:.

- Young Participants
- Parental Consent Form (for parents whose children take part in the research but are under 18 years old or are unable to sign the consent)
- Parents and Guardians (who take part in the interview)
- Professionals

In Annexes 9, 10 and 11 you can find a template to collect preliminary data for participants characterization, specifically crafted for:

- Young participant characterization,
- Parents and guardians,
- Youth workers and professionals.

Annex 1 . Photovoice: instruction for the researcher and notes template

1. Before the session:

The participants' support needs may make it impractical to run a single session with all twelve participants. It is therefore recommended to organise one or more small-group sessions with a minimum of three and a maximum of six participants per group. Depending on the organisation's capacity, up to twelve participants may be involved in the Photovoice activity.

Participants should receive the task at least one week before the Photovoice session to allow sufficient time to collect photographic material.

Task for the participants: *Take photos of things, places, people, or situations that show:*

- *what is important to you;*
- *what makes you feel good;*
- *what makes you feel sad, angry, or stressed;*
- *what you would like to change.*

Take 5–10 photos. Then choose the two or three most important ones, print them, and bring them with you to the session. Prepare to talk about the selected photographs.

Tasks for the facilitators:

- For the meeting, arrange for at least water and, if possible, a light snack.
- If your participants need additional support, for example, psychological support, please make sure that such support is provided.
- Please arrange for two people to conduct the group discussion: a facilitator and an assistant facilitator/note-taker.
- Set up the room so that all participants can sit comfortably and there is space to display the printed photographs. You can use tables or a wall to display them.
- You may record the session (audio only). However, if any participant does not agree to being recorded, or if you feel that recording might discourage people from speaking openly, it is better not to record the session. In this case, the assistant facilitator should take detailed notes throughout the session.
- If participant characteristics have already been prepared (see Annex 9), the assistant facilitator should record only the participants' chosen pseudonyms before the session. If participant characteristics have not yet been collected, they should be completed before the Photovoice session, as preparing them requires additional time in an individual meeting with each participant.

2. During the session:

- Tell all participants that taking part in this session is voluntary. They should share only what they feel comfortable sharing.

Explain that what is said during the session will not be judged by anyone, and ask everyone to keep the discussion confidential. Nothing shared during the session should be discussed outside the group.

- At the start, explain the purpose of the research:

"We are here because we are taking part in the project Our Ability. We would like to learn about the challenges you face, as well as the things that make your life enjoyable and meaningful. We want to understand what is important to you. The information you share will help us better understand your needs. This will enable us to develop new activities and programmes that are useful and enjoyable for young people."

- If the session is audio-recorded, inform the participants:

"I'd like to let you know that this session is being audio-recorded. The only reason for this is to ensure that we can accurately capture your responses. Once we have completed our notes, the recording will be deleted. It will not be shared with anyone except the moderator and the assistant facilitator. Everything you say during this session will be used only for research purposes, and your responses will remain completely anonymous."

- Start the main part of the discussion. Ask the following reflection questions for each photograph:
 - What is in the photograph?
 - Why did you take this photograph?
 - What does it say about your life?
 - What would you like others to understand about you or about this photograph?
- If participants find it difficult to begin, the researcher may model the discussion by sharing one or two personal photographs and briefly explaining why they were chosen. This should be done only at the beginning of the session as an illustration of the task and should not develop into sharing the researcher's own experiences or influence participants' responses or interpretations. If you anticipate that participants may need this type of support, prepare one or two personal photographs before the session.

- Final discussion questions.

Ask both of the following questions at the end of the discussion.

For organisations:

"What could organisations do better or differently to help young persons with disabilities? "

For policy and programme development:

"If you could change one thing to make life easier or more enjoyable, what would it be?"

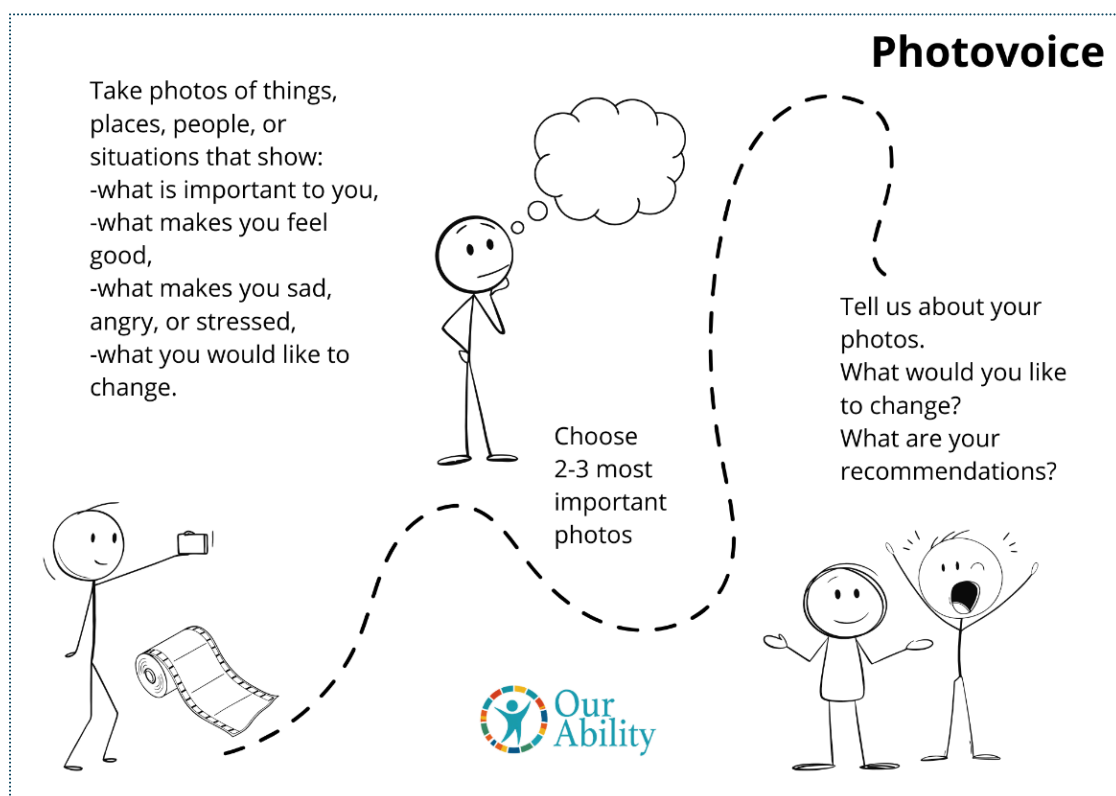


Figure. Photovoice method.

3. Facilitating the group

Moderator/Facilitator

The facilitator's responsibilities are to:

- provide space and time for each participant to talk about their photographs;
- ensure that participants are not judged;
- maintain a relaxed atmosphere, set the tone, and guide the discussion;
- keep the discussion focused on the research objectives;

- listen attentively without contributing personal opinions or participating in the discussion;
- remain neutral, respectful, and non-judgemental at all times.

Assistant/Note-taker

The note-taker does not join the conversation, avoids nodding or reacting, and has the following responsibilities:

- test and set up the audio recording equipment and ensure that it is working properly throughout the session;
- collect demographic information from participants (see Annex 9: Participant Characterisation). If this information has already been collected, the assistant should record only the participants' pseudonyms;
- ensure that all responses remain anonymous;
- remain in the room throughout the discussion in a position where they can see and hear all participants (note: do not sit next to the facilitator);
- observe and make notes on non-verbal communication, including body language, facial expressions, gestures, signs of agreement, disagreement, frustration, concern, confusion, and possible follow-up questions.

4. Closing the session

At the end of the session:

- Thank all participants for their time, openness, and willingness to share their experiences.
- Remind participants that their contributions will be used only for the purposes of this research and will remain anonymous.
- Collect the printed photographs. Label each set with the participant's pseudonym to ensure that the photographs can be linked to the discussion during data analysis.
- If the session was audio-recorded, ensure that the recording is stored securely and deleted after it has been transcribed or the notes have been completed, in accordance with your organisation's data protection procedures.
- Invite participants to ask any final questions or share any additional comments they feel are important.

Photovoice notes		
Date:	Location:	Facilitator/researcher:
Methodological notes <i>[Any interruptions? Reasons for interruptions. How was the schedule? Attitude? Quality of interaction?]</i>		
Number of participants		Activity duration (time):
Fictional names of the participants		
SUMMARIZE ANSWERS TO THE QUESTION: <i>What is in the photo?</i>		
QUOTES (WITH FICTIONAL NAME)		
SUMMARIZE ANSWERS TO THE QUESTIONS: <i>Why did you take this photo? What does it say about your life?</i>		
QUOTES (WITH FICTIONAL NAME)		
SUMMARIZE ANSWERS TO THE QUESTION: <i>What would you like others to understand?</i>		
QUOTES (WITH FICTIONAL NAME)		

SUMMARIZE ANSWERS TO THE QUESTION: What advice or recommendations would you give to organisations that support young people with disabilities, so they can better meet your needs?

QUOTES (WITH FICTIONAL NAME)

SUMMARIZE ANSWERS TO THE QUESTION: if you could change one thing to make life easier or more enjoyable, what would it be?

QUOTES (WITH FICTIONAL NAME)

Annex 2. Individual interviews: instruction for researchers and notes template

1. Before the interview

- Decide whom to invite, taking into account the participant's age, type of disability, and ability to take part in a one-to-one interview.
- Prepare the interview guide, supporting notes, and review the objectives of the interview.
- Check the practical arrangements, including the audio-recording equipment, as the interview will be audio-recorded.
- Arrange a comfortable and private setting, free from distractions, with seating that helps the participant feel relaxed and at ease.
- Provide water and, if possible, a light snack.
- Ensure that the venue is accessible and adapted to the participant's needs (e.g. wheelchair access, communication aids, or other reasonable accommodations).
- Obtain written informed consent from the participant (or, where necessary, from their legal guardian). Consent form templates are provided in Annex 8.
- Collect demographic information (using the templates provided in Annexes 9, 10, or 11) and ask the participant to choose a pseudonym that will be used in the report to ensure anonymity.

2. Facilitating the interview

The success of the interview relies on the interviewer's ability to build trust and balance between guiding the conversation and letting the participant speak freely.

Objectives of the interviewer are:

- Creating a safe and respectful environment in which the participant feels comfortable.
- Collecting detailed personal perspectives and experiences relevant to the research.
- Listening actively and attentively, avoiding leading questions, and encouraging participants to elaborate on their responses.
- Remaining neutral and impartial throughout the interview.
- Adapting the questions to the participant's pace and communication style.

Assistant/Note taker (optional, if present):

- Checking and setting up the audio-recording equipment.
- Ensuring participants' anonymity by recording only their pseudonyms.
- Making notes on non-verbal communication, emerging themes, and key expressions or quotations.

- Supporting the interviewer in managing the time allocated for the interview.

3. When the interview begins

- Thank the participant for their time.
- Explain the purpose of the interview and how the information will be used.
- Inform the participant about the recording and assure anonymity:
“I’d like to let you know that this interview is being recorded. The only reason for this is to make sure we can write down all your answers accurately afterwards. Once we’ve noted the key points, the recording will be deleted. The recording will not be shared with anyone except the project team. Everything you say here will remain completely anonymous.”
- Remind the participant that there are no right or wrong answers — you, as a researcher, are only interested in their personal experiences and opinions.
- Explain how the interview will proceed (*“We will ask you some questions, and you can answer them in your own words. You may also choose not to answer any question.”*).
- Set the tone by starting with a simple, friendly opening question (such as, *“Can you tell me a little bit about yourself?”*).
- If the participant has difficulty starting the conversation, begin by briefly introducing yourself. Share a few sentences about your interests or everyday activities to demonstrate the type of response that is expected.

4. During the interview

- Use open-ended questions and allow enough time for responses.
- Be patient with pauses or silences — they are natural and often allow participants to reflect.
- If the participant is unsure how to answer a question, you may provide a simple example based on your own experience or opinion. However, make sure that the example is used only to illustrate the type of response expected and does not suggest or influence the participant’s answer. After giving the example, always encourage the participant to share their own experiences and perspectives.
- Encourage elaboration gently (*“Can you tell me more about that?”*).
- If time is limited, focus on the underlined (mandatory) questions. The remaining questions can be asked if time allows.
- Adapt your language to the participant’s level of understanding.

5. Closing the interview

- When all your questions have been asked, invite the participant to add anything else they would like to share.
- Ask them to summarize one thing they consider most important from the conversation.

- Thank them sincerely for their participation and remind them how the information will be used.

Individual interview notes		
Date:	Location:	Facilitator/researcher:
Methodological notes <i>[Any interruptions? Reasons for interruptions. How was the schedule? Attitude? Quality of interaction?]</i>		
Number of participants:	Activity duration (time):	
Fictional names of the participants:		

General topic	Question (number)	Summary of the information gathered	Significant quotes from the participants with fictional name
Quality of life			
Freedom (autonomy)			
Happiness and well-being			
Interests and preferences			
Inclusion and belonging			
Other...			

General conclusion

Annex 3. Focus groups: instruction for the researcher and notes template

1. Before the session

- Decide on composition and size - who should be invited .
- Prepare your questions and check your goals.
- Review the arrangements: is the focus group audio recorded?
- Arrange for a comfortable room in a convenient location.
- The room should have a door for privacy and a table and chairs to seat a circle.
- Instead of organising one focus group with twelve participants at the same time, you can arrange two sessions with smaller groups (it is recommended to organise interviews with 6 participants).
- Arrange for at least water, if possible, also a light snack.
- Arrange for 2 people to conduct the focus group: a moderator/facilitator and an assistant/note taker.
- Ask all participants for the written consent to take part in the research (see: Consent templates in Annex 8).
- The assistant facilitator also collects the demographic data (see: Annex 8, 9, 10) and asks everyone to choose a fictional name. The fictional name will be used in the report so that everything participants say stays anonymous.

2. Facilitating the focus group

Moderator/Facilitator

The success of the process relies on the facilitator's abilities — he or she needs to balance between guiding too strongly and not encouraging enough participation.

The facilitator's objectives are:

- To generate a maximum number of different ideas and opinions from as many different people in the time allotted.
- To stay relaxed and set a tone, introduce and guide the discussion.
- To keep discussion within the research framework.
- To listen actively and carefully: not participate, or share views, or engage in the discussion.
- Do not comment or express opinions, be non-judgmental and respectful.
- Promote everyone's participation: try to involve 'quiet' participants.
- If the question is hard to understand, try to clarify it by giving a general explanation (*"A challenge is something that disturbs your work. Do you sometimes think "if not*

for this thing I could do my job much better”? That’s what we want to talk about today.”)

Assistant/Note taker

The note taker does not join in conversation - avoids nodding or reaction, and has a set of specific tasks:

- Test and set up the audio recording equipment, ensuring that the focus group session is recorded properly.
- Remain in the room for the entire discussion, positioned so you can see and hear participants (but not seated next to the facilitator).
- Draw a sketch of the participants’ seating arrangement.
- Observe and take notes on nonverbal communication, emerging themes, possible follow-up questions, body language, signs of agreement or disagreement, confusion, frustration, concern, and other relevant behaviours.
- Record group characteristics, such as how many participants agreed or disagreed with certain points and how often particular themes appeared.
- Act as the timekeeper for the session.

3. When the group meets:

- Thank people for their participation.
- Review the group's purpose. Specific purposes are different depending on the goal of the research as well as the target group and they are indicated in the following annexes (see: Annex 4, 5, 6).
- Inform the participants about the recording and that the session is anonymous.
*“I’d like to let you know that this session is being recorded. The only reason for this is to make sure we can write down all your answers accurately afterwards. Once we’ve noted the key points, the recording will be deleted.
The recording will not be shared with anyone except the moderator and the assistant. Everything you say here will be used only by the project team for analysis, and your responses will remain completely anonymous.”*
- Assure that there are no right or wrong answers.
- Explain how the meeting will proceed (*we will ask questions*) and how members can contribute (*by answering the questions and sharing their point of view and experiences*).
- Set the tone by asking an opening question (such as: *“Tell us a little bit about yourself”*). You can start by sharing a little bit about yourself, if that is necessary.
- Make sure all opinions are heard.
- Ask people to speak up (level of voice is really important); ask people not to talk over one another.

- Try to prepare your own short, personal response to each of the questions in the focus group form. If none of the participants want to be the first to answer a question, you can start by briefly sharing your own experience.
- Remember that silent moments are a completely natural part of any focus group.
- If time does not allow you to ask all of the questions, focus only on the ones that are underlined (see: Annex 4, 5, 6). These are mandatory. The remaining questions can be asked only if there is enough time available.
- You may consider to write down the questions in papers, and create a jar of questions (or 2 jars of questions: one for the obligatory questions and one for the rest of them), then let each participant pull a question out of the jar as a way to promote everyone's participation.

4. Closing the meeting

- When all your questions have been asked, ask if anyone has any other comments to make.
- Ask group members to repeat one thing that you heard here that was really important.
- Thank the group for coming and remind them how the information will be used.

Focus group notes		
Date:	Location:	Facilitator/researcher:
Methodological notes <i>[Any interruptions? Reasons for interruptions. How was the schedule? Attitude? Quality of interaction?]</i>		
Number of participants:		Activity duration (time):
Fictional names of the participants:		

General topic	Question (number)	Summary of the information gathered	Significant quotes from the participants with fictional name
Quality of life			
Freedom (autonomy)			
Happiness and well-being			
Interests and preferences			
Inclusion and belonging			
Other...			

General conclusion

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Annex 4. Interviews with young people with disabilities: purpose and questions – for both individual and group interviews

Purpose

“We would like to talk with you about your life and the things that are important to you. We want to know what makes you happy, what you enjoy, and what is sometimes difficult. Your answers will help us understand your situation better. There are no right or wrong answers — we just want to hear your thoughts and experiences. You can answer only the questions you want to, and you can stop at any time.

Our meeting is a part of the Erasmus Plus “Our Ability” project.”

Questions for young people with disabilities

At the beginning of the interview:

Tell me something about yourself.

How are you feeling today?

Quality of life

1. Can you tell me what a typical day looks like for you?
2. How do you usually feel during the day? (e.g. happy, bored, sad etc.)
3. Why do you feel like this?
4. Do you like the place where you live?
What do you like about this place?/Why don't you like it?
5. What makes your day a good day?
6. What makes you have a bad day?

Freedom (autonomy)

4. What do you like to wear? Can you choose clothes by yourself? (If not, why?)
5. What food do you like best? Do you prepare food by yourself? (If not, why?)
6. Can you decide how to spend your free time? (If not, why?)
7. Can you decide about your money? (If not, why?)

Happiness and well-being

7. Tell me about something that makes you happy / sad.
8. Who helps you when you are sad?
9. What do you do to feel better?

Interests and preferences

10. What do you like to do in your free time?
11. Is there something you don't like to do?
12. What new thing would you like to try? (paragliding, roller skating etc.)

Inclusion and belonging

13. Who are your friends? Tell me something about them.
14. Are there any other important people in your life? Who are they?
15. How do you like to spend time with other people?
16. Are there any places where you want to go, but you cannot? (If yes, why?)

Annex 5. Interviews with parents and guardians of young people with disabilities: purpose and questions – for both individual and group interviews

Purpose

“We would like to learn more about the everyday lives of young people with disabilities - parents’ or guardians’ perspectives are very important to us.

By sharing your experiences, you can help us understand what supports your child’s well-being, what challenges you and your child face, and what makes a positive difference in daily life.

Your insights will help us see how to create better opportunities for choice, happiness, and inclusion. There are no right or wrong answers — we are simply interested in your experiences and opinions.

We are collecting information for the purpose of the Erasmus Plus “Our Ability” project.”

Questions for parents and guardians

Quality of life

1. Could you tell me what a typical day looks like for your child or the person you care for?
2. Overall, how would you describe the quality of life of your child or the person you care for (e.g., health, daily activities, relationships)?
3. What brings them the greatest sense of comfort and well-being?
4. What are the main things that make daily life difficult for them?

Freedom (autonomy)

4. In which areas can your child/the person make their own choices (clothing, food, activities)?
5. How important do you think it is for them to decide for themselves?
6. What difficulties do you encounter when trying to offer them freedom of choice?

Happiness and well-being

7. What makes them happy most often?
8. When do you see them sad or frustrated?
9. How do you manage to restore their well-being in such moments?

Interests and preferences

10. What activities do they enjoy and do with pleasure?
11. What activities do they avoid or dislike?
12. If they had the opportunity to try something new, what do you think they would enjoy most?

Inclusion

13. To what extent do they have friends or social contacts outside the family?
14. How are they received in the community (school, neighborhood, events)?
15. What are the main barriers that prevent their participation in community life?
16. What would help most to improve their inclusion and participation?

Annex 6. Interviews with professionals about the needs of young people with disabilities: purpose and questions – for both individual and group interviews

Purpose

“We would like to gather insights from professionals who work closely with people with disabilities, as your experience gives a valuable perspective on their quality of life, opportunities for choice, happiness, interests, and inclusion. By sharing your observations and professional knowledge, you can help us better understand both the strengths and the challenges that people with disabilities face in daily life. Your input will contribute to identifying areas where additional support or resources are needed. There are no right or wrong answers — we are interested in your experience and expertise. Our meeting is a part of the Erasmus Plus “Our Ability” project.”

Interview Questions

Quality of life

1. Overall, how would you assess the quality of life of the persons with disabilities you work with (e.g., health, autonomy, relationships, and social inclusion)?
2. What do you consider the main areas where they are doing well or making progress?
3. What are the areas where their quality of life is limited (e.g., access to services, autonomy, participation)?

Freedom (autonomy)

4. In what situations do you observe that the persons with disabilities have genuine opportunities to make their own decisions?
5. How do they react when offered several options?
6. What limits do you identify in exercising freedom of choice (e.g., cognitive level, external barriers, lack of resources)?

Happiness and well-being

7. What activities or situations visibly bring joy or satisfaction to the persons you work with?
8. How do you recognize signs of frustration or unhappiness?
9. What strategies do you use to support the person’s emotional well-being?

Interests and preferences

10. What interests and preferences have you identified among the people with disabilities you work with?
11. How do you integrate these interests into the work plan or daily interventions?
12. What barriers do you encounter in valuing their interests (e.g., lack of resources, opportunities, communication difficulties)?

Inclusion

13. To what extent do the persons with disabilities you work with participate in group activities or community events?
14. How would you describe the level of acceptance and interaction from peers and community members?
15. What measures or adaptations could increase their inclusion?
16. From your experience, what are the most effective inclusion practices you have observed?

Annex 7. Life story: instructions for researchers

Instructions: Tell the participant's story in a narrative form. Use small direct quotes when they add value. Keep it short and focused, but preserve the uniqueness of their experience.

Prepare 2 stories per organisation. Include:

1. **Present Situation.** Describe the participant's current life context (where they live, daily activities, routines).
2. **Place of Birth, Age, Family Situation.** Include age, birthplace, family composition, and key relationships.
3. **Community Description.** Describe the participant's community: social environment, support networks, accessibility, or challenges.
4. **Living Conditions.** Include information about housing, accessibility, and support services.
5. **Experiences and Feelings About Services and Support Systems.** How do they perceive the care, education, or disability support systems? Include positive and negative experiences.
6. **Self-Presentation and Values.** How does the participant describe themselves? What matters most to them?
7. **Needs and Aspirations.** Highlight their main needs, hopes, and desires, considering their abilities and interests.
8. **Disability-Related Experiences.** Include experiences related to their disability, including any barriers, accessibility issues, or opportunities.
9. **Discrimination and Disadvantage.** Note challenges or inequalities they face due to disability, gender, social environment, or other factors.
10. **Recommendations on Support and Empowerment.** Include participant suggestions on what could improve their participation, independence, and well-being.
11. **Plans for the Future.** What goals or aspirations do they have? Include quotes if they express ambitions or dreams.

Below you will find the templates for life stories.

Life story 1. Fictional name and age

Tell the participant's story. Support the narrative with *small direct quotes* when relevant. Keep it as short as possible without forfeiting value or uniqueness.

Source: Life story conducted in [region], [country], date

Life story 2. Fictional name and age

Tell the participant's story. Support the narrative with *small direct quotes* when relevant. Keep it as short as possible without forfeiting value or uniqueness.

Source: Life story conducted in [region], [country], date

Annex 8. Consent templates

A. Consent Form for Young Participants – Project *Our Ability* (Easy-read version)

About the project

- We want to talk with you about your life and ideas 😊
- This is part of the *Our Ability* project.
- You can choose if you want to take part in it.

What will happen?

- We will ask you some questions.
- You can say as much or as little as you want.
- You can stop at any time. ❌

Your privacy

- What you say will be private 😊
- Your name will not be written in reports.

Your choice

- Taking part is your choice.
- Saying “no” is OK 👍

Do you want to take part?

☐ Yes, I want to take part

☐ No, I do not want to take part

Optional: Audio Recording 🎤

- We would like to record your voice. Only the project team will listen.
- After we write down your answers, the recording will be deleted. 🎤❌
- You can say yes or no.

☐ Yes, I agree to recording

☐ No, I do not agree to recording

Optional: Photo 📷

- I agree that my photos I share can be used in the public report about the study.
- You can say yes or no.

☐ Yes, I agree

☐ No, I do not agree

Your name (Participant's name): _____

Place and date: _____ Signature: _____

B. Consent Form for Parents and Guardians (who take part in the interview)

About the project

You are invited to take part in the *Our Ability* project, which explores the experiences, needs, and aspirations of young people with disabilities.

What will happen?

- You may be asked questions in a group or individual interview.
- Participation is voluntary, and you may withdraw at any time.

Confidentiality

- All information will be anonymised.
- No names or identifying details will appear in reports.

Your rights

- You and your child/the person under your care may decline to answer any question.
- You may withdraw consent at any point without consequences.

Consent

- I have read and understood the information above.
- I know that participation is voluntary and confidential.
- **I agree to take part (and for my child/the person under my care) in this research.**

☐ Yes

☐ No

Optional: Audio Recording

We would like to record conversations to ensure accuracy. Recordings will be kept secure and used only by the research team. After we write down your answers, the recording will be deleted.

- **I consent to audio recording.**

☐ Yes

☐ No

Optional: Photos exploitation

- **I give my consent for photos presented by my child/the person under my care/ to be used in the preparation and publication of the project report.**

☐ Yes

☐ No

Young participant name: _____

Parent/Guardian name: _____

Place and date: _____ Signature: _____

C. Parental Consent Form (for parents whose children take part in the research)

About the project

Your child (the person under your care) is invited to take part in the *Our Ability* project. The aim of the project is to learn about the experiences, needs, and ideas of young people with disabilities.

What will happen?

- Your child (the person under your care) may be asked questions in a group or individual conversation.
- They can choose not to answer any question.
- They can stop at any time without giving a reason.

Confidentiality

- Everything your child (the person under your care) shares will be treated with respect and kept confidential. No names or personal details will be used in reports or publications.

Voluntary participation

- Participation is voluntary.
- Saying “no” will not affect your child (the person under your care) in any way.
- You may withdraw your consent at any time.

Consent

- I have read and understood the information above.
- I know my child's (the person's under your care) participation is voluntary and confidential.
- **I give permission for my child/the person under your care to take part in this research.**

☐ Yes

☐ No

Optional: Audio Recording

We may record the conversation to remember your child's (the person's under your care) answers more accurately. Recordings will only be used by the research team and will be deleted after the answers are written down.

- **I give permission for my child's (the person's under your care) voice to be recorded.**

☐ Yes

☐ No

Optional: Photos exploitation

- **I give my consent for photos presented by my child (the person under my care) to be used in the preparation and publication of the project report.**

☐ Yes

☐ No

Young participant name: _____

Parent/Guardian name: _____

Place and date: _____ Signature: _____

D. Consent Form for Professionals

About the project`

As part of the *Our Ability* project, we would like to learn from professionals who support young people with disabilities. Your perspective will help us better understand challenges, needs, and opportunities both of our beneficiaries as well as persons who professionally take care of them.

What will happen?

- You will take part in an interview or group discussion.
- Participation is voluntary. You may withdraw at any time.

Confidentiality

- All contributions will remain confidential.
- Data will be anonymised in reports and presentations.

Your rights

- You can choose not to answer any question.
- You may withdraw consent at any time without consequences.

Consent

- I have read and understood the information above.
- I know participation is voluntary and confidential.
- **I agree to take part in this research.**

☐ Yes

☐ No

Optional: Audio Recording

We may record the discussion to ensure accuracy. Recordings will be securely stored and accessible only to the research team. After we write down your answers, the recording will be deleted.

- **I consent to audio recording.**

☐ Yes

☐ No

Name: _____

Signature: _____ Place and date: _____

Annex 9. Young participant characterisation

Fictional name		
Age	Indicate the age of the participant	
Disability	Specify type of disability or relevant functional limitations	
Social profile	Indicate if the participant: - Comes from a socioeconomically deprived family - Has a migrant background - Experiences mental health challenges (e.g., low self-esteem, self-harm, trauma, other disorders, experiences of violence, addictions, lack of motivation, or limited expectations for the future) - Faces any other difficulties (specify)	
Living arrangements	Describe living arrangements: - Living with family - Living with family and attending a daily centre - Living in residential facilities (what is the reason, for how long) - Other (specify)	
Schooling status	Indicate if the participant is: - Currently in school - Not in school	
Education level	Please describe: - Frequented grade/class/level (if at school) - Highest level of schooling reached (if not at school)	
Parenthood status	Choose: With children/without children In case of having children, please describe how many and ages	
Work status	Choose: Currently engaged/not engaged in any form of income generating activity In case of activity, please describe	
Other relevant information	Other relevant information	

Annex 10. Parents and guardians - participant characterisation

Fictional name of the parent/guardian		
Fictional name of their child/ the person under your care		
Child's / the person's under your care disability	Specify type of disability or relevant functional limitations of the child / person under your care	
Other children / persons under your care	Specify how many children/persons under your care are in the family	
Marital status	Specify: Married / Divorced / Widowed / Single / Other	

Annex 11. Youth workers and professionals - participant characterisation

Fictional name		
Profession/ Occupation		
Age		
Sex	Female, Male, Other	
Work experience	Please describe: Total work experience (in years) Work experience with people with disabilities (in years)	

Annex 12. Check list for the researchers

Before the research activity

Preparation & Planning

- Review the purpose, target group, and method (Photovoice / Individual interviews / Focus groups / Life stories).
 - Prepare guiding questions and note-taking forms (Annexes 1–7).
 - Decide who will facilitate and who will take notes (2 people per session).
 - Ensure all materials are ready: consent forms, pens, flipcharts, paper, snacks, etc.
 - Prepare and test recording equipment (audio, if consented).
 - Ensure accessibility (venue barrier-free, quiet, comfortable seating, water/snacks).
 - Prepare the participant characterization forms (Annexes 9-11).
 - Collect signed consent forms (Annex 8) – including for audio/photo use.
 - Check that participants understand participation is voluntary and anonymous.
 - Ask participants to choose a fictional name, or assign one yourself to maintain anonymity.
 - Prepare emotional support if participants might need it.
 - Prepare Satisfaction Questionnaires (recommended at the end of sessions).
-

During the research activity

Facilitation & Interaction

- Begin with a warm welcome and simple explanation of the purpose.
 - Remind participants: “There are no right or wrong answers.”
 - Confirm again that participation is voluntary; they can stop anytime.
 - If recording, announce this clearly and confirm everyone’s consent.
 - Use open-ended questions; encourage everyone to share.
 - Keep the discussion respectful and inclusive — avoid judgment.
 - Keep the session within planned time and maintain a calm pace.
 - Note key themes, quotes (with fictional names), and nonverbal cues.
 - Invite participants to complete the Satisfaction Questionnaires (at the end of session).
 - Thank everyone sincerely for participating.
-

After the research activity

Documentation & Reporting

- Store consent forms securely according to General Data Protection Regulation rules and rules applied in your organisation.
- Complete the notes and participant characterization sheets, if necessary.
- Delete audio recordings once transcribed and verified.
- Review data for clarity, coherence, and ethical compliance.

Materials checklist

- Consent forms (young participants, parents, professionals).
- Participant characterization forms.
- Satisfaction Questionnaires.
- Reporting templates/notes from the research.
- Pens, flipchart paper, post-its, coloured markers.
- Printed photos taken by participants (exclusively for Photovoice).
- Audio recorder (if consent given).
- Name tags / identification if needed.
- Refreshments (water, snacks).

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Our Ability participating organizations:

Tartu Vaimse Tervise Hooldekeskus
Estonia



TARTU VAIMSE
TERVISE HOOLDEKESKUS

Asociația Down Valea Jiului
Romania



Uniamoci
Italy



FAMDIF/COCEMFE-Murcia
Spain



Fundacja Oczami Brata
Poland

