Project Result 3

Youth programs 4 ASD: Pilot Youth programs with the participation of youth with ASD

Piloting methodology

July 2023

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1. Introduction

The project **"YOUTHASD - Upskilling youth organizations for the inclusion of people with ASD"** is funded under the Erasmus+ Programme and it is implemented in five countries: Denmark, Italy, Spain, Greece, and Cyprus. The project aims at providing youth workers and youth organizations with a new, innovative and accessible learning opportunity on ASD. More specifically, the project's objectives are:

- To support the participation of ASD youth in youth organizations' activities
- To increase the attractiveness and accessibility of youth work for ASD youth
- To provide the necessary training methodology and tools to youth workers in order to include ASD youth in their work
- To provide organizational support to youth organizations to include ASD youth in their initiatives by upskilling their administrative and management staff
- To provide youth training opportunities adjusted to ASD needs

At the moment, the opportunities for community engagement and socialization of young people with ASD is mostly limited to ASD related organizations. There are very few initiatives that give the opportunity to youth with ASD to integrate and socialize with their neurotypical peers.

During the implementation of this result, we will organize youth programs in each participating country which will include neurotypical and ASD youth. In total 15 ASD youth will take part in these pilot youth activities.

This result is innovative as it will be among the first times at an EU level that such mixed youth activities will be piloted and its effectiveness measured.

The result is also transferable, because the piloting methodology and the implementation report of the pilot activity will be available in the project website and on the websites of the project partners. The methodology of the piloting will also be available to be used for different target groups and to be adjusted to the needs of interested organizations.

The piloting is a 3-day youth program in each participating country organized by the selected youth workers. Each youth worker will be free to design their own youth programs, but the following values need to be respected:

- The necessary safety measures are effectively put in place
- The youth program promotes EU citizenship, EU values and valuable skills for the youth
- The youth program foresees the socialization of neurotypical and ASD Youth

The expected impact of this result is:

- Increased knowledge and skills for youth workers on including people with ASD in their activities
- Increased understanding of the specific needs and challenges people with ASD face
- Increased self-confidence and leadership and soft skills for the youth with ASD

2.   Training modules

As part of the YouthASD project, a training program has been developed, consisting of 5 different modules addressed to youth workers interested in creating inclusive environments in their work with young people with ASD. It addresses their need for specialized knowledge and further professional development:

Module 1: Introduction about ASD and communication with youth with ASD

The learning objectives of this module are:

- Learn the most essential information regarding autism
- Understand the social communication needs of individuals with ASD
- Distinguish between the various communication support needs of individuals with ASD
- Communicate more effectively with individuals who have ASD.

Module 2: Understanding cognitive and social development in Youth with ASD

The learning objectives of this module are:

- Understand Cognitive and social development in youth with ASD
- Learn how to support the cognitive and social development in youth with ASD
- Identify the cognitive and social challenges for young people with ASD
- Distinguish the behaviour that is triggered by the underlying cognitive and social challenges.
- Adopt the theoretical knowledge into appropriate response when facing young people with ASD

Module 3: Description of the youth needs

The learning objectives of this module are:

- Identify the needs of youth with ASD
- Understand where those needs come from
- Learn about scientific theories that explain some of the needs of youth with ASD
- Distinguish needs and strengths
- Adopt new strategies and activities that can be adopted in order to be more supportive of youth with ASD in meeting their needs

Module 4: Creating a safe and inclusive environment

The learning objectives of this module are:

- Understand people with Autism Spectrum Disorder (ASD) may view the world differently from others.
- Learn how to build a more autism-friendly environment.
- Identify some of the young people's needs with ASD in order to feel help them feel more comfortable and included.
- Distinguish the negative effects of sensory differences.
- Adopt general questions that we can ask ourselves on how to create a physical environment that will reduce anxieties.

Module 5: Communicating with parents and managers in youth organisations

The learning objectives for this module are:

- Understand how to use useful tools that will facilitate their communication with parents,
- Learn through the use of tips provided, how to communicate to managers in youth organisations the needs and wishes of youth with autism.
- Identify useful material that you can suggest to managers in youth organisations that will contribute in the creation of an inclusive and friendly environment for youth with autism,
- Distinguish which of the tips provided can improve effectively the communication with parents of youth with autism,
- Adopt an inclusive and friendly approach for youth with autism in their communication with their parents and managers in youth organisations.

If you are interested in implementing youth activities for young people with ASD, these training modules are an important foundation of knowledge before the planning process of the activity starts.

You can find the training modules on the project website: https://youthasd.eu/results/

3.   ICF

ICF - International Classification of Functioning, Disability and Health - is a WHO classification that was published in Danish in 2003.

ICF is a complex interaction model and a classification that encompasses biological, psychological and social factors. ICF is a widely used and accepted as an international reference framework for describing functional ability. ICF provides a common language across disciplines, institutions, sectors, cultures and nations. ICF focuses on physical, psychological and social functioning in combination with health and contextual factors and thus looks at the citizen's entire life situation.

ICF emphasises that "functional ability" is a very complex ability that is influenced by many factors. Functional ability is not only dependent on body function, activity and participation, but also to a

large extent on environmental and personal factors. In the ICF's understanding, functional ability is: "a general term for body functions, body anatomy, activities and participation. "Functional capacity indicates various aspects of the interaction with a person, with a given health condition and the person's environmental and personal factors". In other words, functional capacity is a person's ability to perform daily activities and participate in society.

With ICF came a new paradigm that looks at functional ability in a broad and dynamic perspective. ICF is basically a supplement to ICD. ICD is an abbreviation for the World Health Organisation's (WHO) "International Statistical Classification of Diseases and Related Health Problems", commonly referred to as the 'disease classification'. However, the diagnosis in itself does not say anything about the person's functional ability or what interventions are needed for the person to resume their everyday life.

In the biopsychosocial model, there is a complex interplay of all factors at all times. The purpose of ICF is to describe functional ability and impairment, not to measure it and can also be used as a planning toll for an activity, if the participant of the activity is challenged in one way or another

Functional ability consists of three components

1. Body functions and structures are the physical, physiological and mental functions of the body.

2. Activity is a person's performance of a task or action and describes functional ability at the individual level

3. Participation is a person's involvement in daily life and describes functioning at a societal level

Contextual factors (2):

1. Environmental factors are the physical, social and attitudinal surroundings. Environmental factors can be either facilitating or limiting

2. Personal factors are linked to the person, e.g. age, gender, social status, coping skills and experience, etc.

4.   How to use the ICF as a planning tool:

When planning an activity with participants challenged in one way or the other, the aim is to ensure inclusivity and equal participation for all included.

When planning the three-day activity for young people with ASD, it is therefore advisable to take the fine components of the ICF into consideration:

 "Body functions and anatomy" refers to the physiological functions (including mental functions) and anatomical structures of the body, such as organs and limbs. It describes losses or changes from normal body function and structure that lead to impairment or limitations. Examples:

- Other relevant diagnosis such as diabetes, epilepsy, reduced hearing etc.
- intellectually disabled.

"Activities" refers to a person's performance of tasks or actions at an individual level, where activity limitation is the difficulty the person has in performing the activity. Examples:

- difficulty with coordination
- reduced balance
- reduced stamina

"Participation" refers to involvement in daily life e.g. work, school, day centre, where participation restriction is the difficulties that may be encountered in involvement in daily life. Participation is considered by many to be the optimal goal of all involvement of the daily life. Where participation contributes to the community and gets something back from the community. Examples:

- Difficulty concentration over a longer period of time
- Difficulty being surrounded by other people
- Challenged if the rules change
- Challenged to understand sarcasm and irony
- Challenged if you are not always at the front of the queue or the first to be chosen
- Challenged with too many sensory inputs etc.

These three components are brought together under a common umbrella that can dynamically interact to describe functional ability and disability.

"Environmental factors" are the physical, social and attitudinal surroundings that surrounds the activity planned for the young person with ASD. These factors are external to the individual and can have both positive (facilitating) and negative (inhibiting) influences on functional ability.

Examples:

- Sensory inputs – can we reduced light, sounds, smells if necessary to facility inclusion of the activity
- Can we make sure that the plan for the activity is clear for the participant e.g. rules (use of pictograms, written plan, verbally explained etc.), introduction to the trainer and other participants in the activity, timeframe
- Create a safe space, where the participant can retreat to if needed.
- A back-up plan if the activity is too complex or challenging for the participant etc.

The "personal factors" are significant and important for the person's behaviour and coping ability, among other things. Personal factors consist of traits, characteristics, competences of the individual citizen (what they bring with them in their backpack) that are not part of health or health-related conditions. These factors can also include gender, ethnicity, age, habits, lifestyle, etc.

Examples:

Is the participant impatient

Does the participant have difficulty listening for longer periods of time?

Is the participant is easily distracted

Does the participant leave the activity and possibly the matrix if it becomes too much?

Does the participant need to have a buddy next to them throughout the activity?

Is the participant very self-conscious?

Will the participant might act out if they are under too much pressure

Does the participant have good or not so good social skills? Etc.

5. General guidelines

The following steps for Project Result 3 are:

- Selection of youth participants. Each partner will launch an invitation / call for participants, publicized through their own websites & social media, associated partners, local networks, cooperating organizations and institutions depending on the national frame and context.

- During this stage the youth workers who are selected to participate and implement the piloting activity will develop the pilot youth programs they intend to organize in each partner country. To this end each partner organization will provide mentoring and support to the youth workers of their countries.

- The piloting is a 3-day youth program in each participating country organized by the selected youth workers. Each youth worker will be free to design their own youth programs, but the following values need to be respected:
  - o The necessary safety measures are effectively put in place
  - o The youth program promotes EU citizenship, EU values and valuable skills for the youth
  - o The youth program foresees the socialization of neurotypical and ASD youth

Partners are responsible to approve the final training programs in each country. At the end of the training, a summative evaluation will be carried out to measure the impact of the youth programs to youth and especially to ASD youth. The youth workers will also complete an evaluation in order to assess any necessary information, we need to include in the project results coming from real-life experience. Young participants will receive a Youthpass for their participation.

- Experience report:

SOSU as the PR leader will collect input by all partners and will draft an experience report, which will document the lessons learnt and experience of the partners during the pilot activities.

● Adaption to the national context. At this step, partners will adopt the experience report to the specific needs of their national context. During this step, partners will add special focus on the piloting results in their countries and provide translations.

In total 15 young people with ASD will take part, which means approximately 3 per partner organisation. Youth workers who are selected to participate and implement the piloting activity will develop the pilot youth programs they intend to organize in each partner country. To this end each partner organization will provide mentoring and support to the youth workers of their countries.

The selection of the youth participants. Each partner will launch an invitation / call for participants, publicized through their own websites & social media, associated partners, local networks, cooperating organizations and institutions and local media.

The piloting is a 3-day youth program in each participating country organized by the selected youth workers.

Each youth worker will be free to design their own youth programs, but the following values need to be respected:

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Young participants will receive a Youthpass for their participation.

When planning activities involving young people with ASD, use the ICF as a guideline/ planning tool for these activities. The goal is not to make sure that all challenges are placed under the right component, but rather that you take all challenges into consideration as well as taking all the necessary precautionary measures, to make sure that the three-day activity is a success for all involved.

It is important to keep some evidence of the pilot implementation.

You will need:

● Participants' list (if online, download the participants' list from the app you used and take screenshots)

● Photos – ask for permission or don't take a photo of their face

- written feedback and evaluations according to template
- National Report

6. Report template

Please use the following structure to develop your Report.

The report should be **maximum 5-7 pages long** and must depict the overall feedback from the trainer and the participants in the piloting workshop.

1. Introduction (a summary description of the Practical and Reporting Phase)

- Participants (a description of the target groups + numbers)
- Scope and Duration (date, time, place, method etc.)
- Processes involved (e.g. training tools, equipment)

2. Key Outcomes

- Achievements and Successes
- Challenges
- Testimonials

3. Feedback from the youth workers /trainer as well as the participants

- Based on verbally feedback as well as the written narrative form from youth workers/ trainers collected during the three-day activity (according to the template) as well as the participants.

4. Conclusions and Recommendations for planning an activity involving young people with ASD to facilitate inclusion

- Conclusions on the material, topic, need from the participants, changes on the content etc.
- Key Policy & Practice Recommendations