# StoryLiving

Using digital storytelling with youth with ASD or mental health disorders:

# A practical guide for youth organisations





### **Project Information**

**Project Title: StoryLiving** – Enabling youth with developmental disabilities & mental health disorders to share their COVID-19 experiences through digital storytelling

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**Project Consortium** 

Coordinator: KMOP - EDUCATION HUB - Greece

**Partners:** The partnership consists of the following organisations:

BILDUNG UND PROJEKT NETZWERKGMBH (BUPNET) – Germany CANARY WHARF CONSULTING LIMITED (CWC) – United Kingdom CENTRO PER LO SVILUPPO CREATIVO DANILO DOLCI (CSC) – Italy FUNDACION INTRAS (INTRAS) – Spain Family and Childcare Center branch in Skopje (KMOP Skopje) The Republic of North Macedonia KMOP - Policy Centre – Belgium

Author: Iliana Konstantopoulou – KMOP - EDUCATION HUB

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# Introduction

There is broad consensus that the COVID-19 pandemic and its aftermath have not only affected people's physical well-being but their mental health as well. According to the World Health Organization (WHO), the pandemicledtoa25% increase in the worldwide prevalence of anxiety and depression<sup>1</sup>. According to related research across the world (Florillo & Gorwood, 2020)<sup>2</sup>, it is estimated that in the months, even years, to come, the need for psychiatric support for individuals will increase due to the COVID-19 outbreak.

As for the age group of young adults, those were already at high risk of poor mental health and substance use disorder, and many did not receive any treatment, even before the pandemic. An estimate is that during the pandemic, 56% of young adults aged 18-24 reported symptoms of anxietyand/ordepressivedisorder(KFF, 2020)<sup>3</sup>. Moreover, young adults were more likely to report substance use (25% vs 13%) and suicidal thoughts (26% vs 11%) than adults in general.

As research suggests, social distancing and the shift in medical care towards the fight against the pandemic have significantly affected the mental health and socialisation of young people at risk of social exclusion, especially those who face mental health problems, such asyouthwithAutismSpectrumDisorders(ASD). For the latter, the social distancing, the shift in priorities in the healthcare sector for the containment of the pandemic and the "infodemic", the rapid spread of terrifying fake news that increases anxiety in individuals, have had detrimental effects on their well-being.

For example, research led by Ghent University reported a greater increase in both anxiety and depression symptoms in autistic adults than in neurotypical adults, which is particularly problematic as this group of people ordinarily shows increased rates of anxiety and depression.

The StoryLiving project seeks to address the abovementioned issues by applying the storytelling method as an innovative recovery methodology. The idea of the project is thecollective development of stories by youth with developmental disabilities or by youth/ young adults with mental health problems based on their COVID-19 lived experiences.

As a society, we need to be able to hear, listen to, and act on young people's stories – stories not only of the challenges and difficulties they are experiencing but also their stories of what they are doing to stay well. That way, storytelling can significantly improve youth's mental health and well-being.

<sup>1 &</sup>lt;u>https://www.who.int/news/item/02-03-2022-covid-19-pandemic-triggers-25-increase-in-prevalence-of-anxiety-and-depression-</u> worldwide

<sup>2</sup> Fiorillo, A., & Gorwood, P. (2020). The consequences of the COVID-19 pandemic on mental health and implications for clinical practice. European Psychiatry: The journal of the Association of European Psychiatrists, 63(1), e32. <u>https://doi.org/10.1192/j.eurpsy.2020.35</u>

<sup>3</sup> https://www.kff.org/coronavirus-covid-19/issue-brief/the-implications-of-covid-19-for-mental-health-and-substance-use/

### StoryLiving

"StoryLiving Enabling youth with \_ disabilities developmental & mental health disorders to share their COVID-19 experiences through digital storytelling" is a European Erasmus+ project led by KMOP - Education Hub in Greece and implemented by partner organisations in Germany, United Kingdom, Italy, Spain, The Republic of North Macedonia, and Belgium. The project aims to support youth with ASD or other mental health disorders at higher risk of social exclusion and isolation during the troubling times of the COVID-19 pandemic by using storytelling as means of inclusion, communication, and empowerment.

The idea underlying the project is that sharing their stories during the pandemic will allow youth with ASD or other mental health disorders to heal by verbalising the experiences, struggles, decisions, fortitudes and weaknesses, which in turn has therapeutic effects on the brain. Storytelling can indeed be applied as an innovative recovery methodology as it is a unique way of expression and can nurture emotional well-being.

To verbalise means becoming aware and seeing the situation from a different perspective, allowing one to notice positive points of any case. When someone chooses to speak up about their struggles, they are set free of what has previously made them feel trapped, and they gain control over what used to have power over them.

Overall, there is a broad consensus that storytelling can be a significant experience and an essential part of the individual's recoveryjourney. In a study (Nurser et al., 2018)<sup>4</sup> conducted on the topic of storytelling as means ofmental health recovery, the finding sidentified five key themes in storytelling, namely a highly emotional experience, feeling safe to disclose, a renewed sense of self and the community, two-way process, and a novel opportunity.

Provided that the COVID-19 pandemic set in motion a shift in digital forms of culture, the StoryLiving project aims to use digital storytelling, a digital form of artistic expression, in order to allow youth with ASD or other mental health disorders to share their experiences during the pandemic.

Thus, the project activates and uses the digital storytelling approach as an innovative and effective digital tool to support the inclusion and healing process of the target groups, but also to raise awareness of the general public about the struggles of youth with ASD and mental health disorders, especially during the pandemic, as these target groups were more isolated than before.

4 Nurser, K. P., Rushworth, I., Shakespeare, T., & Williams, D. (2018). Personal storytelling in mental health recovery. Mental Health Review Journal, 23(1), 25-36. <u>https://doi.org/10.1108/MHRJ-08-2017-0034</u>

## Aims and Objectives

The StoryLiving project aims to support youth with ASD or other mental health disorders to share their experiences during the COVID-19 pandemic by using digital storytelling as means of inclusion, communication, and empowerment.

The objectives of the project are:

- To help youth with ASD or other mental health disorders cope with the pandemic
- To support youth trainers, educators, and social workers and increase their capacity to use storytelling in their work
- To promote the social inclusion of youth with ASD or other mental health disorders through storytelling
- To raise awareness about the particular issues that people with ASD or other mental health disorders faced during the COVID-19 outbreak



# **Project Activities**

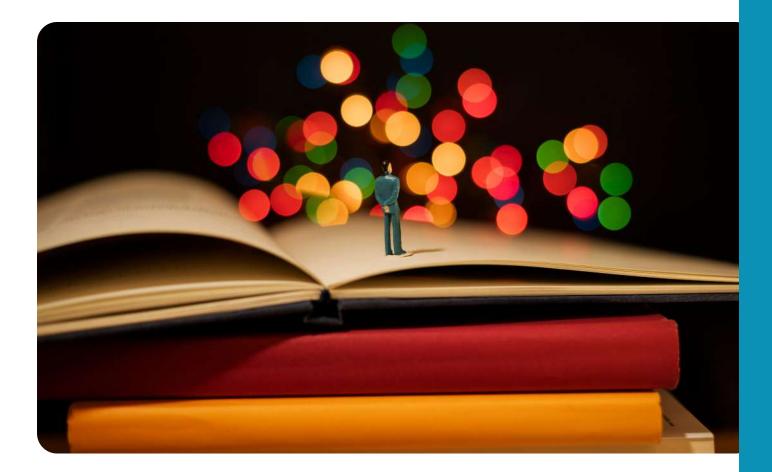
To achieve the objectives mentioned above, the project will develop the **following outputs:** 

- O1: Training program for youth workers, educators, and social workers working with youth with developmental disabilities or other mental health disorders. This output entails the creation of training material for youth workers, social workers, and informal trainers interested in using the storytelling technique and the project's storytelling platform for their own activities to support their target groups.
- O2: Piloting & Development of collective stories by youth with developmental disabilities or other mental health disorders. This output aims to test the training material and methodology developed under O1 both in terms of trainees' satisfaction and on the practical level of stories collection.
- O3: Development of the training & hosting platform. In the context of this output, a platform to host the COVID-19 stories of youth with ASD or other mental health disorders will be developed. The platform will operate as a community to engage and as an awareness-raising tool for the general public, making digital storytelling accessible to more people across the EU.
- O4: Recommendations & Guidelines on using storytelling as a communication and healing process during & after the pandemic. This output will include comprehensive recommendation papers at the national and European levels to promote the use of storytelling as a healing and communication process for youth with ASD or other mental health disorders during and after the pandemic.

Through the training of professionals and youth organisations on how to use digital storytelling for the support of youth with ASD or other mental health disorders and the creation of an online hosting platform for these stories, young people will be able to connect, support each other, and engage in a healing process which will allow them to overcome the struggles of the pandemic. Last but not least, the dissemination of the project results in the majority of EU languages will allow greater transferability across the EU, highlighting the importance of including and supporting vulnerable groups such as youth with ASD or other mental health disorders during the pandemic.

The **StoryLiving Training Program** aims to provide the necessary guidelines and support to youth organisations and support groups for youth with ASD or other mental health disorders on how to implement social inclusion programs and healing programs for their target groups through digital storytelling during the pandemic and after its end.

# The StoryLiving Training Program



During the COVID-19 pandemic, youth with ASD or other mental health disorders have been at higher risk of developing anxiety and depression, as they are one of society's most vulnerable groups.

At the same time, they witnessed a shift in the focus of medical care in the management of the pandemic. The idea of the training program is based on research suggesting that storytelling can be a powerful tool for people to heal from trauma and find a new sense of self and the community.

The training program development was based on thorough desk and field research to identify the current trends in the subjects of inclusion, COVID-19 and ASD or other mentalhealthdisordersandtodeterminegood practices that can be adapted to the project. The desk review included the collection and review of existing data and resources, such as reports, tools, good practices, and initiatives carried out at local, regional, national or EU levels, relating to the inclusion of youth with ASD or other mental health disorders and the exploitation of the storytelling technique in social projects.

In the context of the field research, semistructured interviews were held with youth workers and professionals working with youth with ASD or other mental health disorders to identify good practices and clarify their specific educational needs.

During the following steps, the training methodology was determined based on the definition of learning outcome and the choice of the learning and teaching methods that can lead to the attainment of outcomes. It was decided that the training should cover the following main subjects:

- Understanding the impact of the pandemic on youth with ASD / mental health disorders
- Digital culture and its tools in the use of social purposes Digital storytelling what is it, how can it be effective and how to implement it
- How to assist youth with ASD / mental health disorders in sharing their experience

Last but not least, the material produced for each subject was peer-reviewed to ensure that it complies with the project's technical and quality standards and changes were made to create the final version of the training program.The training program is available here:

### www.storylivingyouth.eu/training-platform/.

The present guide is based on the collected data from the desk and field research and the material produced for the StoryLiving training program. It complements the latter by including guidelines and practical strategies for youth organisations and organisations

### The Present Guide

working to support youth with ASD or other mental health disorders on implementing the digital storytelling program with the target groups.

At the same time, the guide provides further information on the training, the training modules, and the learning objectives they aspire to meet.

It also includes advice, additional resources, and supporting material to facilitate the learning process. It is addressed to youth workers, social workers and informal trainers working with youth with ASD or other mental health disorders, but also to any interested individual or organisation wishing to use the material produced in the framework of the project.

The guide's structure follows the training program's design as presented above. Also, it includes a practical case study in which the training program's material and methodology are put together in a real pandemic story of a young person with anxiety which is provided as a hands-on example for professionals on how to use the digital storytelling technique.

Thus, the structure of the present guide is the following:

- Module 1: How to deliver the training program
- Module 2: Impact of the pandemic on youth with ASD / mental health disorders
- Module 3: Digital tools for storytelling
- 🖌 🔰 Module 4: Digital storytelling
- Module 5: How to assist youth with ASD
  / mental health disorders in sharing their experience
- Putting it together: A real pandemic youth story



# Module

### Module 1: How to deliver the training program

### Module Overview

The StoryLiving Training Program will help professionals, youth workers, and social workers working with youth with ASD / mental health disorders acquire the necessary skills and enhance them to implement training regarding storytelling among youth with ASD / mental health disorders.

### Learning Outcomes

Upon completion of this module, learners will:

- Understand how to develop training which will help professionals, youth workers and social workers working with youth with ASD / mental health disorders
- Enumerate activities and skills related to successful training devlopment
- Enlist resources to successfully develop a training
- Develop necessary skills and enhance them to implement trainings regarding storytelling among youth with ASD / mental health disorders

### Content

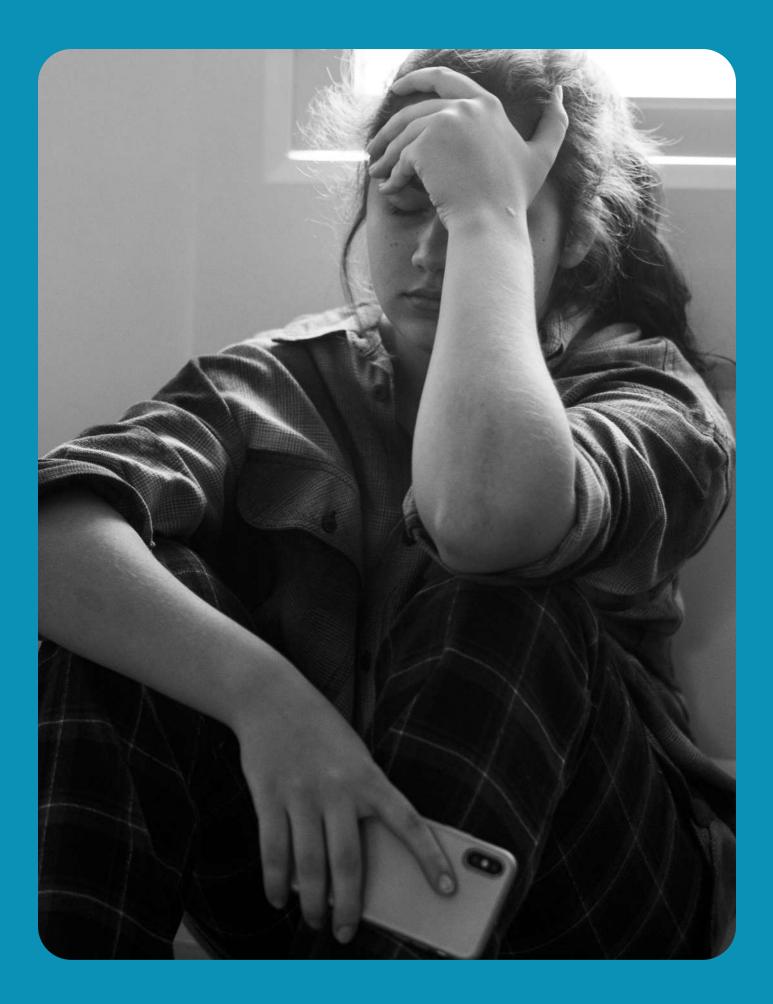
The module's content covers the following topics:

- Target group
- Understanding the StoryLiving Training Program
- The objectives of the Storyliving training program
- Content of modules and their goals
  - Impact of pandemic on youth with ASD / mental health disorders
  - Digital tools for storytelling
  - Digital storytelling
  - How to assist youth with ASD / mental health disorders in sharing their experience
- Ice breaking activities
  - Examples of ice breaking activities

- Activities to Introduce a Topic
- Energizers
  - How to Use Energizers?
  - Examples of energizing activities
  - Energizer to start a module
  - Competence
  - Energizer: Blast from the Past
- Quick tips
- Developing your own resources
- Evaluating the program
  - Questionnaire
  - Feedback
  - Interviews
- Practical assignments
  - Planning a Training Session Organizing Key Concepts for Learning
  - Evaluating training effectiveness
- Self-assessment
- References

### Duration

The overall duration of the module is 2 hours.





# Module

### Module 2: Understanding the impact of the pandemic on youth with ASD / mental health disorders

### Module Overview

This module analyses effects of the COVID-19 the pandemic on autistic people and people with mental health disorders giving an insight on the mitigation tools used. Among these tools, the module analyses deeper the role of storytelling in overcoming pandemic related challenges. The module's objective is to help learners identify the impacts of COVID-19 pandemic on autistic people and people with mental health disorders and to also identify the tools used to mitigate these effects with a particular focus on digital storytelling.

### Learning Outcomes

Upon completion of this module, learners will:

- Understand the impact of the pandemic on autistic people and people with mental health disorders
- Enumerate the mitigation tools used by families and professionals to minimise the impact of the pandemic
- Enlist awareness and curiosity about the possibilities offered by storytelling
- Develop a new perspective on how to use storytelling in times of societal crisis

### Content

The module's content covers the following topics:

- Effects of COVID-19 pandemic on mental health
- Autism and COVID-19 pandemic
  - Physical and mental health
  - Daily life
  - Access to education and work
  - Access to care and treatments

- Different experiences on the spectrum
- Impact on people living with mental health disorders
- Mitigation tools used
  - Parents and family support
  - Special needs teachers and tutors support
  - Personal creative projects
  - Teletherapy
- Storytelling
- Narrative coherence and emotional well-being
- Storytelling during the pandemic
- Storytelling for autism and mental health disorders
- Practical assignment: Write a petition
- Self-assessment
- References

### Duration

The overall duration of the module is 2 hours.



# Module

### Module 3: Digital tools for storytelling

### Module Overview

This module focuses on tools that can be used for storytelling. It includes tools for online collaboration and online meetings that help in the communication and also participation of ASD/MHD youth in the storytelling process. The module also introduces creative digital storytelling tools for different applications and settings. All the tools are presented and explained in a comprehensive way and also give suggestions on how and when to use them. By working through this module trainers will get to know the different tools and also get a chance to try them out. Afterwards they will be able to make informed decisions on which tools to use in their respective settings. The module's objective is to present and explain tools for storytelling, as well as tools for online communication and collaboration, so trainers can make informed decisions on which tools to use for their setting.

### Learning Outcomes

Upon completion of this module, learners will:

- Understand the differences between the proposed tools, their purpose, main features, characteristics and functionalities
- Know a variety of tools that can be used for communicating with and involving young people in digital storytelling as well as a number of tools that can be used for digital storytelling
- Develop an own understanding to make informed decisions on which tools to use for which setting and with which target group
- Apply a variety of tools according to the specific needs and requirements of the respective target group

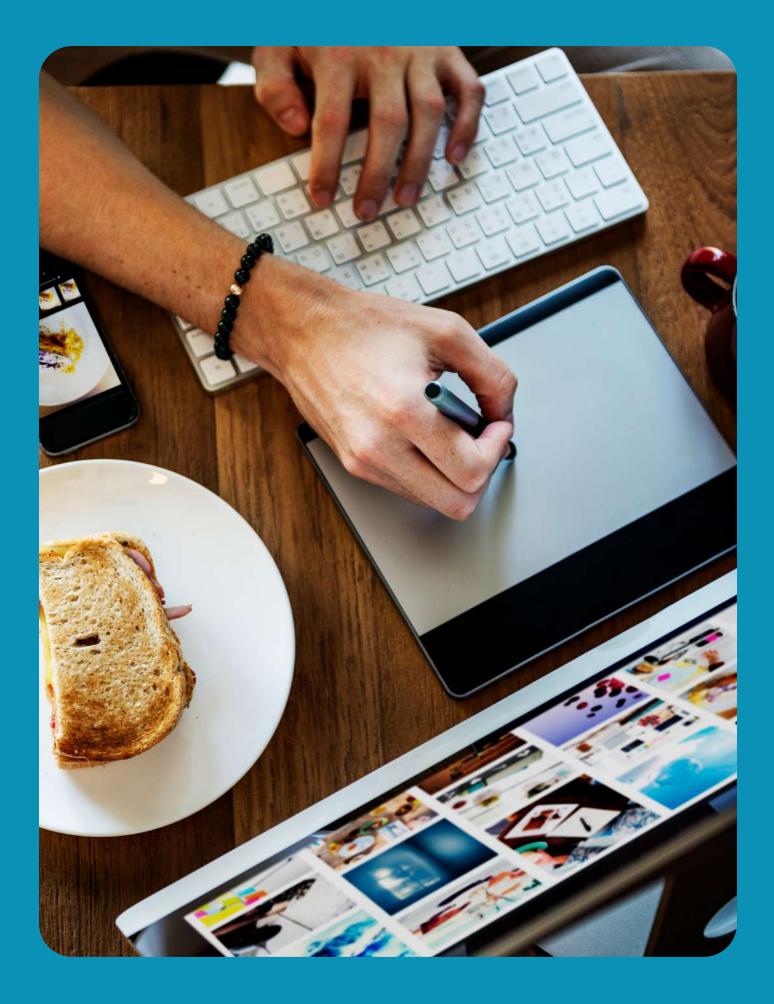
### Content

The module's content covers the following topics:

- Digital communication and participation and storytelling
- Digital Storytelling
- Interactive display of all tools using dialog cards, one set for Storytelling tools and one set for Digital Collaboration Tools
- Digital Communication and Participation
  - Zoom
  - Microsoft Teams
  - Google Hangouts
  - Skype
  - Miro
  - Padlet
  - Social media
- Digital Storytelling Tools
  - Blabberize
  - Puppet Pals HD
  - Toontastic
  - ShowMe Interactive Whiteboard
  - PICLITS
  - Audacity
  - Canva
  - Pixton
  - StoryMap
  - Timeline
  - Creative Cloud Express
  - Adobe Spark Page
  - Unfold
  - ACMI
  - genially
  - SlideStory
  - 30hands Pro
- Other tools to support digital storytelling
- Practical assignment 1
- Practical assignment 2
- Self-assessment

### Duration

The overall duration of the module is 2 hours.





# Module

### Module 4: Digital storytelling

### Module Overview

This module offers an overview of Digital Storytelling: what it is, how can it be effective and tips to implement it with young people with developmental disabilities & mental health disorders. The module's objective is for learners to know about digital storytelling, sometechniques and simple exercises, and some tools for digital storytelling.

### Learning Outcomes

Upon completion of this module, learners will:

- Understand what storytelling is and how to apply it with young people with developmental disabilities & mental health disorders
- Enumerate different storytelling techniques and digital tools to implement them with young people with developmental disabilities &mental health disorders
- Enlist confidence using storytelling with young people with developmental disabilities & mental health disorders
- Develop storytelling abilities

### Content

The module's content covers the following topics:

- Why to use storytelling with young people with developmental disabilities & mental health challenges?
- Some storytelling techniques
- Basic steps to tell a story
- Tips to use storytelling with people with ASD/mental illness
- What digital Storytelling is?

- Digital storytelling as an adaptive tool
  - Storytelling as a visibility tool
  - Storytelling to strengthen group cohesion
  - Storytelling as a creative tool and IT promoter
- Values of storytelling
- Storyliving vs storytelling
- Practical assignment: Connecting up exercise
- Practical assignment: Knowing about me
- Practical assignment: I can be my best friend
- Practical assignment: Treasure map exercise
- Practical assignment: Types of problems
- Self-assessment
- References

### Duration

The overall duration of the module is 2 hours.





# Module

# Module 5: How to assist youth with ASD / mental health disorders in sharing their experience

### Module Overview

This module aims to help professionals, youth workers and social workers working with youth with ASD or other mental health disorders to acquire the necessary skills to implement the storytelling technique in their practice and to enhance them in their related effort. In specific, the module entails information on the obstacles and special considerations in using storytelling with youth with ASD/mental health disorders and on special education and mental health methodologies regarding the use and benefits of storytelling in mental health care.

Moreover, the training material provides tools that professionals may use in order to help youth share their story and equips them with skills for the facilitation and mediation of the storytelling experience. In addition, it describes the step-by-step process of guiding youth to share their story as well as things to take into consideration when adapting storytelling for different people, while it also analyses the practical steps to implement before, during, and after storytelling. Last but not least, the training content is supplemented by a practical assignment in which professionals can apply the skills acquired in a practical case scenario and an overall evaluation of their knowledge gains through a quiz. The aim of the present module is to equip professionals, youth workers and social workers working with youth with ASD/ mental health disorders with the necessary knowledge and skills to assist youth in sharing their experience during the COVID-19 pandemic.

### Learning Outcomes

Upon completion of this module, learners will:

- Understand the obstacles and special considerations in using storytelling with youth with ASD/mental health disorders
- Learn about special education and mental health methodologies regarding the use and benefits of storytelling in mental health care
- Identify tools that they can use to help youth share their story
- Adopt skills that will aid them in the process of facilitating and mediating storytelling
- Describe the step-by-step process of assisting youth to share their story
- Distinguish the means to adapt the storytelling for different people

 Determine the practical steps and processes to engage in before, during, and after storytelling

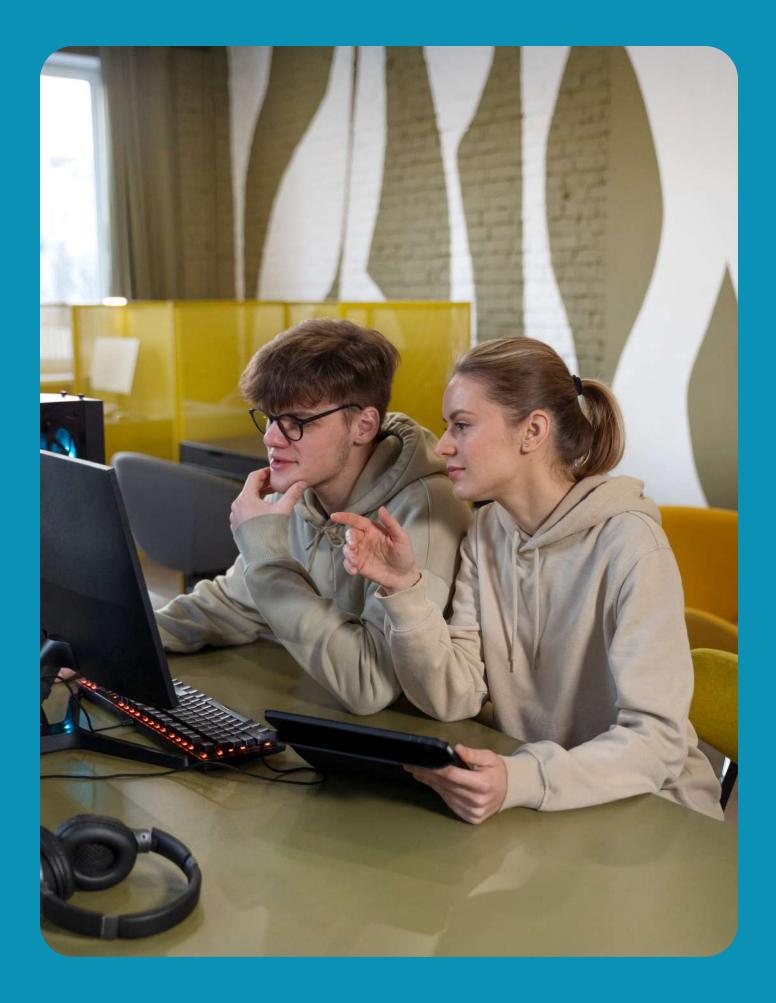
### Content

The module's content covers the following topics:

- Obstacles and special considerations
- Special education/mental health methodologies
- Tools you can use
- Facilitation Mediation
- Guided process
- Adaptation to each person
- Practical steps to implement
- Practical assignment
- Self-assessment
- References

### Duration

The overall duration of the module is 2 hours.



# Putting it together: A real pandemic youth story

### Introduction

This last part of the guide aims to put together the StoryLiving training program's material and methodology in a real pandemic story of a young person with anxiety using the digital storytelling technique. The story was collected Greece the Microsoft Teams online in using application, and the participant gave her consent to publish the story. The storyteller was a 30-year-old female who identified herself as rather anxious and experienced panic attacks during the COVID-19 pandemic. The story's title is "Two years of COVID-19 pandemic: A roller-coaster of fear and oppression", a choice made by the storyteller herself.

Before engaging the participant in storytelling, the "Important things about me worksheet" provided in "Module 5. How to assist youth with ASD/mental health disorders in sharing their experience" was used, which was converted to a google form in order to establish rapport and get to know the storyteller a little better. Then, the participant engaged in the storytelling session and was able to share her story during the COVID-19 pandemic in a cohesive way, while the professional who facilitated the process made encouraging and validating comments to create a safe space.



### Important things about me

This worksheet entails information about things that you consider to be important about you and you would like to share before telling your story in order to know you a little better.

The online version of the "Important things about me" worksheet

### **The Story**

Here follows the story shared in the participant's own words:

"The general picture of the pandemic period and particularly the lockdown period was one of a period of pressure and repression, health anxiety because of the coronavirus, but also fear of repression because of the restrictive measures in place. Even as we speak today, the fear of death and disease has been reduced by the vaccines, but there is still a sense that our lives are on hold, fear of whether this will happen again in the future and whether there will be an outbreak.

The first two weeks of the lockdown felt relaxed, the pace dropped, it was a new experience that I thought would be brief. But as this situation continued, I lost my motivation to get up and do anything. Back then, everyone said to incorporate routines into our daily lives (e.g., physical exercise) and try to be productive to forget about the pressure of the coronavirus. Although I completely understand the logic and our need to do this, it seemed very hypocritical to me to try to feel like we were in control of small things in our daily lives, while at the same time we had no control over anything.

At the time, I was doing my Master's degree, and despite the favourable treatment and the time period given to adjust to the new conditions of remote learning, I was not motivated to learn. Cameras and microphones were turned off, there were no classroom dynamics; I have not seen my fellow students in person from 2019 until today! Postgraduate studies during the pandemic period were generally a traumatic experience. Also, at the time, I was working and going to the office in physical presence, which was an outlet because I could get out of the house. However, it was extremely difficult to combine my studies and especially my thesis, with work duties. The mental cost was great because I am anxious, and I want to be consistent with the obligations I take on. I felt that I was deprived of the joys of life and only had obligations.

At the same time, I only heard negative news: the coronavirus outbreaks and deaths, police violence, injustices and arbitrariness, and femicides. I had panic attacks for the first time, which until then I had only heard of. I also had episodes of overeating; I gained several pounds in a short period of time. I felt like food was the only pleasure we had left. The fatigue was great on a physical and mental level and it affected my intimate relationship: I was irritable, and there were tensions. In terms of my social relationships, I was withdrawn, I felt I wasn't good company to hang out with my girlfriends.

I often heard that I shouldn't complain because at least I was working and studying at the time, while others lost their jobs and had no ways to make the most of their time. But for two years now, I haven't travelled, I haven't done things I like, I haven't seen my friends. I feel deprived of the joys of everyday life and robbed of my carefreeness, optimism, and creativity. And I'm anxious about whether I'll be able to make up for what I've lost. Next month I'm going to a concert for the first time in so long, and I feel scared.

As for my psychotherapy that I had started before the pandemic, I continued it online during the first lockdown.

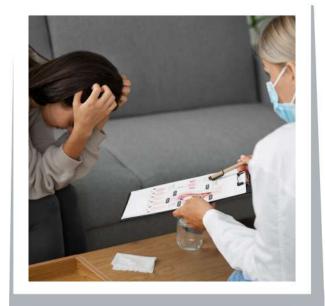
I was very uncomfortable and at the same time, I didn't have as much privacy at home as I would have liked. The therapist, for her part, was trying to make me experience the pandemicsmoothlyandwasthereformedespite all the difficulties, but that did not help me at all.

On the second lockdown, I was able to go to her office again, which made me feel great because I had the opportunity to get out of the house. We wore face masks and that bothered me. I didn't talk much, and she couldn't see my expressions, only the eye area, so I would verbally tell her the corresponding feeling I felt.

This helped me feel in control, that "I would allow you to see as far as I wanted you to see" since I had no control elsewhere. When I took the mask off, and she saw my expressions, I felt very exposed.

I didn't want to give her a hard time, but I didn't want to stop the therapy either. It's something I've been investing in for two and a half years now, and I can see a difference: it has empowered me and made me feel more relaxed about different issues."





### **Closing remarks**

For closure of the storytelling session, we used the practical assignment "Knowing about me" from "Module 4. Digital storytelling". We asked the storyteller to see different images of roads and paths and to select the one that best illustrates her own life path before and after the COVID-19 pandemic.



My life path before COVID-19.

Photo source: Pexels

"The options back then were very clear as shown in this picture where we see a sign and two specific paths one can follow. I would just have to choose between the two."



My life path after COVID-19. Photo source: Pexels

"Unlike the other pictures with round paths, this path looks like a snake. It is not stable or predictable in any way. The route/path is totally irregular and anomalous and I get sick in the road turns!"

### Media

In order to make the most of the digital storytelling technique we asked the participant to share media relating to her real-life story during the COVID-19 pandemic. The storyteller shared a picture taken from her mobile device during the lockdown period and a song from YouTube that she often heard at the time.



This is the view from the storyteller's balcony during the lockdown period. The following link leads to a Greek song titled "O Kipouros" ("The gardener") on YouYouTube:

https://www.youtube.com/watch?v=ASns-OeaPn0&t=28s

The performance comes from the artist Pavlos Pavlidis, and the storyteller stated that she felt the song expressed her feelings during the pandemic. Some of the lyrics are the following: "In the garden of my own loneliness some birds fly above the ashes left behind when the south wind stopped and sing to me, "love will come, love will come...".

Within the walls of my little prison someone reads the map of my palm sees the roads of my lost life and sings to me, "Love will come, love will come...".

> It will come one warm afternoon, all the light that there is it will enter this garden..."



KMOP Education Hub info.education-hub@kmop.org *Greece* education-hub.kmop.org

Germany

**BUPNET** swiemann@bupnet.de www.bupnet.eu

**Consulting Limited** United Kingdom

Canary Wharf koutavelis.e@canarywharf-consulting.com www.canarywharf-consulting.com

Sviluppo Creativo "Danilo Dolci" Italy

Centro per lo alberto.biondo@danilodolci.org www.danilodolci.org

Fundación INTRAS Spain

intras@intras.es Imd@intras.es www.intras.es

**KMOP Skopje** The Republic of North Macedonia

vasileska.k@kmop.org www.kmop.mk

KMOP Policy Centre policy-center@kmop.gr Belgium policy-center.kmop.org



















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