

# CLOWNING FOR PEOPLE WITH DEMENTIA AND CHILDREN WITH AUTISM

An external evaluation of “Clowning Connects Us”



# TABLE OF CONTENTS

<b>EXECUTIVE SUMMARY</b>	<b>6</b>
1. Introduction and methodology	12
1.1. Purpose and objectives of the evaluation	13
1.2. Project activities and structures	16
1.3. Evaluation methodology	18
2. Approaches and processes of ClowNexus	21
2.1. The journey of creating a shared vision for working together	22
2.2. The learning journey	24
2.3. The process of understanding and shaping co-creation	27
<b>PROJECT IMPACT</b>	<b>34</b>
3. Impact for the organisations and the artists	35
3.1. Impact for the organisations	37
3.2. Impact for artists	40
4. Impact for the target groups	46
4.1. General effects of healthcare clowning for both groups	47
4.2. Personal connection as key mechanism	48
4.3. Impact for older people with dementia	51
4.4. Impact for children with ASD	58
5. Impact for care, healthcare and pedagogical staff	62
6. Impact for the families of people with dementia and children with autism	67
7. Sustainability	71
8. Awareness of importance of clowning for external actors	74
9. Lessons learned and Recommendations	78

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- MaVida Park, Velden, Austria
- Medveščak Elderly Home, Zagreb, Croatia
- Park Elderly Home, Zagreb, Croatia
- New Children's Hospital, Helsinki, Finland
- Liinahaka Elderly home, Turku, Finland
- Emmi-Koti Home, Turku, Finland
- Pere Relats Foundation, Barcelona, Spain
- Vázsonyi Vilmos Idősek Otthona, Baross utcai telephely, Budapest, Hungary
- Bajka Kindergarten, Zagreb, Croatia (Josipa)
- Vilnius Šilas School, Vilnius, Lithuania
- Addere Care Elderly home, Vilnius, Lithuania
- Prizma Primary School and Kindergarten, Unified Methodological Institute for Special Education, Budapest, Hungary



## ABOUT THE EVALUATORS

The endline evaluation was undertaken by a team of three experts on behalf of Triskuel Research. **Ioana Popa** is an experienced evaluator and researcher, who also has formal training in psychology with a focus on emotion-centered therapy and wellbeing in organisations. **Irina Pop** is a senior expert with extensive experience in evaluating international development projects in multiple thematic areas.

**Diana Buluga** is a performing artist, cultural manager, and trainer in the use of art as therapy, with experience in developing and implementing artistic programmes for healthcare settings.

## GLOSSARY

**ASD** - autism spectrum disorder

**Efhco** - European Federation of Healthcare Clown Organizations

**HCIM** - Healthcare Clowning International Meeting

**PAR** - Participatory Action Research

**RNI** - RED NOSES Clowndoctors International



# Executive Summary

6

This report is a result of the endline evaluation of the “ClowNexus - Clowning Connects Us” project funded through the Creative Europe Programme and implemented by RED NOSES International, Verein ROTE NASEN Clowndoctors in Austria, Pallapupas in Spain, Crveni Nosevi Klaunovidoktori in Croatia, Piros Orr Bohocdoktorok Alapitvary in Hungary, Raudonos Nosys Gydytojai klounai in Lithuania, Sairaalaklovnit ry in Finland and Stichting CliniClowns in the Netherlands. The European Federation of Healthcare Clown Organizations (Efhco) is an associate partner of the project. The project had the following objectives:



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- **Vulnerable audiences benefit from art created with and for them.**
- **Healthcare clowning organisations and artists gain new skills and international connections.**
- **Cultural and social decision makers have increased awareness of the value of arts for wellbeing.**

The evaluation ran from June to October 2023 to consolidate learning across the countries involved and serve as an endline assessment compared against the baseline developed at the onset of ClowNexus. A mix of methodological approaches was deployed in line with the specific needs of each target group and the key evaluation questions.

## **THE TWO PILLARS OF THE PROJECT: LEARNING AND CO-CREATION**

In addition to working with two new groups of activity participants, older people with dementia and children with ASD, ClowNexus also introduced the project partner organisations and artists to new ways of learning and new processes of co-creation which have influenced the art and process of clowning for the artists involved, shifted organisational perspectives about working with institutions, and in general have had multiple implications for the target groups, their families, medical and educational staff and the arts and health field in general.

The learning journey was a succession of layers of expert information and insights, artistic workshops for testing, reflection and sharing of artistic tools, learning from direct work with the target groups, and then retracing the cycle of listening, reflecting, sharing and refining. From the beginning, the project proposed to experiment with co-creation - a collaborative approach where artists collaborate with beneficiaries, families, and cultural and healthcare workers to enhance the impact of artistic interventions on audience wellbeing. Co-creation took different forms in the different countries and, even though the process was challenging in certain contexts, it gave life to impressive results.

The shared curiosity of the group, nurtured by the philosophy behind the learning and co-creation processes, led them to create a "Co-creation Map" which describes steps to be taken, flexible scenarios and tools that can be adapted for each target group based on the context.

## **OVERALL PROJECT IMPACT**

From learning and using new approaches, to experimenting with new types of clowning processes, working with the target groups and developing shared goals with caregivers, the different elements of change in ClowNexus are linked in virtuous circles where one positive effect makes the others stronger. Consequently, the impact of ClowNexus is greater than the sum of its parts.

The evaluation findings show that the project's results significantly respond to all of the project objectives. The impact for the target groups is best aligned with the first objective of vulnerable audiences benefitting from art created with and for them. This is because, compared to previous ways of working for most of the partners, ClowNexus encouraged repeated visits with the same participants for longer periods of time, allowing for artists' techniques, relationships with care providers and eventually impacts to build up. For this reason, at the level of the target groups, effects are observable both in the short-term category and for the long-term, though the latter would need to be further supported by longitudinal research.

The layering of learning processes, reflection on clowning for the new audiences, and group sharing experiences have created a significant impact that goes beyond the second objective of adding skills and international connections for artists and healthcare clowning organisations.

In what concerns the influence of clowning for care providers, both staff and relatives, immediate effects are observable, particularly improved cooperation with people in need and clowns, and more positive emotions. Co-creation processes, in particular, and spending more time in the same institution have led to deeper cooperation with many care providers. However, these deeper processes have involved only a few caregivers or relatives, and to move from immediate effects for a few people to institutional impacts, it is necessary to have more dedicated exchanges with staff and families. The evaluation has identified examples of healthcare staff and pedagogues adopting humour and art into everyday practice. This suggests that the type of institutional impact sought is possible with intensified exchanges.

Based on evidence collected, we can't affirm that the project has had a systemic impact, such as policies that support greater access to humour and art. However, at the level of the partner institutions, some public authorities in project countries, as well as among new stakeholders from the fields of dementia and ASD, a greater understanding and awareness of the value of arts for wellbeing has been achieved. Not least, the project has shown that healthcare clowning can be effective in new settings and for target groups with different social needs. This provided healthcare clowns and organisations with motivation and a new way of developing artistic interventions that shifts the focus from established formats to the process of developing and adapting tools based on context and target group specificities.

## **IMPACT FOR ORGANISATIONS AND ARTISTS**

All partner organisations have increased capacity to work with people with dementia and children with ASD and more of the artists working for the partners have improved skills to work with these two target groups (average increase baseline to endline is from 46% to 75% for dementia and from 43% to 60% for ASD).

The project facilitated an increase in organizational capacity for all partners and contributed to the democratization of learning processes within the organisations. Notably, ClowNexus prompted the creation of dedicated programmes for target groups like children with ASD and people with dementia and strengthened relationships with institutions, establishing new partnerships and paving the way for enhanced collaboration, funding opportunities, and engagement with professional networks. Overall, ClowNexus has left participating organizations better prepared for future similar initiatives, resulting in an increase in organizational capacity.

The artists gained the knowledge and skills to improve the emotional wellbeing and social inclusion of people with dementia and children with ASD. The project helped them view their clowning in a new light with a deeper understanding of their discipline, tools, and skills. The project's impact extended beyond professional development, fostering personal growth, empathy, and a heightened sense of wellbeing among the artists. Additionally, the clowns gained a deeper understanding of the universal similarities between people, irrespective of their neurological conditions, fostering a desire for inclusivity and social justice that contributed to a more compassionate and inclusive approach to healthcare clowning.

## IMPACT FOR THE TARGET GROUPS

The connection that the clowns establish with people with dementia and children with autism creates the necessary framework for both short- and longer-term positive effects for both target groups.

SHORT-TERM	LONG-TERM
<ul style="list-style-type: none"> <li>➤ The clowns offer people with dementia and children with autism <b>the experience of positive emotions which can provide a relief from stress associated with the condition.</b></li> <li>➤ For older people with dementia, positive emotions take the shape of reduced apathy, sadness or agitation, a more joyful mood and even enthusiasm, better focus, and more physical movement. For children with autism who are in hospital settings for treatment or diagnosis, clowns provide relief from the stress and agitation induced by the medical procedures. In classroom settings children who get to experience the clowns repeatedly react with enthusiasm, curiosity, and joy, improving on their prior abilities to focus on others, express themselves and manage sensory stimulation.</li> <li>➤ Healthcare clowning has <b>an effect of social inclusion</b> providing both children with autism and people with dementia opportunities to interact with each other, staff, and relatives, and providing their families the rare chance to enjoy a performance with their loved ones, and to watch them enjoy something and be enjoyed by someone else.</li> </ul>	<ul style="list-style-type: none"> <li>➤ For both groups, <b>some long lasting effects include more acceptance and interest towards others, improved communication, and self-expression</b>, whether verbally or non-verbally through creativity and playfulness.</li> <li>➤ Caregivers also point to effects of increased self-worth and human dignity for both target groups. Children with ASD may increase confidence and strength during or after clown visits, which was associated with the horizontal relationship they developed with the clowns. The findings also suggest that <b>healthcare clowns can help persons with advanced dementia to retrieve or preserve their sense of self and to experience themselves as valuable persons</b>, which is of utmost importance in dementia care.</li> </ul>

## IMPACT FOR STAFF AND FAMILIES

MAIN TYPES OF EFFECTS FOR HEALTHCARE AND PEDAGOGICAL STAFF IN INSTITUTIONS	MAIN TYPES OF EFFECTS FOR FAMILY MEMBERS
<ul style="list-style-type: none"> <li>➤ Improved understanding of healthcare clowning for the target groups.</li> <li>➤ Closer communication and improved relationships between staff and family members.</li> <li>➤ Inspiration, adoption of humour and playfulness as methods to engage people with dementia and children with ASD.</li> <li>➤ Acquiring new information or perspectives about the beneficiaries.</li> <li>➤ Easier interaction with people with dementia and children with ASD.</li> <li>➤ Improved personal wellbeing at work.</li> </ul>	<ul style="list-style-type: none"> <li>➤ Experiencing gratitude for the joy and playfulness their loved one's experience.</li> <li>➤ Sharing a good moment and collecting good memories.</li> <li>➤ Improved understanding of dementia or ASD</li> <li>➤ Better communication and relationships between families and staff in institutions.</li> <li>➤ Parents of children with ASD are more relaxed in healthcare settings.</li> <li>➤ Parents can take pride and have hope.</li> <li>➤ Parents learn new techniques of interacting with the child.</li> <li>➤ Negative effects for parents of children with ASD: sadness when the child doesn't respond.</li> </ul>



# INTRODUCTION

## AND

# METHODOLOGY

# 1

## 1.1. PURPOSE AND OBJECTIVES OF THE EVALUATION

This report results from the endline evaluation of the “ClowNexus - Clowning Connects Us” project co-funded through the Creative Europe Programme of the European Union. ClowNexus aimed to promote and facilitate access to culture, cultural products, and artistic activities for people with dementia and children with ASD while enhancing the expertise of the European healthcare clowning sector. The project addressed the lack of artistic performances for people with dementia and children with ASD and focused on involving stakeholders such as families and carers in co-creation processes. The objectives of the project were to promote social inclusion, to build the capacity of organisations and artists in the European healthcare clown sector, to promote transnational mobility and internationalisation of artists and cultural managers, and to raise awareness of Arts for Health in Europe (more on the [project website](#)).

ClowNexus was implemented by RED NOSES International as project lead and seven partners. Six clowning organisations developed, actively tested and implemented new artistic formats and approaches in their programmes – ROTE NASEN Österreich (Austria), CRVENI NOSOVI (Croatia), Sairaalaklovnit (Finland), PIROS ORR (Hungary), RAUDONOS NOSYS (Lithuania), Pallapupas (Spain). Stichting CliniClowns Nederland (Netherlands) hosted and co-facilitated the Healthcare Clowning International Meeting (HCIM) in 2022 and coordinated a Participatory Action Research (PAR) project in cooperation with Leyden Academy on Vitality and Ageing. Also, the European Federation of Healthcare Clown Organizations (Efhco) was an associated partner that supported the project's dissemination activities and contributed to data collection for the baseline study.

### **OBJECTIVES OF THE EVALUATION:**

- ▶ Assessing the impact of ClowNexus, including but not limited to comparing the end-of-project values for indicators against the baseline. Indicators focus on the target groups and the capacity of artists and care institution staff to serve specific audiences, collaborate with others to learn, measure impact, and raise awareness of healthcare clowning and its benefits.
- ▶ Reflecting on the lessons learned due to ClowNexus' approaches focused on deep learning and co-creation, how these approaches have influenced the results for the target groups and their impact on the partners' ways of working.
- ▶ Providing recommendations to support the sustainability of the results achieved by ClowNexus.
- ▶ Consolidating understanding of what learning tools and activities were used and providing a nuanced picture of their effectiveness, relevance, and impact.





TYPES OF GROUPS ENGAGED BY THE PROJECT	EVALUATION FOCUS/ KEY QUESTIONS
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<b>Healthcare Clowning Organisations (Project partners)</b>	<ul style="list-style-type: none"> <li>▶ What worked best in terms of collaboration and learning processes?</li> <li>▶ What could be done differently?</li> <li>▶ What are the main lessons learned from Participatory Action Research?</li> <li>▶ How has learning been internalised in transferable formats?</li> </ul>
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<b>Artists / Healthcare Clowns</b>	<ul style="list-style-type: none"> <li>▶ What worked best and what could be done differently with regards to co-creation processes and piloted approaches?</li> <li>▶ Which elements of the learning process were most effective?</li> <li>▶ Which learning experiences were most valuable for the artists?</li> </ul>
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<b>Target groups (older people with dementia and children with ASD)</b>	<ul style="list-style-type: none"> <li>▶ What short-term and long-term effects has the project had for the wellbeing, life-quality and mental health of participating older people with dementia and children with ASD?</li> </ul>
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<b>Care staff of institutions for people with dementia and children with ASD</b>	<ul style="list-style-type: none"> <li>▶ How has the project influenced the relationships of care staff with older people with dementia/children with ASD and their families?</li> <li>▶ What effects has the project had on care staff's own work processes and personal wellbeing?</li> </ul>
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<b>Families of older people with dementia and families of children with ASD</b>	<ul style="list-style-type: none"> <li>▶ How has the project influenced the relationships between older people with dementia/children with ASD and family members?</li> <li>▶ What effects has the project had for relatives of older people with dementia/children with ASD?</li> </ul>
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<b>Decision Makers</b>	<ul style="list-style-type: none"> <li>▶ How has the project influenced the perspectives of decision makers within the partner institutions for people with dementia and children with ASD regarding the impact of healthcare clowning for the institution's processes, staff, beneficiaries?</li> </ul>
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Key evaluation questions were developed based on the terms of reference for the evaluation, evaluation needs and interests expressed by the members of the project teams from RNI and partners during inception interviews, and feedback from RNI's team supporting the evaluation.

## 1.2. PROJECT ACTIVITIES AND STRUCTURES

The project partners set out to address the problematic access of vulnerable people to arts interventions for wellbeing and decided to adapt their working methods to the needs of ASD children and older people with dementia. The project's activities were designed to bring together the artists, experts and audiences. The partners learned from each other's diverse experiences with the new audiences and capitalised on pre-existing contacts with special schools, medical facilities and homes for older people.

## MAIN CLOWNEXUS PROJECT ACTIVITIES (SEE DETAILED INFORMATION AND TIMELINE HERE)

<b>Learning and Research activities</b>	<ul style="list-style-type: none"> <li>▶ Baseline and Endline Studies</li> <li>▶ Development and trial of evaluation and learning tools</li> <li>▶ Participatory Action Research with residents with dementia in long-term facilities</li> <li>▶ Trainings within RED NOSES International School of Humour</li> </ul>
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<b>Clown visits - Piloting new artistic approaches in 6 countries</b>	<ul style="list-style-type: none"> <li>▶ Regular artistic interactions with children with ASD</li> <li>▶ Regular artistic interactions with older people with dementia</li> </ul>
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<b>6 Artistic laboratories in 6 countries</b>	<ul style="list-style-type: none"> <li>▶ 3 for working with children with ASD (Finland, Lithuania, Croatia)</li> <li>▶ 3 for working with older people with Dementia (Hungary, Spain, Austria)</li> </ul>
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<b>International exchange meetings</b>	<ul style="list-style-type: none"> <li>▶ Kick-off meeting</li> <li>▶ Healthcare Clowning International Meeting (HCIM)</li> <li>▶ Closing meeting</li> </ul>
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<b>Advocacy and awareness raising</b>	<ul style="list-style-type: none"> <li>▶ Presentation in an <a href="#">event in the European Parliament</a></li> <li>▶ Co-hosting <a href="#">event in Brussels on "Culture and Mental Health"</a> together with Culture Action Europe</li> <li>▶ Presentation at "<a href="#">Culture 4 Health</a>" Final Conference in Elefsina Greece</li> </ul>
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<b>Communication activities</b>	<ul style="list-style-type: none"> <li>▶ Documentary film and <a href="#">video portraits</a></li> <li>▶ Awareness campaign on World Alzheimer's Day</li> </ul>
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The project has established a comprehensive system of internal structures such as working groups for Project Managers and Artistic Responsibles (ARs) to facilitate effective coordination, communication and collaboration between partners. At the beginning of the project, a Learning Working Group was established to monitor and support learning processes and products. The artistic process was coordinated by artistic responsables from RNI and from the partners. The ARs in Hungary, Spain and Austria guided the learning about dementia, while the ARs in Finland, Lithuania, and Croatia guided the work on ASD.

The project lead team provided constructive and empowering support throughout the project, and their role in fostering links between all teams, maximising learning opportunities and creating a sense of community was much appreciated by the other partners. An online learning platform was developed for internal use of artists to document their learnings and share them with their peers.

The collaborative processes were based on nurturing the feeling of connectedness with the other organisations to better understand their work from the inside and create synergies, openness to see all perspectives and having a higher degree of trust, communication, and a willingness to embrace uncertainty in the creative process.

## 1.3. EVALUATION METHODOLOGY

### DATA COLLECTION

The evaluation employed a mix of methodological approaches in line with the specific needs of each target group and the key evaluation questions. The choice of methods has been sensitive to the nature of the project and target group. Other than research effectiveness and availability of stakeholders, the methods were chosen to be less intrusive, aiming to promote the wellbeing of everyone participating in or affected by the research process. Data collection instruments partly replicated or adapted tools designed in the baseline study (observation checklist, partner survey), and additional tools for data collection were developed.

METHODS	SOURCES AND TOOLS
<b>Review of project documentation and literature</b>	<ul style="list-style-type: none"> <li>▶ Project documentation and reports.</li> <li>▶ Literature provided by RNI and scoped by evaluators for validation of findings.</li> </ul>
<b>Thematic analysis of secondary sources (full list available in Annex 2)</b>	<ul style="list-style-type: none"> <li>▶ 17 video recordings (1 - 25 minutes) with testimonies and perspectives of artists, caregivers, and families.</li> <li>▶ 11 tools / spreadsheets of data with artistic tools and reports extracted from the online learning platform, collected from artists, project managers and artistic directors.</li> <li>▶ Reports and/or databases from research projects conducted during ClowNexus in Austria and Finland, with data recorded by project staff, artists, caregivers, relatives.</li> </ul>
<b>Endline Partner Survey</b>	<ul style="list-style-type: none"> <li>▶ Organisational level survey, adapted from baseline survey, mostly closed questions.</li> <li>▶ Answered by the 6 partners who implemented work with the target groups.</li> </ul>
<b>Interviews</b>	<ul style="list-style-type: none"> <li>▶ 26 interviews with clowns and artistic directors (roles sometimes overlap).</li> <li>▶ 9 interviews with project managers and learning managers.</li> <li>▶ 21 interviews with members of caregiving staff (of elderly homes, hospitals and educational institutions), of which 14 through direct interviews and 7 written interviews.</li> <li>▶ 4 interviews with other stakeholders (researchers, policy stakeholders).</li> </ul>
<b>Direct observation of clown visits</b>	<ul style="list-style-type: none"> <li>▶ 13 direct observation visits carried out in a total of 6 institutions in 5 countries, of which 12 were clown visits for people with dementia and 1 for children with ASD (visits in educational institutions limited because of summer).</li> <li>▶ The same observation form was used as in the baseline evaluation with small coding differences. The results were analysed both quantitatively (number of observations recorded) in comparison with the baseline indicators using Excel, and a qualitative thematic analysis was carried out for the type/description of effects observed.</li> </ul>

METHODS	SOURCES AND TOOLS
<b>Most Significant Change</b>	<ul style="list-style-type: none"> <li>▶ Testimonies about the most significant change were collected from caregivers and indirectly from a parent (offered during a radio interview). Testimonies were collected either in-person during interviews or through printed collection forms which were distributed and explained during in-person visits and then retrieved by email.</li> <li>▶ Most testimonies were provided by participants in their own language and translated.</li> <li>▶ The testimonies were grouped thematically and slightly edited, before being presented to project staff and artists during a workshop in Vienna in Sept. 2023, where the participants prioritised and analysed the stories together using a fishbowl technique.</li> </ul>

### ANALYSIS AND TRIANGULATION

Qualitative data from interviews, direct observation and secondary sources was analysed using thematic analysis. A coding tree for thematic analysis was first developed based on the key evaluation questions and relevant literature and refined with emerging findings during the process. Quantitative data from the survey and from the direct observation forms was analysed in comparison with quantitative data extracted from the baseline report. Throughout the analysis, the following measures were taken to ensure the reliability of findings:

- ▶ Triangulation between different sources: the data collection process and consequently the analysis were designed so that, in as much as possible, each key question would be answered from different types of sources: project staff, artists, caregivers, families, target groups, either through direct interviews and observation or, where primary data collection was not possible, by supplementing with available secondary data. Data sources used in the analysis are mentioned in the beginning of each impact chapter. The findings regarding the target groups are based on the greatest diversity of sources including direct observation of clown visits, interviews with staff, clowns, and secondary sources. Unless mentioned specifically as a single occurrence, all findings reported are based on multiple accounts not only from different people but also different categories of stakeholders. The only exceptions are the findings under "Impact for artists" which are based exclusively on interviews with artists and artistic directors, and where each finding is supported by more than three interviews. The different sources were also used to give weight to the findings in that findings which appeared more often and from more diverse sources were given more weight in the report.
- ▶ Verification with relevant literature: scientific literature from the fields of artistic interventions, dementia care and ASD were used both to develop the initial coding tree for thematic analysis, and to verify that emergent claims about findings have been identified in the wider research. While the relevant sources were not quoted and cited in the report for reasons of brevity, a list of the references consulted is provided in the annexes.

## LIMITATIONS

While efforts were made to ensure inclusive and participatory data collection from as many groups of stakeholders as possible, several constraints of timing, availability of stakeholders, and ethical considerations limited the possibilities for data collection.

The timing of the evaluation coincided with the summer period, which excluded the possibility of conducting field visits in schools and kindergartens and limited the availability of staff working with children for interviews. Given the fact that dementia visits were less affected by the summer break, there was disproportionately more data collected from the field which relates to dementia compared to ASD. Time constraints also did not make it possible to conduct ethical data collection with the target groups themselves. Family members were not present during the 12 dementia visits observed, and it was not possible to organise them outside the facilities. Family members were present during the ASD visit, but they were only observed and not interviewed directly for ethical considerations. Input from families has been analysed mostly via secondary data from research done by the organisations.

Comparisons between baseline and endline data should be interpreted in the context of several limitations. The baseline observations were collected in a total of 4 visits in 3 countries<sup>1</sup>, and the endline observations in a total of 12 visits in 5 countries. Neither of these constitutes a large number of observations to make inferences. There is also not enough information to assess the degree to which the observations were conducted with the same or different institutions and participants. Data collection instruments are prone to subjectivity when implemented by different observers as to what specific behaviour of a participant can be described as an effect in a certain category<sup>2</sup>. There was also variation in the duration of visits, number of participants in the room during the visit, moment of the day, number and frequency of previous clown visits with the same participants etc. Finally, the progressive nature of dementia affects comparisons of effects over time.

## VALIDATION

Following an initial data collection and analysis stage, some of the preliminary findings were validated during the project closing meeting in Vienna (Sept. 2023) through two workshops, one which was focused on the journey of the artists and a second which was focused on impact for the target groups from the perspective of caregivers presented through the Most Significant Change testimonies. A second presentation and validation session with project stakeholders was held online in November 2023.

<sup>1</sup>The baseline evaluation was carried out during the Covid-19 pandemic, which is why the observation in the baseline was carried out by project partner staff with remote guidance from the external evaluator.

<sup>2</sup>In the baseline evaluation the analysis of observation data combined the reactions included in the categories "Mood" and "Stress" into one single indicator called "Emotional status". In the endline the data was collected separately for the two indicators but for the sake of comparison the chart shows the average values for mood and stress combined.

# APPROACHES AND PROCESSES OF CLOWNEXUS



This project's widespread impact was catalysed by deliberately focusing on the learning journey, the exchange between the partners and taking steps to introduce co-creation as a natural part of clowning. To fully grasp the impact generated, it is important to look at the processes that shaped the project from the beginning. This chapter explores the most important overarching processes:

1. The journey of creating a shared vision for working together
2. The learning journey
3. The process of understanding and shaping co-creation

## 2.1. THE JOURNEY OF CREATING A SHARED VISION FOR WORKING TOGETHER

The creative process takes time to nurture the creativity of the artists and often involves many iterations that may seem chaotic but are part of the necessary storming phase that leads to embraced work. The combination of all these factors - the transnational nature of the project, the diversity of the institutions involved, and the development of artistic intervention tools for two specific audiences, which were new for many of the participants - resulted in the process of refinement of guidelines for work and agreement on conceptual approaches.

Many of the artists and project managers interviewed described the kick-off meeting as a moment of confusion and anxiety because they were unsure of what was expected of them, or because there was no common understanding of new concepts (such as co-creation) and what to expect at the end of the road. Many anticipated working on two formats developed specifically for each of the two target audiences but had difficulty understanding how that one format for each target group could be applied in the different national contexts.

With the necessary time and space to get to know each other's experiences and contexts, the group of artists and cultural managers involved in ClowNexus then moved in synchrony in an iterative process that no longer created confusion, but a desire to discover and build together.

” This is for me the biggest effect, not to create together, but to really listen to each other and allow ourselves to change. So, there are no holy cows, no crystal glasses, everything is touchable. (Artistic Responsible)

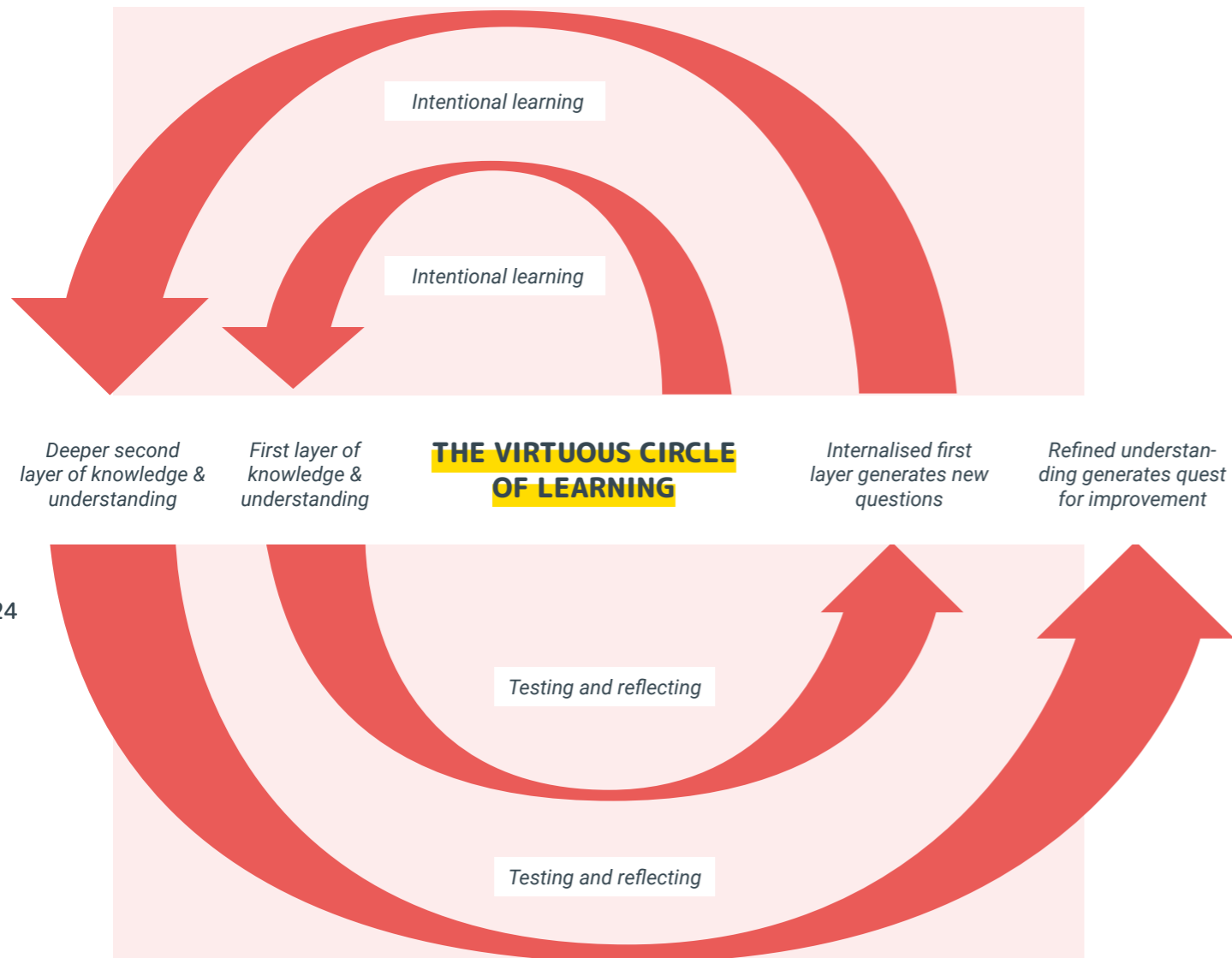
Once the partners let go of the expectation of a 'final common product', the focus moved from choosing and developing one common specific clown format to continually expanding the understanding of working with the target groups. This resulted in a set of flexible tools and scenarios which can be adapted to suit different contexts.

## 2.2. THE LEARNING JOURNEY

The learning journey in ClowNexus was a gradual process, initially focused on gathering and exchanging information, then delving deeper through testing, reflection, and sharing. As questions were answered, they transformed continuously. The participants involved in the learning process deconstructed topics and understood nuances, and their learning acquired progressively more meaning. For me the biggest learning was in the third laboratory, but it wouldn't have been possible without everything before which led to that. (Clown artist)

The learning pillar of ClowNexus wasn't just about specific learning instances; it was a transformative journey where each step potentiated the others, fostering a cycle of becoming and understanding.

” The learning pillar of ClowNexus wasn't just about specific learning instances; it was a transformative journey where each step potentiated the others, fostering a cycle of becoming and understanding.



The process of gathering knowledge and getting to know the realities of the two target groups was often compared in interviews to a 'deep dive'. Some found the process lengthy and demanding, but all came to value it as necessary to identify the artistic possibilities that would have the greatest impact.

WHAT MADE THE LEARNING PROCESS EFFICIENT AND EFFECTIVE	ACTIVITIES (details on the project website)
Relevant practical information and access to experts	<ul style="list-style-type: none"> <li>› Laboratories</li> <li>› Trainings</li> <li>› HCIM</li> </ul>
Hearing the voice of the target groups, families, and care staff	<ul style="list-style-type: none"> <li>› Laboratories</li> <li>› Co-creation</li> <li>› Artistic interventions</li> <li>› Participatory Action Research</li> </ul>
Learning from diversity and exchange	<ul style="list-style-type: none"> <li>› Laboratories</li> <li>› Project meetings</li> <li>› HCIM</li> </ul>
Time and space to test, gain insight and reflect	<ul style="list-style-type: none"> <li>› Laboratories</li> <li>› Transfer of knowledge</li> <li>› MEL tools</li> <li>› 3<sup>rd</sup> party observation</li> </ul>

Relevant practical information and access to experts from the fields of dementia and ASD were key to successful learning and creative discovery in ClowNexus. Workshops and artistic laboratories served as crucial links to experts in the early stages, providing insights into the realities and needs of the target groups. Later, they linked participants with practitioners who added nuances to enrich participants' knowledge. Discussions on themes like mourning and sorrow, examined in the laboratory in Barcelona, were recognised as important nuances that contributed to greater understanding of the needs of audiences such as people with dementia and their families. The participants were able to view dementia and autism from multiple angles by having access to new organisational viewpoints. The laboratories, alongside the trainings (e.g. the International School of Humour) and the HCIM, fostered a sense of belonging to a community of like-minded professionals.

After acquiring practical knowledge, ClowNexus added a crucial layer of information by incorporating **the voice of the target groups, families, and care staff** (more on this [here](#)). The artists found this experience to be "very revealing" as it assisted them in placing the experts' information within the everyday lives of individuals, moving beyond medical diagnoses. The interaction with care staff was considered particularly meaningful in gaining perspective. For the group working with children with ASD, meeting the mother of a child with autism during one of the laboratories was eye-opening for many of the artists in terms of understanding the need of children with ASD to be approached with openness and no expectations<sup>3</sup>.

<sup>3</sup>To learn more about the "don't demand" principle in practice, access the section "[Tools in practice](#)" on the ClowNexus website.

” ... The way she was saying „don't demand!“ when you go to the room and there is a kid with ASD, don't demand. I was thinking it was not only for kids with ASD, it is for everyone. (Clown artist)

Creating space for direct input from the target groups themselves was crucial to better understand the perspectives of the groups. Also, experiencing through play the world of target groups served as the foundation for other learnings, engaging the artists socially, emotionally, and cognitively.

**Learning from diversity and exchange** in an international context provided a valuable opportunity for artists. Beyond artistic collaboration, the international group exposed them to various healthcare clowning approaches, organisational priorities, and cultural conventions. Discovering similarities and differences inspired them and expanded their artistic borders, acted as a mirror for self-reflection and understanding their own work.

” The contact we made with our clown colleagues was very special and it gave me confidence - if this is how I feel with someone I don't know at all and he/she can give me this feeling of safety, love and warmth immediately, then the clowns can change the world. I will never forget those people. (Clown artist)

In ClowNexus, artists and cultural managers felt a personal connection to each other and a total acceptance and openness to each other's ideas. There were instances of synergy where the collaborative efforts seamlessly integrated the different voices and gave the project participants a sense of collective purpose.

The creative process included **time and space to test, gain insight and reflect**, giving artists the opportunity to analyse their own artistic practice. Testing the tools and information during clown visits was the next important layer. By taking time to test new methods and perspectives, the artists learned what thoughts and ideas look like in a real-life scenario. There was surprise that some methods actually work in practice, not only in theory, and new nuances were added of when to use certain methods and how to combine them.

During the laboratories when the artistic tools were first tested, before they were used with the target groups, reflection became an important layer in ClowNexus. The intentional design allowed artists, typically focused on the present moment, to step back and understand their actions. This proved invaluable, especially when integrating new tools and developing formats.

Self-reflection became ingrained in clown routines, facilitated by existing organizational tools and the monitoring and evaluation tools specifically developed during ClowNexus. Acting as an artist's diary, the Learning Platform aided artists in organising self-reflection, offering qualitative indicators of their artistic work. Detailed accounts and critical analyses shared with others, like neuropsychologists coordinating ASD diagnoses, provided valuable insights for both the artist and the institutional care staff in understanding a child's behavior and response.

The adoption of monitoring and evaluation tools varied among organisations. Some partners used the tools developed through ClowNexus extensively, while some organisations and artists found other outlets for reflection, such as mutual observation and reflection within an extended clown group. In some cases, reflection was facilitated by the presence of a person outside the clown duo who observed the

visit and participated in a subsequent debrief. Instances of observation and reflection by third parties provoked the artists to answer questions they wouldn't necessarily ask themselves and helped them to understand their craft and internalise growth. The homework assignments between the laboratories created the framework to facilitate this dialogue, which soon became a routine practice.

” Before ClowNexus, analysing our work meant: “What a good day!” - “Yes, it was a good day!” - “Ok, bye-bye!”. After ClowNexus, was it like - “What a good day! But why? What are we doing? Why are we doing it? And how do we do it?”. It is better than before. Before, we had intuition, but in time we went further. (Clown artist)

The last part was the reflection with the „clown family“ inside the labs.

” For me ClowNexus was not just about clowning for people with dementia, but also learning about clowning in general, and witnessing great clowning in the labs. It was so inspiring, to question what clowning can be. (Clown artist)

As a result of this learning process, the artists observed in themselves a change in their way of thinking and talking about clown work. The reflexive exchange, the learning focused on deconstructing concepts (rather than transfer of knowledge) and the trust inside the group made the artists dive deeper in understanding the basics of clowning.

### 2.3. THE PROCESS OF UNDERSTANDING AND SHAPING CO-CREATION

One of the key concepts around which the whole project plan has been built is co-creation - a collaborative approach where artists work with beneficiaries, families, cultural and healthcare workers to enhance the impact of artistic interventions on audience wellbeing. Emphasising collaboration, experimentation, inclusivity, audience engagement, and iterative processes, co-creation fosters genuine relations built on trust. In a medical, nursing, or educational setting, it transforms relationships between artists and institutional staff, and carefully accommodates beneficiaries and family members. Artists guide the creative process with expertise, while staff, family members and the audience themselves provide information about life events as well as feedback, informing the artistic process.<sup>4</sup>

When designing ClowNexus, the leading project team gave intentional space for co-creation and proposed it as an overarching approach to guide the work with the target groups. Initially the concept generated insecurities and questions. One concern was about the concept's distinction from existing practices of improvisation with beneficiaries, and it led to a new understanding of co-creation as occurring not just “in the moment”, but also in the “rehearsal room” and preparation phase. Another clarification concerned the potential to involve not only other artists in an artistic co-creation, but to also involve caregivers, families, and the beneficiaries.

<sup>4</sup>Weeseman Y, Scherer-Rath M, Christophe N, Dörr H, Bood ZM, Sprangers MAG, Helmich E, van Laarhoven HWM. Co-creative art processes with patients: A theoretical framework and qualitative study among artists. *PLoS One*. 2022 Apr 7;17(4):e0266401. doi: 10.1371/journal.pone.0266401. PMID: 35390040; PMCID: PMC8989196.

Even though, at times, the context did not allow a full co-creation process, the artists found ways to explain their work, gather insight from care staff and family members and involve them in creating targeted artistic interventions. These practices included:

**1. Debriefs with staff**

› Before and/or after the clown visits, to integrate the ideas and needs of the staff in their interventions and to discuss the observed changes.

**2. Background information about the beneficiaries**

› Before working with a group of beneficiaries, the clowns gathered relevant information about each person, to integrate in their play or to protect their mental wellbeing.

**3. Responding to staff requests for advice**

› As the communication with the medical staff improved, the health team sometimes asked clowns for advice when dealing with autistic children or older people with dementia or requested workshops where clowns can share their knowledge and approach.

**4. Exchanges with family members**

› Clown artists tried as much as possible to get feedback from the families of the target groups and to share with them the individual effects of clown techniques.  
› The best results were obtained when family members directly observed or participated in a clown visit.

The partners encountered several **challenges to co-creation** which were determined by the context rather than the actions of the artists and project managers, and which made co-creation work differently in practice:

› The challenges posed by the COVID-19 pandemic required rapid adaptation and creative solutions, especially when working with vulnerable groups such as the older people. Restrictions on in-person visits to care facilities led to the introduction of online visits, with only a few institutions initially equipped with the technology needed for online visits to happen. Despite the difficulties, the pandemic also created new opportunities and inspired the development, in collaboration with institutional carers, of new formats for engaging with older people, from online solutions to outdoor activities.

› The individual cognitive and communication particularities were a determinant in involving audiences into co-creating artistic formats.

› The physical presence of the families in the same space as the clowns or lack thereof was an obstacle to involve them in co-creation.

› The continuity of the work with the same beneficiaries influenced the level at which the artists can cooperate with family members, pedagogues and dedicated medical staff.

› Fluctuation in staff and, more importantly, in the person in charge of the liaison meant that some processes were stuck in the „establishment of contact“ phase.

› The more hierarchical layers there were in the care institutions, the more difficult it was to have all the relevant people on board with the co-creation process.

› During the project, some institutions closed wards where clown visits took place. In at least one case, the entire facility shut down.

› Differences in resources meant that some institutions were understaffed, and the artists had to form bonds with overworked and / or underpaid personnel who lacked the motivation or the energy to work with the artists, this in turn altering their attitudes toward clowning.

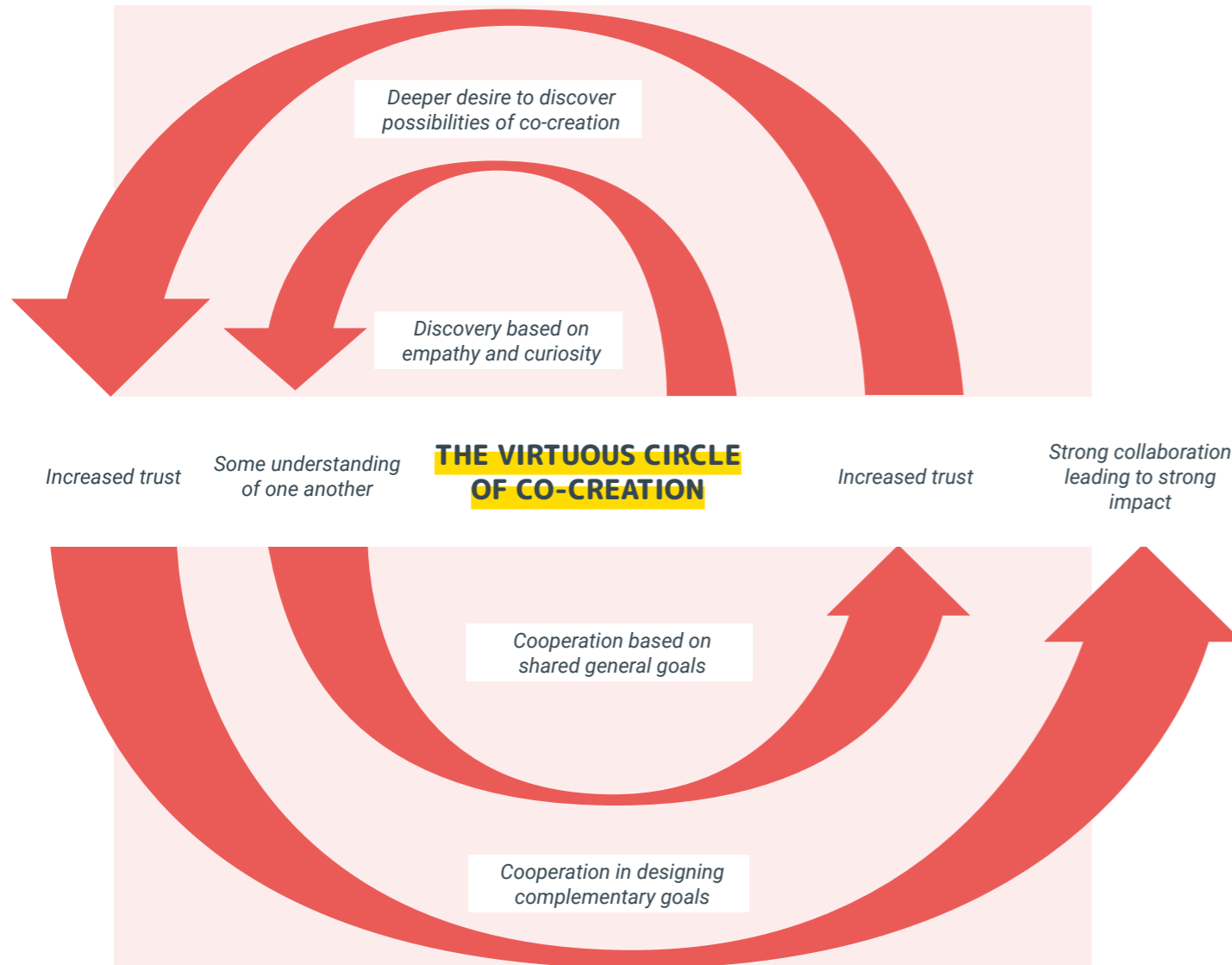
Despite encountering a variety of challenges to create full co-creation processes, the artists themselves and the organisations were surprised to discover a strong need and desire for this kind of collaboration.

” There was one nurse who was really, really hesitant. Her attitude was “I have to be a part of this project, because my manager has decided this, but I’m not sure at all about clowns yet”. And then at the end of the project, she was the biggest fan because she got to really understand the work and how they can help each other. (Clown artist)

The co-creation processes had a significant impact on relationships and facilitated the development of interventions that were responsive to the needs of the beneficiaries and considered the realities of the institutions and families. It was discovered that it worked better in organisations that already had a connection, while also enabling stronger connections in new organisations or with stakeholders that came for the first time in contact with healthcare clowning. Co-creation created a deeper understanding of clowning and stronger relationships, but in those institutions where there was limited understanding of the process and potential impact, co-creation was not necessarily desired.



One important lesson learnt was that co-creation is not transactional and the key lies not only in the institutional openness to clowning, but in a mutual curiosity to understand the reality of all participants, with the target groups in the centre. It is important to acknowledge that the caregivers have a difficult job and to be respectful of their work and start from an equal footing of curiosity. This realization shifted the approach of hesitant institutions and planted the seed for successful co-creation.



” Starting the cooperation with the institutions was not easy at the beginning. When we offered them a workshop (...) it was not easy to go over the fact that this is an extra time and effort from their side. We turned the process around and asked them to teach us (...) and they were happy to give us something for our improvement. After this it was already easier, because they became more and more curious. (Clown artist)

Where the context permitted, co-creation came to life with impressive results. Co-creation took different forms in the different countries depending on the artists’ perception of what it is, how it can be done and what can be achieved and, on the constraints, mentioned above.

**Finland**

- › Sairaalaklovnit tested and piloted new approaches in their work with children with ASD in different cities. The most elaborate and successful co-creation happened in the New Children’s Hospital in Helsinki, based on the long history of collaboration: Co-creation with medical staff supporting the diagnosis process gave the artists valuable insights into ASD and testing procedures.
- › A pilot programme where one clown artist accompanies one child and their family during the hospital stay.
- › Interventions to support medical staff in the testing.
- › A multi-sensorial play moment to facilitate observation of child’s behaviour in the testing context.

**Croatia**

- The artists developed the logic of their interventions for people with dementia by involving both the staff and the family members of the residents. This was possible through an extensive preparation:
- › The artists visited the elderly home without being in their clown costumes or characters and observed the interaction of the staff and the residents.
  - › Meeting with the family members to present the project. The families filled a questionnaire about the residents’ preferences and backgrounds.
  - › The artistic interventions were developed in connection to the profiles of the residents.
  - › Ongoing sharing with staff continued, the latter providing detailed notes on each resident’s progress and suggesting ways of working.

**Spain**

- For Pallapupas ClowNexus provided the opportunity to improve ways of working:
- › Pallapupas conducts a minimum of two visits per week in the same institution, fostering emotional connections between artists and people with dementia and allowing the artists to refine their practice.
  - › Before each visit, artists spend an hour with health facility staff for updates on any new developments concerning the residents visited. This enables personalised interventions based on current conditions.
  - › After each visit, artists record observed changes in a shared database, aiding institutional carers in monitoring patient progress.
  - › This collaboration resulted in a Dementia Care Mapping study during ClowNexus, which showed that the clowns elicited positive responses from participants and indicated success in working with advanced stages of dementia.

**Lithuania**

- In Lithuania, the co-creation process with ASD children had a more organic structure, evolving based on relationships between each pedagogue and the artists:
- › The artists visited mixed groups almost weekly. The groups were coordinated by different pedagogues each year, restarting the co-creation process.
  - › The clowns held initial meetings with pedagogues to understand each child’s characteristics and to agree on the timing and structure for visits.
  - › After each visit, detailed reviews with the pedagogical team occurred, discussing the activity, and gathering observations. With consent, teachers shared photos and videos with parents and passed on their feedback and observations to the clowns.

**Hungary**

- The clown visits for people with dementia are coordinated with the mental health professionals in the elderly homes. There has been constant communication on choice of artistic tools, and feedback discussions to evaluate the impact on the target group. A gradual engagement of family members with the artistic process was key to discover what works:
- › The artists made a common show for the residents and relatives but discovered that the residents interacted more freely without relatives present.
  - › The relatives were also invited to just observe the clown visit and then to be participants in a scenario around common household chores.
  - › Both visits were used as starting points for discussions of the experience with relatives and to provide space for them to share their own experiences and thoughts.

**Austria**

- In Austria, the programme for older people has a history of 20 years, but never really focused on dementia. ClowNexus created the opportunity to focus on this target group and to co-create with staff and family members:
- › Clown visits were frequently attended by a group of relatives, after which both staff and families completed observation forms.
  - › A focus group was organised with artists, staff, and family members to share ways of working and expectations.
  - › The organisation produced a booklet summarising the key findings and lessons learnt and presented them to staff and families.
  - › Although the artists worked closely with only a few family members, the relationship became close and the feedback from relatives about the positive changes in their parents’ behaviour and mood was invaluable for the artists to have a greater understanding of the clowning process and its effects.

**SOME EXAMPLES OF CO-CREATION WITH HEALTHCARE AND PEDAGOGICAL STAFF AND FAMILIES**



## PARTICIPATORY ACTION RESEARCH

Apart from the national co-creation processes, because of the exchange activities with experts interested in promoting the wellbeing of people with dementia, a new research activity - Participatory Action Research - was added to ClowNexus.

The research was coordinated by the Leyden Academy of Ageing and Vitality in collaboration with RED NOSES International, CliniClowns Netherlands, ROTE NASEN Clowndoctors in Austria and ROTE NASEN Deutschland. Core research groups were formed in three countries and focused on three participatory action research processes: one in the Netherlands in two care institutions, one in a care institution in Austria and one in Germany.

Each group involved artists, nursing and welfare staff and family members who met several times for approximately one year to define and work on the research questions through group conversations, video analysis, interviews with colleagues, focus group discussions or specific exercises. The discussions focused on the collaborative achievements of clowns and healthcare professionals and the sessions involved co-creation moments and increased understanding of the roles, common goals, and boundaries of collaboration.

The presence and history of clown visits varied per site. In Austria and Germany, clown visits appeared to be firmly established, while in The Netherlands, there were two sites with different scenarios. One site had a long-standing, favourable relationship with the clowns, while in the other, Amsterdam, the care staff lacked prior experience with clown visits. The PAR component of ClowNexus provided insights into how co-creation can affect relationship dynamics at various stages, and the influence that co-creation processes can exert on relationships over time.

### **Lessons learnt and perspectives on future co-creation approaches**

Based on interviews with those involved, in the dynamic world of ClowNexus, the concept of co-creation has proven to be transformative. Although not without challenges, co-creation has deeply impacted artists and organisations, and has convinced many of the potential for co-creation in future interventions.

1. Co-creation takes time. For the co-creation to reach its potential, time needs to be budgeted.
2. Co-creation is a process that needs to be coordinated. The artists should be an equal participant in a process of co-creation. At times, creating the necessary framework and facilitating the process might impede with the clarity and space artists need to participate in the process and, in some instances, this led to artists de-prioritising co-creation in their practice. In Austria, having a dedicated person in charge of managing the learning and research aspects greatly improved the effectiveness of co-creation processes.
3. Co-creation doesn't end, it reaches another phase. Co-creating has different stages. The initial stage involves transforming the environment from isolated units to a unified framework, forming a solid partnership that progresses towards a shared goal. This phase requires the most resources. Subsequently, regular co-creation activities take place within this framework, where goals and approaches are consistently negotiated and refined.

4. Co-creation creates the setting. Having a fertile setting for working together matters and this is what co-creation facilitates. Some organisations envision a change in future relationship building practices, others see a positive cost/benefit ratio just when working with a new target group. Either way, co-creation creates the framework for everyone involved to bring their share.

5. Co-creation is not a process meant to persuade, but it is an invitation to dance. Shared curiosity and openness for others are key, as you need to establish a relationship based on trust and let everyone in as equals.

6. Co-creation enhances impact for the target groups through partnership. While positive effects of clowning for the target groups have happened without co-creation, artists, staff, and family members alike indicate that co-creation has multiplied or deepened the effects.

7. Context matters. There are many variables that can make or break a true co-creation process. Clowning organisations and artists need to relieve themselves of the pressure of succeeding in co-creation to embrace its possibilities.

8. The possibilities of where co-creation with the target groups can lead are as diverse as the audience. Given the atypical cognitive and communicative abilities within the autism spectrum and the varying stages of dementia among the target groups addressed by ClowNexus, artists need to navigate a wide spectrum of possibilities for co-creation with the target groups.

9. Include family members in co-creation processes. Co-creation can become a powerful process when it gives space for needs and desires of family members, and allows common ground to increase impact for the beneficiaries.

10. Background information is relevant to understand the impact of clowning. Personalised discussions to understand the interventions in the personal context of each beneficiary can generate pivotal insights for the artists. While artists can interpret visible responses like laughter, relatives and staff can identify effects and their magnitude.

11. Confidence encourages the clown artist to take on the role of an equal partner. Enhanced relationships, knowledge, and hands-on experience increases the artists' confidence in engaging with staff and family members and taking more risks.

12. Discovering co-creation will go beyond ClowNexus. In exploring what the imagined future looks like for the artists and organisations involved in this project, we discovered clear plans to go deeper through co-creation, or just ideas about where to go. This forward-thinking approach reflects a collective determination to nurture and sustain the spirit of co-creation, ensuring a quest to increase the impact and relevance of artistic endeavours.

# Project Impact

In the section below we present the findings corresponding to the project's impact, grouped into chapters as follows:

- › **Chapter 3:** Impact for the organisations and artists
- › **Chapter 4:** Impact for the target groups: older people with dementia and children with ASD
- › **Chapter 5:** Impact for healthcare and pedagogical staff
- › **Chapter 6:** Impact for the families of people with dementia and children with autism

## IMPACT FOR THE ORGANISATIONS AND THE ARTISTS

## AT A GLANCE SOURCES FOR THIS CHAPTER

- Perceptions of 26 clowns and artistic directors and 8 project managers and learning managers captured through interviews.
- Direct observation by a third party (evaluators) - 13 instances of observation.
- Analysis of data recorded by clowns on the learning platform, narrative reports, secondary sources.

## KEY FINDINGS

ClowNexus inputs for organisations and artists	Impact for the artists	Impact for organisations
<ul style="list-style-type: none"> <li>▶ A complex and layered access to knowledge and understanding.</li> <li>▶ Diversity of experiences and perspectives.</li> <li>▶ Access to the voices of the target groups and their carers.</li> <li>▶ Space and time for testing, reflection, and self-reflection.</li> <li>▶ Working artistically with people with dementia and children with ASD.</li> <li>▶ Democratization of the learning process inside organisations.</li> <li>▶ A community of peers.</li> </ul>	<ul style="list-style-type: none"> <li>▶ New tools and skills.</li> <li>▶ Self-awareness and rediscovery of the clown.</li> <li>▶ A greater appreciation of cultural diversity and increase in cultural competence.</li> <li>▶ A multi-dimensional understanding of the target groups' universe.</li> <li>▶ Bravery and increased confidence and sense of competence.</li> <li>▶ Clarification of professional and personal values.</li> <li>▶ Internalising the importance for reflection and self-reflection.</li> <li>▶ Affective wellbeing of the artists.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Strong connections among participating organisations.</li> <li>▶ Enhanced organisational capacity, both at the management level and for the artistic teams.</li> <li>▶ Validation and acknowledgement of their self-worth as an organisation.</li> <li>▶ New organisational objectives, new formats and approaches.</li> <li>▶ Increase in expertise in working with ASD and dementia.</li> <li>▶ Dedicated programmes for the two target groups.</li> <li>▶ New institutional partners, strengthened relationships with different stakeholders, new funding opportunities and new donors.</li> </ul>

For both the artists and the organisations involved, ClowNexus has been a vehicle for growth and learning. The project facilitated an increase in organisational capacity for all partners and contributed to the democratisation of learning processes within the organisations. Notably, ClowNexus prompted the creation of dedicated programmes for the two target groups and strengthened relationships with institutions, establishing new partnerships and paving the way for enhanced collaboration, funding opportunities, and engagement with professional networks. Overall, ClowNexus has left participating organisations better prepared for future similar initiatives, resulting in a qualitative increase in organisational capacity.

The artists gained the knowledge and skills to improve the wellbeing and emotional health of people with dementia and children with ASD and helped them put their entire clowning in a new light reaching a deeper understanding of their discipline, tools, and skills. The project's impact extended beyond professional development, fostering personal growth, empathy, and a heightened sense of wellbeing among the artists. Additionally, the clowns gained a deeper understanding of the universal similarities between people, irrespective of their neurological conditions, fostering a desire for inclusivity and social justice that contributed to a more compassionate and inclusive approach to healthcare clowning.

The project also proved that clowning can be effective in new settings, dispelling initial concerns within partner institutions about the effect of clowning for children with ASD or people with dementia. This provided ClowNexus partner organisations with increased motivation and a new way of developing artistic interventions beyond specific conditions, shifting the focus from the format to the process of adapting interventions.

## 3.1 IMPACT FOR THE ORGANISATIONS

### IMPROVED CAPACITY

Organisational learning primarily occurred through consortium partner exchanges, bringing diverse experiences and different approaches.

ClowNexus has fostered **strong connections** among participating organisations. International collaboration, notably with non-RED NOSES network organisations like Pallapupas and Sairaalaklovnit, added value by offering fresh perspectives and sharing unique practices. The collaboration with Finland and Spain was particularly fruitful, introducing new work ties, expertise, and new viewpoints. For instance, Austria and Finland's approach of employing artists as full-time clowns sparked discussions on work balance and organisational development. Simultaneously, ties within RED NOSES strengthened, creating a sense of a unified professional and personal family among ClowNexus participants. Regular communication among members facilitated mutual advice and support, exemplified by Croatia assisting Austria with a networking workshop. Furthermore, organisations became more open to collaboration with other NGOs, artists, and experts, promoting knowledge-sharing and a more robust collective impact.

For organisations new to European projects, ClowNexus brought a two-fold **understanding of the complexity of such projects and increased capacity to run international events**.

” I think that although the project was challenging with all the reporting and organising especially during Covid, in the future it would be a lot easier for us as an organisation to participate in a European project or even initiate one. (Project manager)

An enhanced organisational capacity reported by most partners resulted from the coordination approach of the leading project team by intentionally granting partners ownership of their processes and encouraging an itinerant organisation of laboratories. While organising their first major international event was initially daunting, it empowered participants to showcase local work and establish connections with local experts and created greater capacity within the national organisations.

The project also had an effect of **validation and building the organisations' self-esteem**. By putting their work and methods side by side with those of other countries, the participating organisations understood they have a lot of value in the experience they can share with the others.

ClowNexus had the effect on an organisational level of **increasing knowledge about healthcare clowning** for the two groups. This was done through the artists representing the organisations, but also by creating **pathways for transfer of knowledge** to the other members of the respective organisations. The democratisation of the learning process inside the team of ClowNexus was carefully embedded in a way of working, so that more people from the organisations have access to it, not only the artists directly involved in the visits.

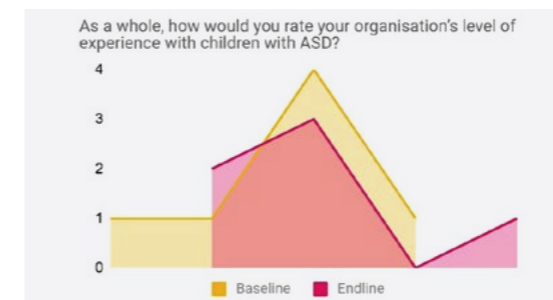
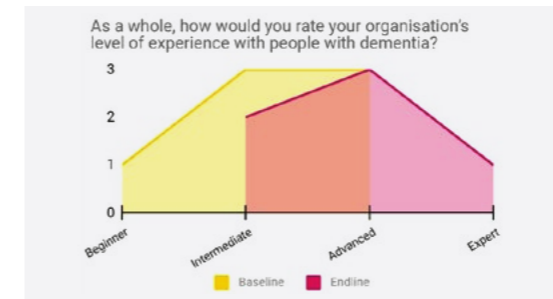
The internal processes of each organisation - reports, local/regional/national workshops, using regional multipliers, dissemination events, national camps - ensured a **robust sharing of experiences and learning**. Organising the laboratories or other activities (e.g., the multiplier workshops) at national level had a significant impact on those artists and members of the organisations who were not directly involved in ClowNexus as it provided an opportunity for the entire organisation to participate in the project activities. This extended the number of artists who can work with the two target groups and the common learning had an impact also in other programmes of the organisations. While sharing information within the national organisation had some limitations (e.g., comprising a lot of information in short transfer sessions) and occasionally left responsible individuals feeling overwhelmed, conducting these sessions empowered those involved in ClowNexus.

### NEW FORMATS AND APPROACHES FOR VULNERABLE TARGET GROUPS

Almost all the partner organisations had worked with the two target groups before but did not have specific interventions to respond to the specific needs of the target groups. Children with ASD (even those visited in neurological wards) were met in the same way as the other children encountered in the hospital or in programmes like Caravan Orchestra in schools. People with dementia were present during visits in elderly homes, but the organisations did not have dedicated programmes. So, for many of the organisations, ClowNexus marked the beginning of dedicated programmes for the two target groups, and for all organisations that did clown visits during ClowNexus it also shaped how future programming will look like.

Changes in the way of working as a result of the work inside ClowNexus resulted in new formats and approaches for the partner organisations. For Pallapupas, ClowNexus provided a platform to delve deeper into the work with dementia and has given this work more weight in the organisation. In the case of Sairaalaklovnit, ClowNexus was the very beginning of working with residents in elderly homes and the determining factor that helped them expand their scope of work as an organisation. Before this project, their work was only with children. As part of ClowNexus they began pilot visits with older people in care homes in Helsinki, Turku and another city and soon after they received funding to continue their work with older people on a weekly basis, in 5 cities, for 3 more years. For working with children with ASD, the Finnish organisation also tested a pilot activity - accompanying the child during the diagnosis, one clown to one child and introducing a short multisensorial performance for ASD children. The Lithuanian organisation has created a performance based on the experience of working with children with ASD in ClowNexus. In Austria, there are new formats like artistic interventions within the daily nursing care. There are many more examples and overall, the number of new formats and **artistic tools** available to organisations has increased, but the biggest impact may be the shift towards a new way of working, where the focus is on **scenarios** combining different artistic tools adapted to each context.

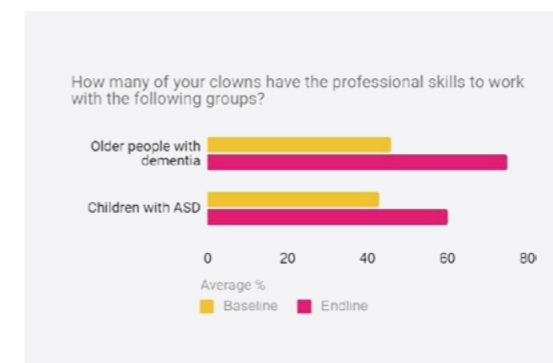
In general, all six partners who worked directly with the target groups in the project evaluate their organisational level of experience as higher now compared to the baseline, having started at different levels.



Even though the quantitative shift at organisational level seems relatively modest (in general one level of expertise upwards), what the qualitative evaluation has revealed is that in qualitative terms - methods, understanding of needs, expertise of clowns - there was a **substantial increase in expertise in working with ASD and dementia for each organisation**.

The increase in the overall perceived level of experience in working with these two target groups is also consistent with an increase in the number of artists who have the skills to work with both target groups from the beginning of the project to the end (expressed as a percentage of the artists working for the organisation).

The first partner survey in the baseline evaluation also identified a number of specific challenges faced by the partners in working with the target groups. Access to funding and donor support were the most widely identified challenges. Difficulties were also identified in finding the right artistic formats and relationships with relevant institutions, particularly for working with children with ASD. In the endline evaluation, the partners were asked which of the initial challenges had improved significantly as a result of the project. All the organisations consider they had significantly overcome most of the initial difficulties, with access to institutions and donor support proving to be more pervasive challenges for about half of the partners.



### NEW STAKEHOLDERS AND STRONGER PARTNERSHIP CONNECTIONS

ClowNexus had a significant impact in strengthening the relationships with the healthcare and educational institutions where the organisations were already present, based on the experience and expertise the artists accumulated during the project and the role that they took in specifically addressing the needs of the target groups.

“ This project has helped us to go one step forward into creating quality standards and being perceived as professionals and essentials in elderly homes and hospitals for the patients, families and care staff. (Project manager)

The **co-creation process** also resulted in increased confidence the artists have in these institutional relationships and the reciprocity of the bond. The sharing of information with the institutions allowed artists to complement the care process, leading to more trust and a solidified relationship that moved the perspective from “service provider” to “partner”. This has led to actual changes in how healthcare institutions integrate the participation of the clowning organisation in their work.

<sup>5</sup> [https://www.rednoses.org/fileadmin/international/4\\_What\\_we\\_do/3\\_Scientific\\_Research/Children\\_with\\_disabilities\\_programme\\_evaluation.pdf](https://www.rednoses.org/fileadmin/international/4_What_we_do/3_Scientific_Research/Children_with_disabilities_programme_evaluation.pdf)

For example, in one ward with children with more prominent challenges, the clowns were allowed to pass the glass wall that was initially the barrier between the children and the clown. In another hospital, the clowns now have access to more previous information about each child, always in respect with data protection and privacy law.

In addition to stronger relationships with the institutions the organisations previously worked with, ClowNexus brought **new institutional partners for the healthcare clowning organisations**. These included new elderly homes or special education institutions working with children with ASD, but also associations specialised in dementia and Alzheimer, public policy or academic departments focused on social care. Through activities such as the International Learning Laboratories or HCIM, the organisations reached new professional networks, started cooperations with experts in the field, other NGOs and opened new connections with social care as well as the arts and health field. The innovative work done under the umbrella of the project also opened pathways of collaboration with academia, [national institutes](#) and long-term connections with researchers.

Changes in the dynamics with institutional partners meant also **new funding opportunities and new institutional/public donors** for the organisations, especially in Finland. This was a direct result of the efforts to find co-financing for the activities in ClowNexus or a result of the evidence of their expertise and impact gained through ClowNexus.

### 3.2. IMPACT FOR ARTISTS

#### PROFESSIONAL GROWTH

Clowns used their creativity to deliver engaging interventions for the target groups. ClowNexus has provided an optimal framework for the artists to learn **new artistic tools and skills**. Artistic techniques fit for the specific audiences with dementia or ASD were proposed and tried out by groups of artists in the international learning laboratories. The artists then tested those techniques in their own work with the target groups and adapted them to best suit the context and the needs of the audiences.

**More information about the specific tools and how they can be used for the target groups is available on the project website in the [Artistic Tools section](#).**

#### ARTISTIC TOOLS FOR PEOPLE WITH DEMENTIA AND CHILDREN WITH ASD DEVELOPED OR TESTED IN CLOWNEXUS

<b>Music</b> <b>Dancing</b> <b>Playing with sound</b>	<b>Roleplay</b> <b>Storytelling</b> <b>Using space</b>	<b>Senses</b> <b>Movement</b> <b>Creating with objects</b>
-------------------------------------------------------------	--------------------------------------------------------------	------------------------------------------------------------------

For many artists, ClowNexus was their first opportunity to work on a large-scale, long-term project with a culturally diverse group of healthcare clowning organisations and artists. The pooling and sharing of artistic and creative resources was invaluable to the development of the artists, who emphasised that the exchange and collaborative work broadened their horizons and gave them the opportunity to explore many artistic tools, skills, and approaches. As a result, artists borrowed different methodologies from each other, tested them and, at times, adapted them to suit their contexts.

The longer time allocated in ClowNexus for preparation, reflection and testing fostered a deeper understanding and appropriation of these techniques by the artists involved.

The project also provided many opportunities to learn from experts, target groups, medical and educational staff and families, which gave the artists **a multi-dimensional understanding of the target groups' universe**. Spending time with older people with dementia and children with ASD and their carers gave artists the opportunity to observe and pay attention to emotional states and reactions, feel the mood, assess the appropriateness of their interventions, adapt as necessary and create specific artistic content. Time spent together also facilitated the establishment of a trustful relationship, essential for creating a safe and comfortable environment in which the artists and beneficiaries could develop the strong connection which acts a foundation for positive effects for the target groups. This **allocation of time** was seen by the artists as a precious gift, both for the target groups and for themselves.

” I want them [older people with dementia] to feel that when we come here, this is something we choose to do. We want to be here. “I see you right now and I will stay here as long as you need me.” (Clown artist)

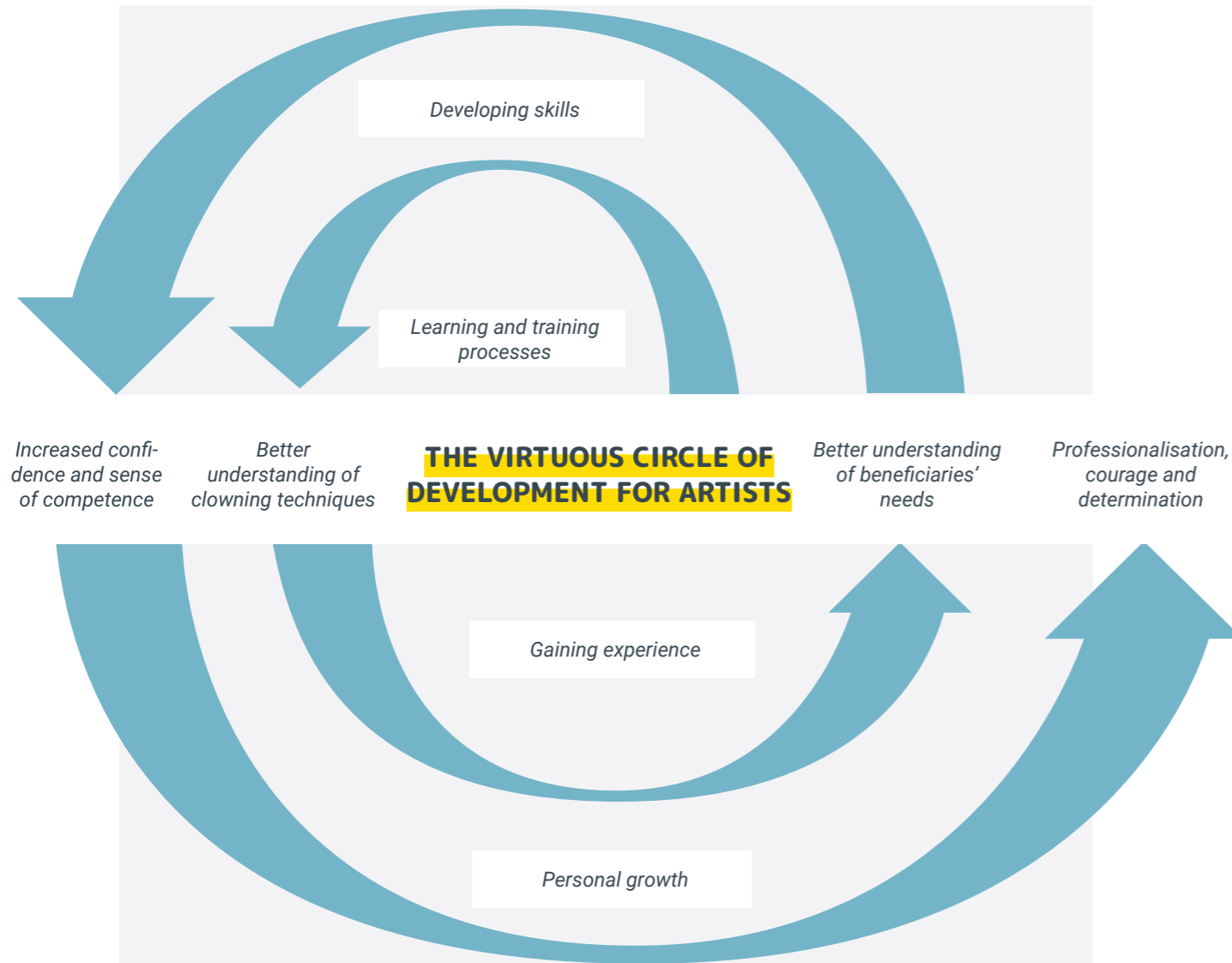
Comparing interventions for people with dementia and those for children with autism, both of which are neurological conditions, artists found out that many of the artistic techniques used are interchangeable or similar - music, physicality, mirroring and imitation, the use of objects and so on. However, in working directly with the two audiences, the artists understood the similarities and differences between them, as well as the many nuances within the autism spectrum and among dementia conditions, and **learned to adapt their pace, energy, and approaches based on the specific needs of their audience**. Clowns discovered the language of their audiences and took the time to learn ways of intervention personalised to the specific needs of the beneficiaries.

Clowning for older individuals with dementia occurred particularly in residential elderly homes, where most residents are in moderate to advanced stages of dementia. Here, the artists adapted to a slower rhythm and provided clear communication due to potential confusion or anxiety. Direct contact and closeness, such as hugging, were often effective. In dementia care, music fostered social acceptance and empathy, with clowns incorporating familiar tunes to evoke positive emotions. Storytelling enhanced communication and emotional expression, while physical movement and mirroring techniques created connections and empathy.

Conversely, working with children demands a quicker pace and more active engagement, as they tend to move rapidly and may lose interest easily. Children with autism benefitted from clowns employing mirroring, movement, and sensory tools to establish connections. Playing with objects and sensory stimuli aided self-regulation, and social stories helped prepare children for clowning activities, reducing anxiety, and increasing engagement. Music and sound further contributed to language development and non-verbal expression for children with ASD.

” A valuable learning is that even if they are called “a vulnerable audience” that doesn't mean they need to be treated like butterflies. You can shake them a little bit, they want to be shaken, actually they want the same thing that we want. (Artistic Responsible)

Many of the artists directly involved in the ClowNexus project have run workshops for colleagues in their organisations or other groups of artists, sharing their knowledge and experience and the artists said that this role **increased their confidence and sense of competence**. Explaining concepts and techniques to others helped the artists to better organise their thoughts and gain clarity in their understanding of the work.



### CHANGES IN THE ARTISTS' RELATIONSHIP WITH THEIR OWN CLOWN CHARACTER

The learning experiences in ClowNexus, layered with direct experience with the target groups, helped the artists to create a proper space for analysis and reflection of their work and of clowning in general. Compared to previous interventions, ClowNexus encouraged artists to deconstruct their artistic practices, clarified methodologies by putting them into words, and cultivated a conscious perception of the importance of their work.

Working artistically with the two target groups has proved to be an inspiring and eye-opening journey of **self-awareness and rediscovery of the clown**. The artists involved described it as a remarkable experience to put the inner world of the clown under the microscope.

” It touched my essential meaning and being. What is a clown? Who is my clown? Who am I as a clown? What do we want, why do I go to them as a clown, why would they need me, what is the purpose of going there? (Clown artist)

For most clowns, self-awareness meant returning to basics, remembering how to be fully present, and having “a million antennas” to listen to. Rediscovering the clown involved a deeper exploration of creative capacities and approaches, encouraging artists to innovate, take risks and find new ways to relate to their audiences.

### THE CLOWN IS FREE

**The clown is free** is a core concept in the art of clowning, highlighting a state of creative and emotional liberation. Clowns can express themselves authentically, without restraint or self-censorship.

*In my clown character, I have the freedom to open doors and to go in places and have the right to be there, because I'm really curious, I'm open, I'm not stuck to any social standards and hierarchies, I can just go in between. I see everything and I can put myself in the position of a child, of the parents, I can put myself on the side of the staff, the doctor, the cleaning person, the visitors, the people who push the beds. I look instinctively at the human part of playfulness and childishness. This is what I like and what I am able to do. (Clown artist)*

**Vulnerability.** A free clown is emotionally vulnerable and open to experiencing and revealing a broad spectrum of emotions, from joy and laughter to sadness and fragility. They don't hide behind masks but embrace, understand, and accept their feelings. Connecting with a beneficiary can only happen when one knows their strengths and weaknesses. This state of mind has the beautiful advantage of letting emotions flow during a visit.

**Playfulness and spontaneity.** Play is a significant element of clowning; a free clown embraces life with playfulness and curiosity. They embrace play as a way of engaging with the world and encourage others to play. A free clown can respond spontaneously to the present moment. They improvise, play, and explore, leading them to unexpected and delightful interactions. The importance of the here and now, when working with people with dementia and autism, focuses on the importance of being fully present and engaged in the actual moment during interactions.

**Non-judgment.** Free clowns don't judge others or themselves. They accept their imperfections as well as those of the people they meet. This non-judgmental attitude creates a safe and inclusive space that encourages people to let their guard down. From this lack of judgment, they can get on the same level as the person in front of them, and labels such as dementia or autism disappear, allowing honest communication to occur.

**Fearlessness.** A free clown is fearless in their work approach. They are prepared to take risks, make mistakes, and face challenges with resilience and a healthy sense of humour. Consciousness, planning, talking, preparing, and knowing the structure are essential parts of the artists' work, but when the red nose is on, clowns must let it all go and act without fear, knowing that all the knowledge is in the background. ClowNexus gave the artists the necessary experience and practice to be free in their clowning.

One of the most important effects of the work with these two target groups was the realisation that the clown should have no expectations in relation to the outcomes of the visit. By **letting go of expectations**, clowns created a space where older people with dementia and children with ASD felt at ease and had the freedom to respond in a way that best suits their needs and emotional condition, ultimately contributing to a positive experience.

” *We connect because we don't expect anything. They can just be themselves however they want, and we are in the perfect middle ground - we are still adults, but we are in for the fun so they can play with us. (Clown artist)*

One of the effects of ClowNexus for the artists was **the realisation of the importance for reflection and self-reflection**, which helps artists adapt their approach to the needs of participants and leads the artist to **a better understanding of the self**, directly impacting the quality of their work with vulnerable groups. Often working in unpredictable and challenging environments, the artists became more adaptable and more able to solve problems and respond quickly to changing circumstances or defuse tensions through humour and empathy.

Confident in their ability to act in all circumstances and with sufficient knowledge of the context in which they were working, the artists **felt brave to take risks**, accepting uncertainty. They were no longer discouraged or frightened by moments of low engagement, for example, but remained open to move forward with spontaneity and intuition.

By taking risks and seeing where they lead them, the artists involved in ClowNexus had the opportunity to see their work in a different light. The vast majority of the artists interviewed said that, as a result of ClowNexus, **they are more confident in themselves and value their work more**.

” *In my clown character, I have the freedom to open doors and to go in places and have the right to be there, because I'm really curious, I'm open, I'm not stuck to any social standards and hierarchies, I can just go in between. I see everything and I can put myself in the position of a child, of the parents, I can put myself on the side of the staff, the doctor, the cleaning person, the visitors, the people who push the beds. This is what I like and what I am able to do. (Clown artist)*

## PERSONAL GROWTH AND WELLBEING

Interaction with people with dementia or autism provided the clowns with an empathetic understanding of the challenges of these two groups, but it also highlighted the very basic and universal similarities between people regardless of their neurological condition and cognitive abilities. Working with new audiences helped the artists become more **culturally competent**, acknowledge their own biases, and have a greater appreciation of cultural diversity.

Empathy allowed the artists to understand and share the feelings and experiences of those with whom they interacted, fostering a sense of trust and connection. For instance, the artists often reported that after a few visits they were forgetting that the children they were playing with had ASD.

” *We are not so different. In some way, we are all the same. And we are all looking for love and acceptance. (Clown artist)*

**These empathetic interactions instilled an important sense of social justice in the artists**, reflecting what they had also heard from disability rights activists before: that it is not that these groups have special needs, but that society is failing to create the conditions and opportunities to fully allow them to participate. ClowNexus has put the spotlight on two groups whose voices often do not have the power to be heard on their own, are under-represented in the public sphere and often excluded from society. One of the recurring issues identified in discussions with the artists was a desire to do more for these groups and for society to become more inclusive. Many artists have expressed a wish to use their unique skills to raise public awareness, promote acceptance and inspire meaningful change.

Being challenged to embrace self-awareness and reflect on their motivation or purpose **helped the artists ensure that their work aligns with their personal values and aspirations**. Viewing time as a gift when working with special audiences reflects a value-based, human-centred, and empathetic approach that recognises the inherent worth of every individual and underlines the importance of providing meaningful and compassionate interventions with a positive impact on wellbeing.

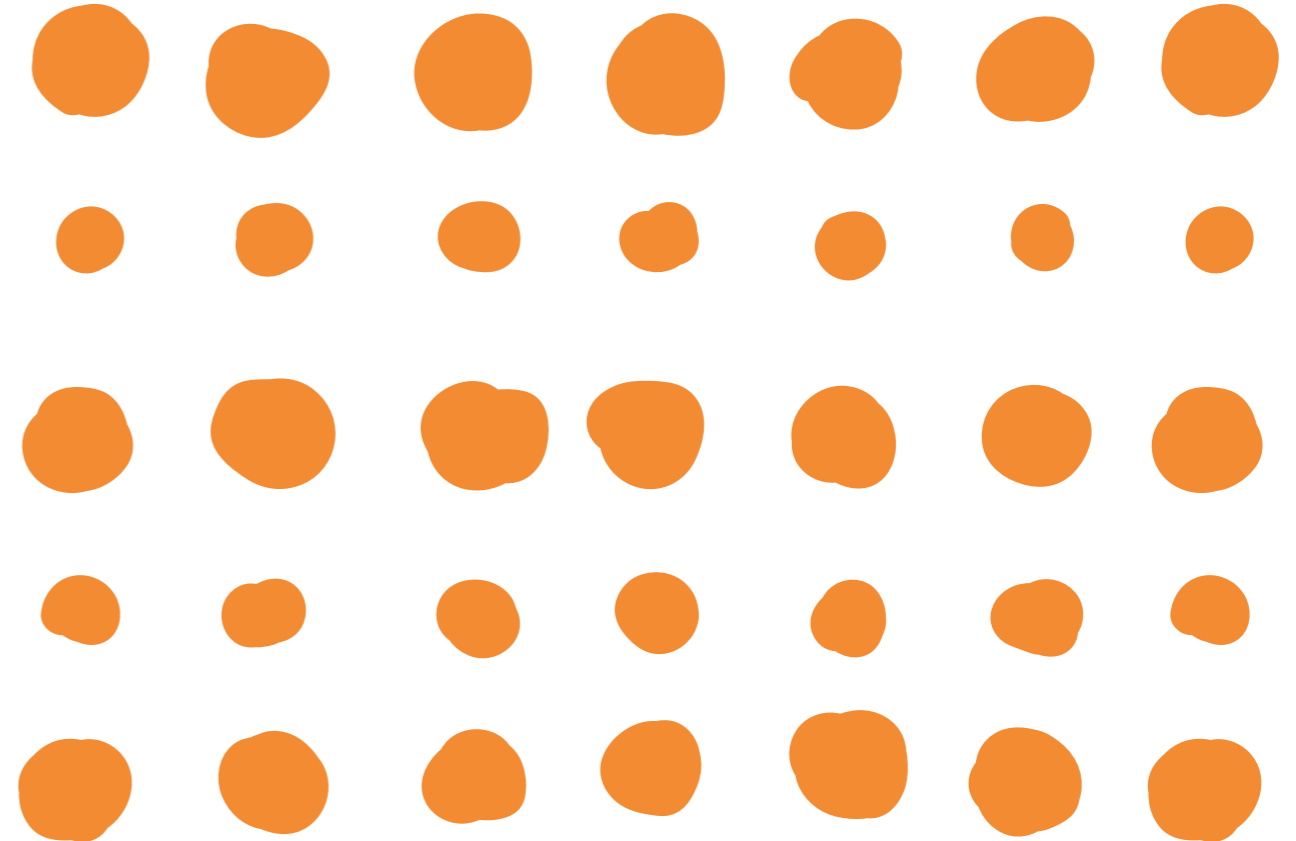
Last, but not least, **ClowNexus protected the affective wellbeing of the artists**. The strong sense of belonging to a community was an important protective factor for the artists' wellbeing, especially in the context of the pandemic. Working in vulnerable environments can take a toll and seeking peer support and debriefing helped to cope with these challenges. Also, the changes they made in their clowning and in the relationships with the institutions and other stakeholders created an enabling environment for the clown artists' self-discovery. The pressure to succeed in relation to the person in front of you can cause clowns to feel stressed and anxious, affecting both their professional and personal wellbeing. Letting go of expectations allowed clowns to be present and flexible in their interactions, reducing the fear of disappointment. Also, becoming braver, they now approach their work with more self-worth.





# 4

## IMPACT FOR THE TARGET GROUPS



### 4.1. General effects of healthcare clowning for both groups

In the short term, **the clowns offered people with dementia and children with autism the experience of positive emotions and the safe space to be as they are, resulting in relief from stress associated with the condition.** This finding holds true for both target groups as confirmed by a multitude of different sources in the evaluation. Nonetheless, the precise nature of the changes and the mechanisms that trigger them may differ not only across the target groups but also for the same group in different contexts or stages of the condition. For older people with dementia, positive emotions took the shape of reduced apathy, sadness or agitation, a more joyful mood and even enthusiasm, better focus, and more physical movement. For children with autism in hospital settings for treatment or diagnosis, clowns provided relief from the stress and agitation induced by the medical procedures, and the possibility to have a positive experience in the hospital. In classroom settings, as the clowns brought an element of change into an already familiar situation, the positive effects were not immediate. In fact, for some children there was initial reluctance and occasional anxiety. As they became more familiar with the clowns, the positive emotions of curiosity and joy were a catalyst for improved focus on other people, self-expression and managing sensory stimulation. The nuanced changes are explored in the following sections of this chapter.



Another important finding which is similar for the two target groups is the effect of social inclusion brought by the healthcare clowns. In hospital diagnosis processes, children interacted with each other with the help of the clown, sometimes to the surprise of parents and medical staff. The findings also indicate positive effects of stress relief for the parents of children with autism in healthcare settings, as well as opportunities for the parents to better understand the child's condition. In educational settings, children were reported by caregivers to have increased acceptance of others, improved social skills and more group cohesion. For older people with dementia the clowns also stimulated more group activities and joyful collective moments, but the stronger findings concern the relationships with family members and the possibility for both patients and relatives to enjoy quality time together. This finding is particularly important since the condition has a significant and progressive impact on relationships which affects all family members. Not least, the clown visits and performances were a rare occasion to experience art for these two target groups, both of which may experience a high degree of social isolation and have difficulties in accessing artistic performances made for the public. This was also highly relevant for family members, to have the opportunity to enjoy a performance with their loved ones, and to watch them enjoy something and be enjoyed by someone else in return. These effects for both target groups and relatives are also explored in the chapters "Impact for staff" and "Impact for families".

In the absence of longitudinal research with the same participants, it is difficult to assess whether the project has already produced a longer-term impact for the target groups. However, findings from both caregivers and artists indicate that some effects have had a lasting impact after the clown visits. Moreover, there were a number of institutions in which clown visits occurred regularly over the course of almost a year or more which would allow for longer term effects to develop, as suggested by the relevant literature. For both groups, such effects include more acceptance and interest towards others, improved communication, and self-expression, whether verbally or non-verbally through creativity and playfulness.

In interviews and most significant change testimonies, caregivers also pointed to effects of increased self-esteem and a sense of dignity for both target groups. While such effects require long-term interventions and validation through a more complex research process, indications that orient toward these findings are present in direct observation and in secondary sources and are worth including among the potential effects of longer-term healthcare clowning interventions. Children with ASD have expressed themselves in ways that suggest more confidence during or after clown visits, which was associated with the relationship they developed with the clowns. The findings also suggest that healthcare clowns can help persons with advanced dementia to retrieve or preserve their sense of self and to experience themselves as valuable persons, which is of utmost importance in dementia care<sup>6</sup>. These effects are further detailed for both target groups in the respective sections.

## 4.2. PERSONAL CONNECTION AS KEY MECHANISM

For the external observer, the clowns' intervention appears to be nothing less than magic (the clowns get reactions from the children or the older people that the staff or the families don't see in any other context). But it is important to note that healthcare clowns are not magicians, even though the results seem miraculous. And that the reactions are due to the connection the clowns form with the children or the older people.

<sup>6</sup> Norberg A. *Sense of Self among Persons with Advanced Dementia*. In: Wisniewski T, editor. *Alzheimer's Disease* [Internet]. Brisbane (AU): Codon Publications; 2019 Dec 20. Chapter 13. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK552152/> doi: 10.15586/alzheimer's disease.2019.ch 13

The incredible power of connection (observed and recounted by many of those interviewed) creates the necessary framework in which the curative effects appear<sup>7</sup> and consequently, the impact of healthcare clowning on the target groups takes shape. According to the literature, the necessary and sufficient conditions for curative effects to be generated by a relationship are:

- › **The vulnerability of the beneficiary (the factor that highlights the added value of clowning in the very specific contexts of dementia and ASD).**
- › **The genuineness of the "other" (in this case the healthcare clown).**
- › **Unconditional positive regard of the "other" for the beneficiary.**
- › **Accurate empathy.**
- › **Perception of genuineness (the "other" must be seen as genuine, not playing a role for the beneficiary).**

All these active ingredients of the curative connection are perfectly integrated in the work of healthcare clowns and were activated during the work in ClowNexus. **The profound human connection that the clowns can establish with people with dementia was the fertile ground in which positive effects could grow.** The surprising connection in the encounter between clowns and people with dementia was probably the single most highlighted finding from all the observers - members of staff of elderly homes, family members and even evaluators during direct observation visits.

”There's a lot of emotion (...)when clowns visit us, and for people with dementia, that emotion is there. Memory is lost, language is lost, motor skills are lost, but the emotion is not lost. And clowns can connect with that emotion in a way that we, other therapists, cannot connect so easily.” (Elderly home staff)

Staff members saw several ingredients which make the connection stick: the clowns' intuitive, empathetic, and mindful approach of each person, their use of non-verbal communication<sup>8</sup>, their clumsiness which makes older people feel understood and accepted the way they are. Different professionals who work in elderly homes have highlighted the difference between healthcare clowning and other types of therapies and programmes for older people, and that particularly in cases of more advanced dementia it's difficult to engage older people in activities, but the clowns had a special access to them through the personalised connection and the lack of expectations.

**By unconditionally accepting the children with autism, the clowns established a calming, non-hierarchical connection within which the children could express themselves and thrive.**

Repeatedly in interviews and written accounts we saw the surprise that the clowns can connect so intensely with children with autism, sometimes from the first time they meet them, and more so when they have time to build a relationship. As the artists describe it, there was something in the clown that appealed to children. Because children with ASD in hospitals, schools and special education centres are always expected to participate in activities with educational purposes, medical procedures or in therapeutic sessions, the clown's lack of expectations was an invitation to play.

<sup>7</sup> This is also validated by the classic theory of Jerome D. Frank who defined the patient-therapist relationship – also labeled the therapeutic bond (Orlinsky and Howard 1986), the therapeutic relationship (Strupp and Binder 1984), and the helping alliance (Luborsky 1984) – as both the vehicle of therapy and the major determinant of its outcome. Frank's definition of therapy is "a set of activities that involve systematic, time-limited contacts between a person in distress and someone who tries to reduce the distress by producing changes in the sufferer's feelings, attitudes, and behavior".

<sup>8</sup> Kitwood, T.(1998). *Toward a theory of dementia care: ethics and interaction*. *The Journal of Clinical Ethics*, 9, 23–34 argues that in people with dementia, non-verbal system tends to remain intact and may even be enhanced.



“  
 The most important thing about children spending time with the clowns is that a child can be whoever he or she wants to be by being here and now, in this moment. When I saw how the children instantly connected with the clown, I began to wonder what it is that clowns do that is so miraculous. I understood that clowns approach each child openly, showing acceptance and willingness to communicate.  
 (Pedagogue)

### 4.3. IMPACT FOR OLDER PEOPLE WITH DEMENTIA

#### AT A GLANCE SOURCES FOR THIS CHAPTER

- Direct observation by a third party (evaluators) - 12 instances of observation, mostly in group setting and few in individual rooms, with a total of approximately 107 people<sup>9</sup>.
- Perceptions of 13 clowns captured through interviews.
- Perceptions of 15 members of staff of elderly homes captured through direct interviews (13) and written accounts (5).

#### KEY FINDINGS

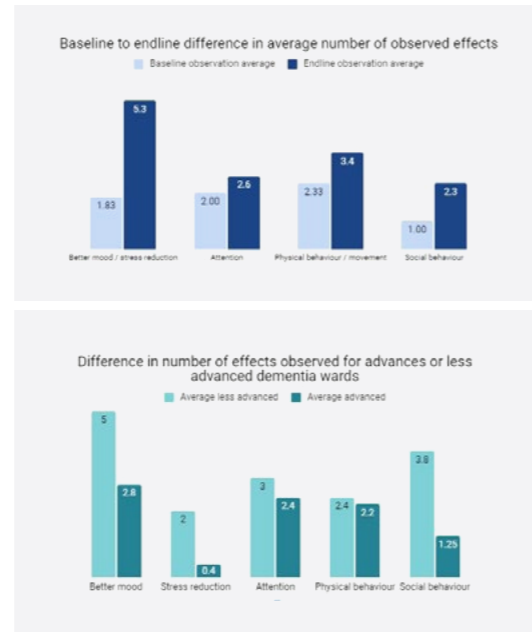
	The clown brings	Immediate effects	Potential Long term impact
<b>The clown is fully present in the moment</b>	Presence and humour (making an entrance, greeting, feet tapping etc.)	<ul style="list-style-type: none"> <li>› Collective reactions and good atmosphere.</li> <li>› Individual positive emotional responses of smiling, laughing, clapping.</li> <li>› Reduced apathy and sadness.</li> <li>› Reduced agitation and anxiety.</li> <li>› Reduced aggressive or self-aggressive behaviour.</li> </ul>	<ul style="list-style-type: none"> <li>› Anticipation, enthusiasm, reduced apathy.</li> <li>› Feelings of safety and cooperation.</li> <li>› New memories.</li> <li>› Improved communication through body language.</li> <li>› More self-expression, creativity, and playfulness.</li> <li>› Improved self-worth.</li> </ul>
	Individual closeness and time	<ul style="list-style-type: none"> <li>› Individual positive emotional responses of smiling, laughing, clapping.</li> <li>› Reduced apathy and transitioning from a passive presence to active engagement.</li> </ul>	<ul style="list-style-type: none"> <li>› Strengthened feeling of belonging to the group.</li> <li>› Stimulation of memories about the past.</li> <li>› Increased verbalisation on familiar topics.</li> </ul>
	Music and dancing	<ul style="list-style-type: none"> <li>› Increased attention and memory stimulation: tapping rhythms, humming tunes, singing songs with lyrics.</li> <li>› More physical activity, including for people with low mobility.</li> <li>› Stimulation of long-term memory.</li> <li>› More social interaction with each other and with members of staff.</li> </ul>	
	Presence and humour (making an entrance, greeting, feet tapping etc.)	<ul style="list-style-type: none"> <li>› Long concentration spans.</li> <li>› Stimulation of imagination and playful behaviour.</li> <li>› Stimulation of long-term memory.</li> <li>› More social interaction with each other and with members of staff.</li> </ul>	

<sup>9</sup> The number 107 represents a total headcount by evaluators, but a few people were walking in and out so the number is an approximation.

The artistic practices carried out within the ClowNexus project aimed to complement the therapeutic approaches of the medical and nursing staff and were based on addressing both the needs of the people with dementia and the needs of their families and the healthcare professionals.

In the endline evaluation, a higher number of effects was observed<sup>10</sup> compared to the baseline across all categories of effects. These can be explained by the clowns developing better skills and tools to work with the target groups compared to the beginning of the project, as well as a progression in building relationships with the beneficiaries. Both explanations are supported by the qualitative findings below regarding the effects of clowning for people with dementia.

The positive effects observed in both baseline and endline evaluations across all categories are confirmed by a research conducted at mid-project by RED NOSES Austria.<sup>11</sup>



More interestingly though, the qualitative data regarding the types of effects and their underpinning mechanisms gathered in observation suggests that there are other differences in terms of not just the number of effects but also their nature, and these are explored in the following sections.

While the findings are encouraging, there are **significant limitations** (detailed in the [Limitations section](#)) implicit in the data collection process which suggest that the quantitative findings should be utilised as trend indicators rather than fixed.

The changes observed and reported within each category - mood, stress reduction, attention, physical and social behaviour - are nuanced and described within the relevant context in the following sections of this chapter.

## IMMEDIATE EFFECTS

### MOOD

#### Main effects for people with less advanced dementia

- Collective responses, lightening up the atmosphere in the room.
- Smiling, expressing familiarity with the clowns, switching from a neutral mood to joy.
- Movement and memory stimulated by music.
- Humour, imagination, creativity, and social reactions, over longer stretches of focused time, stimulated by scenarios involving role play.

<sup>10</sup> Observation of clown visits was carried out by three evaluators during 12 in-person visits in five countries, using the same instruments as the baseline evaluation. The observation form allows the user to register (count) reactions of people with dementia during a clown visit into five categories: mood, stress (reduction), attention, physical behaviour and social behaviour. In the baseline evaluation the category "social behaviour" was named "connections/relationships". In the endline evaluation we have decided to change the name of the category to better reflect our understanding of the difference between, on the one hand, connection between clowns and target groups, and on the other hand social interactions between members of the target groups and members of staff during a clown visit.

<sup>11</sup> RED NOSES Austria, Healthcare clowning and dementia, 2023, Researchers: Simone Seebacher, Ingeborg Türk-Chlapek, Katharina Lessiak; Project-Management: Christina Matuella; Project-Team: Anna Russegger, Ingrid Türk-Chlapek, Sara Zambrano.

#### Main effects for people with more advanced dementia

- Stimulation of interest and attention including for people low mobility and bedridden.
- Expressions of joy and laughter.
- Stronger responses were generated by clowns calling their names, touching their shoulders or hands, or engaging in personal conversations on familiar topics (or in familiar languages).

**Improvements in mood** were the most common effect of clown visits for people with both more and less advanced dementia, but there are significant differences between the two groups in terms of numbers of effects as well as factors which targeted the reactions.

Caregivers who work in institutions indicated that **"happiness in the moment"** was one of the most important changes the clowns brought to dementia care, and that this opinion is shared by family members of people with dementia. Caregivers reported that, for people with more advanced dementia, the reactions were positive, but they only lasted for the moment, after which many people wouldn't remember the clowns.

In wards with less advanced dementia, there was usually a collective positive reaction when the clowns first entered the room. Most people started smiling when the clowns walked in, looked up and **switched from a neutral mood to amazement, joy, and excitement**. During the visits, there were moments when people with dementia interacted with the clowns as a group - bursting into laughter at the same time, improvising together after being offered RED NOSES, or many people clapping and cheering. In all these occasions, the collective responses created a sense that people are **participating in a shared experience** which appeared to lighten up the mood for the whole room.

Far fewer collective reactions were observed in wards with advanced dementia, which can be explained on one hand by the pre-existing limited social interaction between people in the same room, many of which sit alone<sup>12</sup>. Some group reactions were observed (i.e. four people greeting the clowns when they entered, three women singing at a table, collective laughter at funny sounds made by the clown) but most reactions were individual and generated by close and personal approaches by the clowns. According to members of staff, sometimes the positive mood remained in the room even for several days after the clowns left. This has been reported more for groups with less advanced dementia, where, after the clowns left, the residents talked about what they experienced, and enjoyed remembering what they did with the clowns.

Stronger responses were stimulated by personal and close approach by the clowns. In the close presence of the clowns who tried to engage them in conversation, most people made eye contact and eventually exchanged words, smile, or laugh. Staff members also highlighted the importance of individual attention, particularly in the frequent context that the staff have very limited time to allocate to each individual.

During visits when some residents were in bed, it happened often that the people in bed invited the clowns to get closer, expressed joy and laughed when the clowns interacted with them personally.

<sup>12</sup>The observation context was also different as people with more advanced dementia were observed in smaller groups of three, five or mostly seven, and a few times in individual rooms.

## STRESS REDUCTION

### Main effects

- Reduced apathy and sadness
- Reduced agitation and anxiety
- Reduced aggressive and self-aggressive behaviour
- Relief of isolation

Clowns can have a positive effect of **reducing stress and associated behaviours**, as indicated by observation, testimonies of staff and indirect feedback from family members.

**A decrease in apathy and perceived sadness** has been observed for some residents having both advanced and less advanced dementia. It has frequently been observed that people who initially did not respond to a prompt by the clowns, eventually engaged when offered closer attention or when the artist adapted the interaction to a one-on-one context.

Decreased anxiety and physical agitation have been reported for residents who were prone to agitation, particularly in wards with more advanced dementia.

” *A woman who has mobility problems is quietly watching the clowns and following their acts from the couch. A member of staff explains that she is always very agitated and loud, yelling that she wants to go home, trying to open the door and leave. The nurses are surprised that in the presence of the clowns she is not agitated but quietly focuses on them. (Direct observation)*

Staff members have also reported that clown visits **reduced the potential for aggressive or self-aggressive behaviour** in people with dementia. Sometimes this happened simply because they were focusing on the activity of the clowns, like in the examples above. At other times however, it has been even reported that clowns purposely intervened and managed to calm someone who was very tense, making it easier for the care staff to continue to consult the person and obtain cooperation.

Some caregivers in institutions were particularly touched by the ability of clowns to connect with residents who were bedridden, for which basic communication was a challenge, and who were sometimes in the final stages of their lives. Staff members of elderly homes emphasised the ability of clowns to connect with sensitivity and empathy, through soft songs and hand holding, and to create uplifting moments for older people and for those around them. The visits of clowns were also considered an important relief and distraction for older people who do not have relatives who visit.

In wards with people with more advanced dementia, it has also been observed that some residents had no reactions or even negative reactions to the clown visit, although these cases were relatively rare (observed in a total of 9 people out of approximately 107). Examples include people being unresponsive for the entire duration of a visit, refusing to participate in games, appearing disturbed by the noise.

## ATTENTION / FOCUS

### Main effects

- Eye contact and focus on the clowns
- Intense and long concentration spans when the clowns are performing with props
- Attention and memory stimulated by music and rhythm

**Heightened focus** during clown visits has been reported for groups with different stages of dementia. Some people made eye contact as soon as the clowns entered, for other residents it took closeness and individual attention from the clowns to engage. Calling people by their names, verbal games and shoes tapping across the room usually elicited many people's attention. Members of the staff described it as a shift between being only passively present to active engagement, or as change in their focus from staring blankly to concentrating on the clowns. In wards with more advanced dementia, it was more common that the attention was captured, then drifted away, then was recaptured with more engagement.

As already pointed out in the section about mood, performances and activities which involved role play and objects **generated periods of intense and occasionally prolonged concentration**. During these activities, it was often observed that people's senses became more focused. They would listen carefully to hear where the cat sounds were coming from, they would very slowly pat a toy dog, or took a long time to feel the softness of a scarf or stare in fascination as the clowns performed.

The importance of attention was also highlighted by relatives and staff members in the elderly homes involved in ClowNexus in Austria. Relatives and staff not only marked attention as one of the biggest improvements they observed for people with dementia, but they also expressed a wish for more clown visits to occur in smaller groups or individual settings to maximise attention of both clown and resident. As a result, the dementia team in Austria decided to stay longer with some patients and developed mini scenarios for individual visits<sup>13</sup>.

## PHYSICAL BEHAVIOUR - MOVEMENT AND BODY LANGUAGE

### Main effects

- More movement generated by activities
- Movement of people with limited mobility
- Dancing which stimulates joy and memory

The observed and reported reactions in terms of physical behaviour are similar for groups with different stages of dementia. The increased alertness and enthusiasm were natural precursors to **increased movement by older people with dementia** during clown visits. People would fidget in their chairs, lean over the tables out of curiosity to see what the clowns have brought. In more active games they would raise their arms and coordinate movements to interact with a ball or in a parachute game.

The results are similar even for people with limited or very limited mobility, even though the range of movement was smaller, the desire and effort to move were visible in many instances of observation as well as in interviews.

**Dancing during clown visits was not only about movement, but it was also joyful, social, and it stimulated memory**, and more than once older people's need and ability to dance has taken staff members by surprise.

” *There is an older man in the ward who was a college teacher and used to play an instrument, so when the clowns played music, he started to dance. But we know that he has real problems with motor skills, sometimes he even needs help with walking. It was really nice for us to see that he was so relaxed and started to dance. (Elderly home staff)*

<sup>13</sup> Based on questionnaires filled by relatives and staff members in Austria, as reported by RED NOSES Austria in the Narrative Report of November 2022.

## SOCIAL BEHAVIOR

### Main effects

- More social interaction in group activities
- More joyful interactions between residents and staff

The clown visits stimulated social interactions among residents or between residents and staff members. Staff of elderly homes in general have reported that social interaction was more intense during clown visits. Also, group activities happened more. Examples of interactions include residents talking to each other about the clowns, commenting on how they look with costume props, or retelling situations with the clowns to the nurses and laughing. Group activities had a big impact.

” We had a group game going on, and the older people started to be so active in the game, that us clowns were just there standing and looking at how they were playing (...). There was this one man we were meeting for the first time, and he was there actively going after the ball under the sofa, and I was thinking - “maybe this senior is always playful and childish and energetic”. But then the nurse said it was the first time he was joining an activity, and it was the first time they saw him laughing and smiling.” (Clown artist)

## LONGER TERM PERCEIVED EFFECTS

Both staff and artists observed that continuity of clown visits with the same groups for a longer period was conducive both to stronger effects in the moment and to longer term impact for the beneficiaries. Continuity allowed the artists to get to know the beneficiaries and refine the intervention, it created a more relaxed and trustful relationship with staff and residents, and it allowed for the residents to establish an emotional connection with the clowns which stimulated emotional memory. This in turn generated more profound changes for the people with dementia, in addition to the momentary effects already identified.

There were several types of positive effects generated by the fact that people remember the clowns, both before a visit and afterwards. We are describing these effects as “long-term” because they have been reported by staff members, clowns and family members as having a lasting impact after the clown visits.

Numerous reports from staff and clowns point to the fact that older people with dementia who were visited regularly by clowns in the ClowNexus project, including many people with more advanced stages of dementia, **preserved memories of their previous experiences with the clowns** even when they didn't remember the clowns themselves. Such memories were easily stimulated by music, characters or activities from previous clown visits or seeing faces with RED NOSES.

” In Hungary, in 2022 one of the elderly homes was closed and all the residents were relocated. The clowns started to visit one of the new locations one month later. On their first visit, they met an older woman who had moved there from the closed location. When she saw the clowns, her face lit up and she said: „I knew that you were searching me, and I was sure that you would find me! Finally you did!” It was a surprising moment, also for the staff. Although she did not recognise the person, she remembered the red nosed clowns. (Reported by an healthcare clowning organisation)<sup>14</sup>

<sup>14</sup> From Piros Orr Narrative Report Nov. 2022, edited for brevity.

**Anticipation, reduced apathy and enthusiasm** occurred when forthcoming clown visits were announced by staff members. Revealing feedback about the importance of anticipation of something good was received from a relative in Austria who was frequently in her mother's room when the clowns were coming. She recounted that her mother would not remember a clown visit the next day, but that as soon as she heard the music, the ukulele, and she anticipated that the clowns are in the hallway, her entire physical and emotional state changed, because she knew that something exciting was coming up.

**New memories were created that people with dementia want to hang on to.** After the clown visits, many participants felt the need to talk about the visitors they just had. They remembered for a while what they did with the clowns, and they talked about it with the staff. According to care staff, many of them would forget the context and the people by the next day, but when the clowns come back, so do some of the recent memories, which was considered important by staff members who observe short-term memory to be problematic for people with dementia. Consistency of visits has been an important factor for these effects, and artists have noticed that gaps longer than a month between visits led to fading connections with residents. As a general feeling though, in some rooms the staff have said that “after the clowns leave the happiness lasts for days”.

During clown visits, it has been observed that older people with dementia have frequently used body language either to communicate with the clowns, particularly when verbalisation was problematic, but also to show emotions even when their language was not impaired. Staff members have reported that some **changes with regards to body language persisted** after clown visits in relationship with the staff.

**Clowning encouraged self-expression, imagination, creativity, humour, and playfulness.** During clown visits, older people with dementia engaged in imaginative play and used their own creativity not only to respond to the offer to play but also to create something of their own. They also wanted to become funny and to show what they can do, and to have a communal feeling that they did something together. They made jokes, they created elaborate stories building on the scenario suggested by the clowns, and they showed pride in making others around them laugh. This has been observed both in rooms with more and less advanced dementia residents. This is in line with the studies that suggest that humour can be a protective factor for older people with dementia and laughter is used by patients with dementia to acknowledge communication difficulties and show awareness of their non-competency<sup>15</sup>.

” Several residents, a clown and a nurse engage together in a game of fortune telling in coffee cups. One woman tells the clown to run away because she sees a wolf in the coffee cup, then laughs. (Direct observation)

According to staff members, one of the most important effects of the clown visits for people with dementia was that they generated openness and made people more accepting of each other, strengthening the feeling of belonging to the group.

The scenarios involving everyday activities, as well as the clowns' genuine interest and patience to hear people's stories, stimulated the recall of memories about the past and generated touching moments when older people with dementia re-lived positive times in their lives. For the observers who tell these stories, the significance of these moments could simply not be quantified, and they hold high importance also for the clowns.

<sup>15</sup> Lindholm, C. (2008). Laughter, communication problems and dementia. *Communication & medicine*, 5 1, 3-14.

”There was this older man, nurses told me he doesn’t talk, and that in his mind he is probably in his childhood. I took his hand and we were walking to the window and we were looking at the hill and I said this hill’s name is Sljeme. And then he was trying to say something, he couldn’t, I was not rushing, just holding his hand, as he said: “mother, father, me”. (Clown artist)

An important effect that clowns didn’t realise on the spot was increased verbalisation by older people with dementia who usually don’t speak. They found out about this later from surprised members of staff. further detailed for both target groups in the respective sections.

#### 4.4. IMPACT FOR CHILDREN WITH ASD

##### AT A GLANCE SOURCES FOR THIS CHAPTER

- Direct observation by a third party (evaluators) - 1 instances of observation, group setting with a total of 6 children.
- Perceptions of 12 clowns captured through interviews.
- Perceptions of 6 members of staff of hospitals and educational institutions captured through direct interviews (1) and written accounts (5).

##### KEY FINDINGS

	The clown brings	Immediate effects	Long term impact
<b>The clown is fully present in the moment</b>	<ul style="list-style-type: none"> <li>➤ Approach with sensitivity and lack of pressure.</li> <li>➤ Interest in the child as she or he is in the moment, not as he or she could/should be.</li> <li>➤ Inviting playfulness.</li> <li>➤ Use of senses.</li> <li>➤ Music and physical play.</li> </ul>	<ul style="list-style-type: none"> <li>➤ Relief of stress for medical procedures and in classrooms.</li> <li>➤ Joy and humour development.</li> <li>➤ Improved non-verbal and verbal communication.</li> <li>➤ Improved attention and ability to manage sensory issues.</li> </ul>	<ul style="list-style-type: none"> <li>➤ Acceptance of others, social skills, and group cohesion.</li> <li>➤ Improved abilities for self-expression.</li> <li>➤ Increased self-esteem.</li> </ul>

The benefits of healthcare clowning for children with autism have begun to be studied in academic research<sup>16</sup> and evidence is building up as to the magnitude and types of positive effects. In this chapter we aim to connect this knowledge to the work done in ClowNexus using qualitative data collected from artists and experts in medical and educational facilities working with children with ASD in the six countries.

#### IMMEDIATE EFFECTS STRESS REDUCTION

##### Main effects

- Calmer for medical procedures
- Positive experience in the hospital
- Reduced stress in school settings

In hospital settings, both nurses and artists have reported that the presence or direct actions of the clowns were frequently able to **reduce the emotional distress associated with medical procedures**, either before an operation as it happened in Spain, or during diagnosis procedures in Finland.

The positive experiences with the clowns also meant that at the end of the hospital day, the children experienced the hospital not only as the place where they had to sit through procedures, but also as a place where they had fun.

”The clowns bring another meaning for meeting them here than to assess them. There is also this element that someone is here for you, to create space for you and the best environment for you to be in. (ASD Diagnosis nurse)

Group education settings can also pose a challenge for children with or without ASD, and there are accounts from pedagogues about how the clowns have had a **calming effect for young children who were very stressed**.

#### HUMOUR AND JOY

##### Main effects

- Enthusiasm, anticipation, and joy
- Learning to understand humour
- First access to art for some children

Pedagogues in schools and therapy groups have reported that children looked forward to clown visits when they were announced (for instance, with a clown picture or symbol), and the children with verbal abilities often asked when the clowns would come. All the relationships of the clowns with groups of children in educational contexts showed a gradual evolution. Initially some children were more fearful and preferred to be more observers than active participants, but with each visit they became more adventurous in playing with the clowns and showed them signs of affection.

The clowns explored the use of humour by repeating funny situations until the memory of the fun makes them funny, or explaining the punchline so that next time the same funny situation will make more sense and can be perceived as funny, thus **making humour more accessible for children with autism**. According to feedback received by educational and medical staff from parents, clown performances were **some of the first artistic experiences for the children**, if not the only time some of them had access to an artistic performance. Most families avoided taking children with ASD to performances, even those for children, for fear that their children might be stressed, react strangely, or be considered strange by others. These findings have also inspired many of the clowns who worked with autism to create or facilitate more artistic formats and cultural opportunities for children with autism, known in some contexts as „relaxed performances“.

<sup>16</sup> Shefer S, Leon Attia O, Rosenan R, Wald OA, Ende H, Gabis LV. Benefits of medical clowning in the treatment of young children with autism spectrum disorder. Eur J Pediatr. 2019 Aug;178(8):1283-1289. doi: 10.1007/s00431-019-03415-7. Epub 2019 Jun 26. PMID: 31243575, <https://pubmed.ncbi.nlm.nih.gov/31243575/>

## IMPROVED VERBAL AND NON-VERBAL COMMUNICATION

### Main effects

- Advances in vocabulary
- Development of non-verbal forms of expression

Children who had some ability to speak have made advances in their vocabulary which staff members and in one case a family member attribute to the clown visits. Non-verbal forms of expression have also developed for many children, which staff saw as a result of mirroring between the clowns and the children. By repeating what the clowns do, children learned new facial expressions, gestures, and body language.

## ATTENTION AND IMPROVED ABILITY TO MANAGE SENSORY ISSUES

### Main effects

- Increased ability to make and maintain eye contact
- Increased ability to accept sensorial stimulation beyond previous limits of comfort

One of the main observations of staff members who witnessed clown visits for smaller children was the surprise at how much the clowns were able to capture the attention of children and make **eye contact**. Curiosity of both the clown and the child, physical and sensorial play, which were able to **help the child focus on the interaction** with the clown and away from sensorial challenges in the environment.

Another finding which is strongly connected to the continuity of visits in schools is that the clowns were able to start with very small and simple actions just to incite curiosity and later were able to **expand the limits of comfort** for the children and propose much more complex activities towards the end.

## LONGER-TERM PERCEIVED EFFECTS

**Children's reduced fear of strangers** has been witnessed by the clowns themselves, who gradually saw children who were initially reluctant and anxious opening up and eventually forming a bond with the clowns. Beyond the experience of the clowns, this has also been confirmed by a nurse who diagnoses autism, and who also added that the results can last because "after the clown visit, the child's „interaction window“ often remained open and it was easy to continue working with the child”.

”From the first class I remember one boy, he was sitting under the table and when we tried to reach him, he made specific movements to suggest to be left alone. So we decided to leave him under the table, in his safe space. We had about 8-10 visits to this class, and with each visit he was coming little by little out from under the table, little by little smiling, and at the end of our visits, he was sitting on the table, giving high fives for the clowns.” (Clown artist)

Many of the staff members who work with children with ASD in group educational contexts have concluded that the work of the clowns has led to **more cohesion within the group and social interactions**. The clowns proposed many group activities which the children wanted to join, and the children ended up playing together with their peers, in a context which felt free and fun.

For the clowns this was an intentional element of their work - to create opportunities for the children to connect to each other, to give something to each other and pay attention to those around them. In Hungary, in one school, the clowns were visiting one group of children with ASD, but not a second

group. At the end of the school year the organisation received the surprising feedback that, in the institution's regular evaluation of the improvement of the kids' abilities, they recognised that the group which had been visited by the clowns had improved much more than the other group, especially in co-operation with each other and their connection to funny situations and humour<sup>17</sup>.

”Clowns were involved in the group's daily activities for two hours, and then they joined the regular class activities. Step by step the children accepted them as part of the group for that day. During the break, the clowns opened up their food box which contained 1 strawberry. It became the starting point of a game the clowns started with the question „Who is this for?“ The first reaction was from a child, „I think this is for me.“ Clowns started to play with the situation. It was an open play, without any expectations or suggested solutions from the clown's side, just being present and accepting the situation which brought a lot of funny moments. The impact was really surprising, because as the children started to get involved more into the game, they started to cooperate as a team. Finally together, they divided the strawberry into 8 pieces and had a common eating.” (Piros Orr Organisational report).

Educators have suggested that in the interaction with the clowns and with each other, children developed **improved abilities for self-expression** and became creators themselves as they responded to the clowns by answering with their own facial expressions and gestures. One child with severe communication difficulties had created his own sign language, which he was able to teach to the clowns and they were able to communicate. Creativity and open-endedness in the clowns' performances was also appreciated for allowing the children to be free in their self-expression, to take something the clowns offered and turn it into whatever they liked.

There are several reports from educators and artists who identified positive outcomes which can be associated with elements of **self-worth and human dignity**. Medical staff whose job is to observe and evaluate children's behaviour have said that in the interactions with the clowns, children tend to show the best of their skills and may even surpass expectations.

”The biggest gain is that in the hospital the meeting with the clown is the only situation in which the child can succeed. In all other cases, the situation is created for us and it is stressful for them - we assess, evaluate, push them to their limits and get information out of them. (ASD diagnosis nurse)

In one case in Austria there was such feedback coming from a child with higher abilities who was able to reflect and had good communication skills. He told his mother that the first encounter with the clowns was strange, but after a while he became stronger and braver to experience being a part of a fantasy play.

<sup>17</sup> Piros Orr Narrative Report, May 2023.



**IMPACT  
FOR CARE,  
HEALTHCARE,  
& PEDAGOGICAL  
STAFF**

**5**



## AT A GLANCE SOURCES FOR THIS CHAPTER

- Direct observation by a third party (evaluators) - 13 instances of observation of clown visits for people with dementia and children with ASD.
- Perceptions of 21 members of caregiving staff (elderly homes, hospitals, and educational institutions), of which 14 through direct interviews and 7 through written interviews.
- Perceptions of 26 clowns captured through interviews.

## KEY FINDINGS

### Changes in perception, procedures and ways of working with beneficiaries and families

- ▶ Improved understanding of healthcare clowning methods and effects.
- ▶ Improved relationships and communication between staff and families.
- ▶ Inspiration, adoption of humour and playfulness as methods to engage people with dementia and children with ASD.
- ▶ Acquiring new information or perspectives about the beneficiaries.
- ▶ Easier interaction with people with dementia and children with ASD.

### Personal wellbeing at work

- ▶ Good atmosphere at work
- ▶ Group cohesion
- ▶ Laughter and joy
- ▶ Respite from regular tasks

The findings suggest that overall institutional appreciation is very high regarding the clowning programme for people with dementia<sup>19</sup>. In some of the new institutions there was an initial fear that the clowns would bring too much energy for dementia wards, or that clowning was only fit for children, but those fears were overcome in the end. The artists interviewed also felt that the attitudes of members of staff have improved, and that they have developed a good relationship with staff members.

It could be observed, however, that in most institutions working with people with dementia, the clowns engage more with social workers and occupational therapists, rather than with nurses and care staff. It was also these non-medical members of staff who were most often involved in the processes of co-creation, and who most frequently responded to interview requests for the evaluation. There are isolated testimonies that some staff members, particularly nurses who interacted less with the clowns, may still preserve an attitude of restraint towards healthcare clowning.

For organisations who worked with children with autism in hospitals, the trust built over the years has led to very strong collaborations between medical staff and artists. The cooperation between artists and staff members varied a lot in educational institutions, even within the same country and with the same team of artists. Even though the effects look similar for caregivers for people with dementia and caregivers for children with ASD, the sections below focus on each audience separately to describe the findings within their own context and significance.

## CAREGIVERS IN DEMENTIA SETTINGS

Members of staff reported an **improved understanding of healthcare clowning for people with dementia** because they attended workshops or discussions, and because they witnessed the work of clowns in the institution. They saw the positive effects of co-creation and how their cooperation helped the clowns interact with people with dementia.

<sup>19</sup> It has to be taken in consideration that we interviewed those members of the staff that were inclined to help with the evaluation process and those that remained in a relationship with the clowns or organisations until the end of ClowNexus.

Artists also saw that because of the more intense communication, staff members started to suggest more activities and ideas and sometimes they contributed during clown visits and wanted to be a part of the experience. Staff shared more feedback with the artists during open discussions after the visits, and they also shared photos and videos more often with family members, they communicated feedback from families to the artists. This in turn helped the artists reflect on the impact of their work and spread the lessons learned in the organisations.

Having relatives participate in co-creation meetings alongside staff led to **improved relationships between staff and family members**. Observing clown visits and sharing feedback through questionnaires or live discussions gave families a better understanding of how their loved one's experience life in the elderly home and their relationships with the staff.

Seeing first-hand the work of the clowns provides tools, **inspiration, ideas on adoption of humour and playfulness as methods to engage people with dementia** for staff members in their own work with people with dementia. The presence of the clowns was sometimes an entry ticket for staff members to be funny themselves, to introduce small changes in their interaction with people with dementia, participate in role play, put on a red nose, join a dance, and communicate with the residents in new ways.

The caretaking staff indicated an added benefit that during clown visits they were able to see another side of the residents, thus **acquiring new information or perspectives about the residents**. Sometimes they found out new information about people's preferences and memories. They also saw new ways of communication that residents respond to which they can use particularly with older people who no longer communicate verbally.

**Clowns facilitated more interactions between residents and staff during their visit**. Staff reported that clowns had a calming effect for people who are otherwise agitated or even aggressive, and the presence of the clowns could help calm people down and feel safe, which in turn helped staff perform their care routines with more ease. It is important however to notice that in some cases, clowns would adopt a caretaker position during the visit even without willing to do so, and this could create challenging situations.

**Personal wellbeing at work for staff members who participate in clown visits increased**. During in-person observation visits, nurses were smiling and greeting the clowns, often laughing, joining in imaginative games with the residents, trying on RED NOSES, joining in song or role play, stopping their work to watch the interactions between the clowns and the residents and, more than once, looking touched to observe. Care staff also reported that at times, clowns provided a respite for the nurses to do other things, knowing that the residents were calm and enjoying themselves.

”In the institution, the clowns generate a more human, cheerful, spontaneous, creative atmosphere and manage to bring us together, creating cohesion.” (Elderly home staff)

## HEALTHCARE AND PEDAGOGICAL STAFF WORKING WITH CHILDREN WITH ASD

In the case of educational institutions, with the exception of Hungary where the clowns and staff members began the collaboration holding workshops for each other, in the other countries collaboration between clowns and staff and co-creation were more organic and developed gradually, more in some schools than in others, depending on the interest of the staff members.

Co-creation usually took the form of clowns consulting the staff about ideas to implement with the children, and staff giving feedback, or more rarely the other way around, with staff proposing certain ideas for the clowns to try out.

### **ACQUIRING NEW INFORMATION OR PERSPECTIVES ABOUT THE CHILDREN WITH ASD**

In neurological wards in Finland where ASD diagnosis is done, nurses interviewed for the evaluation frequently reported that observing children watch the clowns and interact with them helped in the child's assessment process; they could observe new and different aspects of a child's behaviour compared to a regular medical and psychological assessment. This finding from staff members was also observed in-person during the evaluator's observation visit in Finland.

” *“In the show, I could observe things that I can't observe if I am only making tasks with him on the table. For example, one big thing that I never knew when the children went under the water (a blue scarf symbolising the ocean) and he was so happy about it and he went and faced another child on purpose and made eye contact and smiled. That is a very big finding about his interaction skills for me, to see he wants to share his happiness and he wants to share it with another child. That is a lot of information for me about his interaction skills.” (ASD diagnosis nurse)*

### **EASIER INTERACTION WITH CHILDREN WITH ASD FOR MEDICAL PROCEDURES.**

Another effect which we have not been able to verify during the evaluation but was reported by one of the organisations, was that in Spain where clowns accompany children before operations, medical staff realised how useful clowns were in calming children with autism and started to call them specifically and invited clowns to have small workshops with staff on how to approach children with ASD. Also, in Finland, where clowns were accompanying children through the diagnosis procedures, the medical staff started to integrate the clowns' interaction in testing scenarios.

### **INSPIRATION, ADOPTION OF HUMOUR AND PLAYFULNESS AS METHODS TO ENGAGE CHILDREN WITH ASD**

There are even more findings reported both by clowns and staff members, in medical facilities as well as in educational institutions, which indicate that staff members learned certain skills and tactics from the clowns which they went on to apply in their regular work with the kids, because they had seen their effectiveness during clown visits. Such examples include:

- Educators who mirror children's facial expressions and gestures to make them feel understood.
- Nurses who play more with the kids, act funny and spend time on the floor with children.
- Nurses asking themselves „what would a clown do now?”
- Educators starting to use simple props in educational activities (scarf, ball, canister, toy, pieces of paper, etc.), and presenting them to children using facial expressions, gestures, and body language to focus students' attention and keep it longer.
- Educators who are inspired to play more, “really to play”.
- Educators refocusing attention on the overall wellbeing of the child.

### **PERSONAL WELLBEING AT WORK FOR STAFF MEMBERS WHO PARTICIPATE IN CLOWN VISITS.**

Many concrete examples of interactions with teachers indicate that continuity of clown visits was also a big part of the recipe for creating an impact for staff members. Just as the children were more reluctant initially and needed time to open up, also the teachers relaxed with time and with trust-building, and started to participate in the clown visits with more curiosity and openness to what they can learn from it.

# 6

IMPACT  
FOR THE FAMILIES  
OF PEOPLE WITH  
DEMENTIA AND  
CHILDREN WITH  
AUTISM

## AT A GLANCE SOURCES FOR THIS CHAPTER

During the endline evaluation process it was impossible to interview relatives of people with dementia and children with ASD, although parents and children were observed together during the in-person visit in Finland. Consequently, the impact on the families has been assessed to a limited extent using accounts by staff and clowns, and secondary data from reports of meetings with families during the project.

## KEY FINDINGS

- › Experiencing gratitude for the joy and playfulness their loved one's experience.
- › Sharing a good moment and collecting good memories.
- › Improved understanding of behaviours linked to dementia or ASD.
- › Better communication and relationship between families and staff in institutions.
- › Parents of children with ASD are more relaxed in healthcare settings.
- › Family members can take pride and have hope.
- › Family members can learn new techniques of interacting with their loved one.
- › Negative effects for parents of children with ASD: sadness when the child doesn't respond.

Relatives had an overall positive regard for the presence of healthcare clowns in the facilities for people with dementia. Even those who did not participate in clown visits have occasionally offered positive feedback and declared themselves happy that their relatives benefit from the programme.

In educational settings, it was usually the case that clowns themselves had little if any interaction with parents and relied on the feedback communicated by educators from parents. One exception was in Lithuania, where the father of a young girl was so impressed by the clowning programme that he maintained personal contact and even spoke on radio about the positive impact clowns had had for his daughter.

### Effects of clowning for relatives of people with dementia

Clowns and staff members often reported that relatives who visited while a clown was present were curious and enjoyed participating. According to the PAR study, the positive attitude of the family members also had an impact on the success of the clown visit. Watching their relatives participate in a clown performance helped family members experience the person with dementia in new ways, with a different energy, and to have new insights on their inner world.

Clown visits have offered rare opportunities for family members to enjoy spending time and doing something fun together. Watching a third person perform, while being together, meant both the relative and the person with dementia were able to experience a common positive experience. Relatives have also expressed gratitude at the possibility of collecting beautiful memories with their loved ones, which they appreciated deeply because of the difficulties faced in dealing with dementia and because they anticipated losing their loved ones in the near future. Participating in role play was also an effective way for the family members to share memories about the past.

The discussions organised with family members after attending clown visits in Hungary and in Austria revealed that some of the experiences were quite powerful

for family members. For example, in Hungary, the son of a woman with dementia remembered that his mother would take him to a puppet show when he was a child, and he always wanted to share his excitement and joy with his mother by looking at her from time to time. He understood during the clown intervention how happy his mother was bringing him to the puppet theatre and enjoying his joy, and now he felt the same with his mother<sup>19</sup>.

Relatives could also develop a better understanding of dementia, becoming more open and accepting of all aspects of the condition. According to staff members, the participation of the relatives in activities with clowns, as witnesses to a visit or in discussions, has helped some relatives be more appreciative of the experiences brought by the institution in the lives of the residents, to see that their older relatives can enjoy friendship, community and pleasant moments even when they have dementia and live in an institution.

### Effects of clowning for parents of children with ASD

Effects of stress relief and relaxation for parents have been reported both in the context of pre-surgery clown visits in Spain, and in diagnosis procedures in neurological wards in Finland. Medical staff explained that parents are usually very concerned, nervous, and the hospital visits are difficult for both parents and child. The clowns had a calming effect on the children and consequently the parents relaxed and sometimes even joined in the fun.

” An additional benefit observed by medical staff was the opportunity for parents of children with autism to be proud of their child, particularly in the context of an autism diagnosis process. “The child enjoyed today and he will definitely remember what happened. His mother told me yesterday that he had never been to a show, to the movies, to theatre, to anything. She used the word „this would be interesting”, but I think they were also fearful. I think that she is happy about it now and she is eager to tell her husband. I have known her for three years and I think she is quite proud of her son and their contact.” (ASD diagnosis nurse)

Medical staff from the neurological wards in Finland have indicated that they, as well as parents, got new ideas of how to interact with children, replicating techniques they saw worked for the clowns. Another significant finding medical staff have emphasised is that they were better able to explain to parents certain behaviours of their child and how they relate to ASD. When parents and medical professionals watched together the child interacting with the clown and commented on what they were seeing, this facilitated the parents' understanding of ASD characteristics. Apart from having the opportunity to illustrate significant behaviour for the parents, the medical staff highlighted their appreciation for the clowns for being able to facilitate positive reactions of the children that are especially rewarding for a parent going through the ASD diagnosis process with their child.

” There was only one kid with the clown and I sat with the father watching. It was their first assessment. That child had very, very limited interaction skills. It was amazing that he even noticed the clown in less than 5 minutes. The clown gently played the ukulele and the child started imitating the clown. The father had tears in his eyes. „I've never seen him do anything like that”, he said. I had just explained to him many things about his child that were autistic traits, and it was so nice to share with him that his son was also doing something amazing. (ASD diagnosis nurse)

<sup>19</sup> Piros Orr narrative report May 2023.

Even though medical facilities took precautions to inform the families in advance about how the hospital clown works and why, the encounters between children and clowns did sometimes cause sadness for parents, particularly when the autism diagnosis was new and the child did not react to the clown at all, or acted very differently from what would have been expected, thus confirming the diagnosis.

Although most of the visits in ClowNexus for children with ASD happened in institutional settings, some cases of family visits in Austria point to the potential for healthcare clowns to play a positive role in family and community contexts as well, bringing relaxation for families and inclusion for the children. The clowns in Austria visited a family with four children, of which one is diagnosed with autism and two with ADHD. During the visit the mother as well as the neighbour's children were present, and the clowns witnessed interesting positive effects. On the one hand, the mother was able to relax and play alongside the children, and on the other hand, the siblings and the neighbour's children also enjoyed the time together and created an inclusive context for play in which the child with autism could freely choose how much to interact<sup>20</sup>.

” *Not just the boy with autism, but also the sisters, the mother, and the neighbours, they all needed to play, and this was very good for inclusion. Everyone who was there, we all played together. The boy with autism, he was a youngster and he was able to take his time, to come, to go, to come.*” (Clown artist)

<sup>20</sup>RED NOSES Austria narrative report



# 7

## SUSTAINABILITY

### **7.1 CONTINUING AND EXPANDING WORK WITH THE TARGET GROUPS**

Within the partner organisations, every single one plans to or is already continuing to work with both target groups. The healthcare clowning organisations involved in ClowNexus are also expanding the group of artists who work with people with dementia and children with ASD, using the artistic techniques, formats and lessons learned from the project. In most countries the process of consolidating the experience with the target groups has already started through learning and sharing workshops between the artists involved in the project and other artists employed by the organisation in other regions or institutions.

#### **Several steps are being implemented by the partners:**

- Approaching other institutions.
- Transferring the knowledge and skills to more artists within the organisation.
- Expanding to more regions with the support of the artists already trained.
- Developing new artistic formats for the two target groups, to be used in institutions but also for wider audiences in theatres.

Within RNI, there are plans to transfer the knowledge to other partner organisations that were not part of ClowNexus. The current project partners have also expressed the wish and expectation that the collaboration, learning and sharing initiated within ClowNexus between the partners will continue to be supported by RNI in the future as they deepen and expand the work for older people with dementia and children with ASD. The idea of regularly coming back together in the form of laboratories to share results and insights has been proposed as a follow up to the project.

### **7.2. GENERATING FUTURE FUNDING OPPORTUNITIES**

In Finland, the new programmes for older people with dementia which were initiated during ClowNexus have already generated important new funding opportunities. Both central level authorities (Ministry of Social Affairs and Health) and local authorities in Turku and Helsinki have started to provide funding for healthcare clowning for older people, and the organisations' work in elderly homes has already been extended to five cities for the next three years. The new work with older people and the increased funding available for this work has also had important implications for how many of the artists employed by the organisation are involved in work for older people, and the knowledge from ClowNexus has been rapidly transferred and internalised for most of the artists working for Sairaalaklovnit. The project has also marked a change for the Finnish partner from being funded primarily from culture and arts programmes, to establishing itself as a social care provider and being funded by the governmental agency that funds social work (STEA).

### **7.3. CONTINUING AND MULTIPLYING THE CO-CREATION APPROACH**

As a result of ClowNexus, the organisations experienced the benefits of co-creation with caregivers and family members and are now planning to focus more on creating deeper relationships with the staff in institutions and with relatives.

Several organisations have mentioned having started processes to deepen protocols of cooperation with institutions or to do workshops with relatives in upcoming projects.

In Austria where the Participatory Action Research process was implemented, there are plans to use the methodology and principles of PAR in other institutions, not only for the two target groups but in general when developing relationships with new institutions.

### **7.4. SHARING THE ARTISTIC AND LEARNING TOOLS AND THE CO-CREATION MAP WITH OTHER STAKEHOLDERS**

All the experience and knowledge accumulated within ClowNexus has also increased the confidence of the partner organisations to share the knowledge and methodology of the project more widely so that other stakeholders can make use of them.

The artistic tools have been collected and described for external audiences in a [collection of artistic tools and scenarios on the project website](#), and tools used during the process for learning, reflection and collecting data have also been documented in a [Learning Toolkit](#).

The co-creation map developed because of ClowNexus is considered, particularly by the artistic directors, as a useful product that can be used by other external stakeholders - artists, organisations, experts and relatives, as an orientation guide to integrate different tools, methods and scenarios to work with people with dementia, children with ASD and other vulnerable groups with similar challenges.

### **7.5. INSPIRATION FOR INCLUSION AND ACCESS TO ART FOR THE TARGET GROUPS BEYOND HEALTHCARE CLOWNING**

The artists involved in ClowNexus, having acquired a better understanding of the degree of social isolation of the target groups, have been inspired by the project to put their newly acquired knowledge and interest to use for the target groups beyond their role as healthcare clowns. Some of the ideas mentioned by the artists include creating sensory theatre for children with ASD, developing relaxed performances for older people with dementia and artistic formats in which people with dementia can participate, creating formats to engage with families and ideas of using art as a form of activism to increase social sensitivity and openness towards people with dementia and children with ASD.

# 8

## AWARENESS OF IMPORTANCE OF CLOWNING FOR EXTERNAL ACTORS



### AT A GLANCE SOURCES FOR THIS CHAPTER

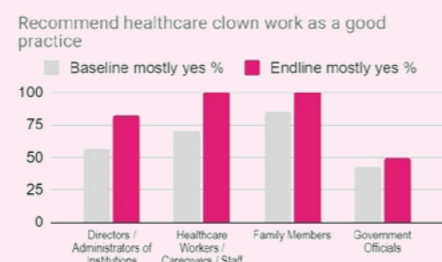
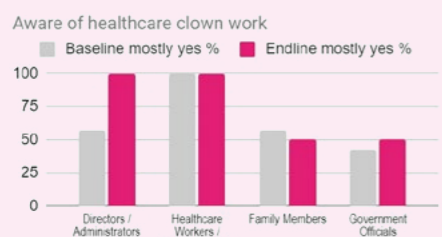
- Survey of 6 healthcare clowning organisations, ClowNexus partners.
- Analysis of project documentation, reports and secondary data.
- Perceptions of 9 project managers and artistic responsables.
- Interview with one external stakeholder.

### KEY FINDINGS

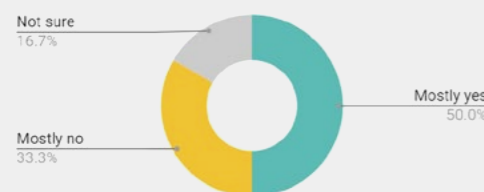
Activities that led to increased awareness and changes in perception towards healthcare clowning	What change looks like
<p>A documentary (and a series of short videos) featuring interviews with representatives of the two target groups, mental health experts, relatives, artists, caregivers, capturing clown interventions in dementia and ASD care.</p> <p>Strong connections with the European Cultural Network "Culture Action Europe" - the project lead of "Culture 4 Health" - and participation in three of their events, taking part in conversations on how to advance the arts and health sector, in making recommendations on the development of policy.</p> <p>Together with Culture Action Europe, the ClowNexus team organised an event at the Lithuanian Permanent Representation in Brussels on "Culture and Mental Health. Policies and Practices" where they showed the documentary and facilitated a discussion with policy makers.</p> <p>With the occasion of running the Artistic Laboratory in the countries, there were discussions with relevant stakeholders about Arts and Health approaches in national policies.</p> <p>Participation in big events and congresses at national level where representatives of the health sector could have access to information about the work done in ClowNexus and about Arts and Health practices.</p> <p>Extensive communication and representation activities.</p>	<p>RNI was invited specifically at the closing conference of "Culture 4 Health" to present ClowNexus and present video material. ClowNexus was added to their mapping tool.</p> <p>RNI was invited as speakers to an event in the European Parliament (organised by the EACEA and MEP Sabine Verheyen) because they were implementing a Creative Europe project.</p> <p>ClowNexus was included in the good practice brochure of the European Commission as a Creative Europe project.</p> <p>Research done within ClowNexus of facilitated by the project and implicitly the impact of healthcare clowning for mental health was presented in research groups, at conferences about neuropsychology, for healthcare workers or in international conferences dedicated for the wellbeing of the target groups (e.g. Alzheimer Europe).</p>

One of the objectives of ClowNexus was to contribute to the visibility and awareness for arts for wellbeing in Europe. Partners contributed to improved understanding and appreciation of clowning by leveraging existing partnerships in the national and international cultural sector and by forging new links with cultural networks, advocacy organisations and policy makers. It also raised awareness of the benefits of participatory arts experiences for vulnerable audiences, highlighting the added value of the arts for health and wellbeing.

By the strengthening of existing relations with the institutions and other stakeholders and the creation of new relations as we have seen at the level of [impact for organisations](#), most of the time through [co-creation processes](#), the project contributes to a systemic change in the arts and health sector.



Generally, in your context, do people consider clowns to be part of the care team?



The endline evaluation showed a project-wide increase compared to the baseline in perceived awareness and confidence in recommending clown work as a good practice across all stakeholder categories<sup>21</sup>.

The increases are most notable where directors/managers of institutions and family members are concerned. The findings from interviews with

artists and project managers from the organisations largely suggest that these changes are related to new ways of approaching institutions and involving family members in co-creation.

The growing importance that facility managers place on the complementary role of health clowns in care was also confirmed during the visits conducted for the evaluation in seven facilities. This perception is consistent with the survey results and is evident in the interviews and in the time and dedication the managers devoted to the evaluation visits.



Beyond the communication, awareness-raising and specific activities directly aimed at advancing advocacy goals, a wider impact of promoting the positive effects of clowning and humour for vulnerable groups will be achieved through sharing the resources generated in ClowNexus. The data collected has wider implications for ongoing EU policy and discussions within EU

cultural organisations on arts and health. The ClowNexus organisations now have a documented expertise in healthcare clowning for people with dementia and children with autism that can be shared with professionals in other fields to replicate ideas and methods. The increased capacity of the organisations to measure, evaluate and document their impact will enhance effects in this direction.

The work done by the partners in general and within ClowNexus was valued by those who want to advance cultural policy and understanding of the field. The wealth of experience, the documentation of impact and evidence-based methodology, the level of professionalisation and the willingness to share perspectives were highlighted as determining strengths by the stakeholders interviewed.

<sup>21</sup> There is no change in awareness of healthcare / staff because it was already at 100% in the baseline and remained so in the endline. The data for family members' awareness appears to show a slight decrease, but that is because the baseline surveyed 7 partners while the endline surveyed 6 partners (who implemented direct activities with the target groups), and the number of partners who answered "mostly yes" for family members awareness is in fact the same for baseline and endline (3).

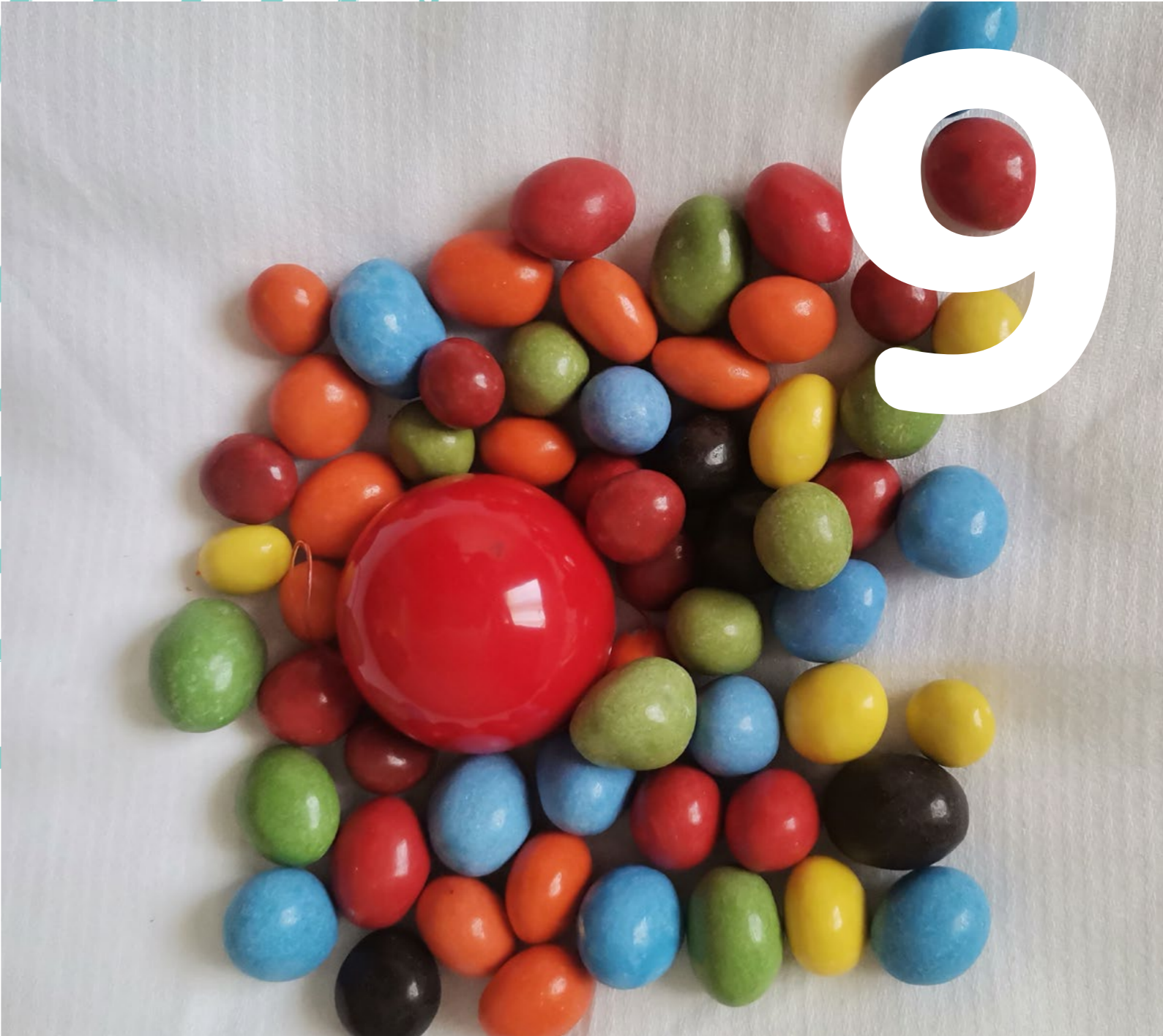
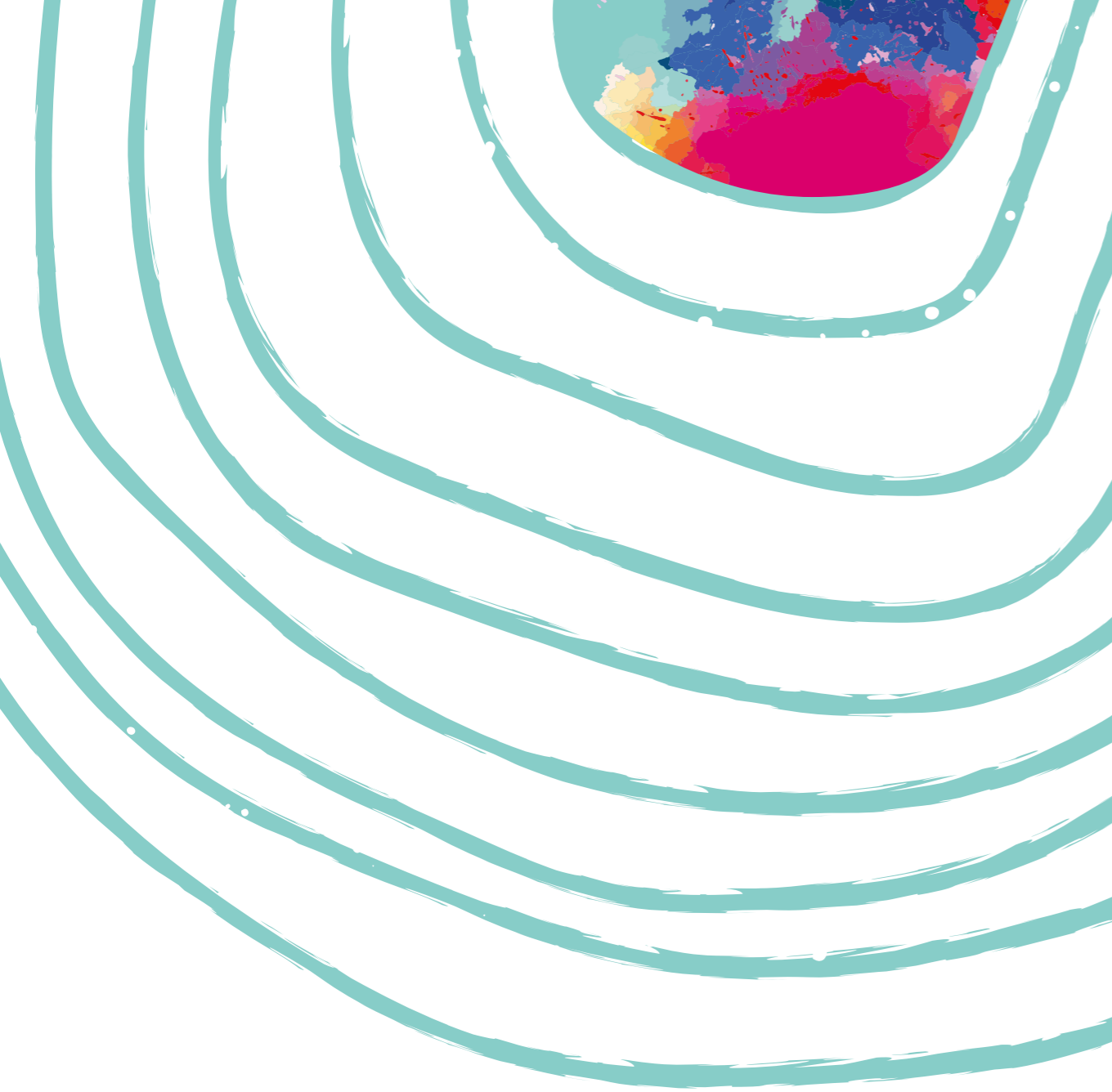


Representing ClowNexus at various occasions, both nationally and at European level, has helped allies to reaffirm the importance of investing in the arts and health field and has advanced strategic thinking by providing insights and a higher level, more structural perspective on achievable outcomes within the field.

The ClowNexus team made a significant contribution by presenting the documentary at the event held at the Lithuanian Permanent Representation in Brussels. By conveying artists' voices through video and through in-person participation, they played a crucial role in shaping understanding at a practical level.

” For me, this (the documentary) was the strongest awareness raising there is.  
(Institutional stakeholder)

As European institutions are more accustomed to working with intermediaries such as cultural managers and rarely interact directly with patients, medical staff and artists, the debate can remain at a more conceptual level. Especially in fields that are still in their early stages, as is the case with the Arts and Health sector, providing a platform for the voices of those actively involved is crucial in moving from conceptual debates to reality-oriented strategies. Through its resource development, knowledge sharing and compelling narratives, the ClowNexus portfolio has become a valuable and recognised resource in the field that will continue to have a ripple effect for the Arts and Health field.



# LESSONS & LEARNED RECOMMENDATIONS





## COLLABORATIVE LEARNING, EXCHANGE, AND PEER-LEARNING

The project encountered initial challenges related to expectations, particularly related to co-creation and the expected results of the artistic process. A certain lack of clarity in roles and responsibilities also caused confusion and misunderstandings in the beginning.

› **Recommendation:** A more structured approach and starting from a clearer framework, with more know-how about co-creation processes, could make collaboration more effective. The exchange activities and the working groups proved there is a substantial need and benefit for collaboration between artists and organisations. Some artists expressed a desire for additional collaborative learning activities in the future.

› **Recommendation:** Collaboration and exchange can be further facilitated, suggesting to incorporate study visits to work alongside artists from different countries.

Joint meetings facilitate a sense of community and a shared journey towards a common goal, which intensifies the need for more regular contact. While the work in groups dedicated to each target group was helpful in the learning activities, cross-cutting exchanges between the 'dementia' and 'ASD' groups were also helpful for the artists, and more such activities would have been useful.

› **Recommendation:** If there are two distinct target groups, facilitate more cross-cutting exchanges between the people involved (e.g., more exchange between the dementia' and 'ASD' groups).

› **Recommendation:** Additionally, the project lead can facilitate the framework for engaged conversations and dialogue between everyone involved, in addition to set the framework of common activities and working groups.

When addressing a new target group, the layered approach tested in ClowNexus proved to be effective. Breaking out of the traditional mindset of thinking in formats and instead adopting the new method of working with a set of tools and then piecing them together in different ways into scenarios was considered very important. Just as importantly, the time and space for reflection allowed for a more conscious approach of not just the tools used, but the clowning as a whole.

› **Recommendation:** Focusing on scenarios and creating coherent sets of tools\* rather than fixed formats has the potential to be multiplied beyond dementia and autism with any new target group, especially for those target groups where instant adaptation to contexts and individuals is recommended. Time for conscious reflection about the tools used and their impact is also necessary for a successful adaptation for new audiences.

\*View tools online: [Artistic tools - Tools in practice](#)

## CO-CREATION

Co-creation and institutional relationships work like a virtuous circle. Co-creation happened more in those institutions where there was a partnership already established. At the same time, co-creation creates a deeper understanding of clowning so it can be more beneficial at the beginning of the partnership. There are many variables that can make or break a true co-creation process. Shared curiosity and openness for others are key to establishing a relationship based on trust.

› **Recommendation:** Although it may seem easier to start co-creation processes in institutions where the relationship is already established, we recommend that priority be given to developing co-creation processes in new institutions. The initial effort may be greater, but the impact on the overall institutional relationship will be greater and, in the long run, the effort to maintain day-to-day collaboration towards shared goals will be much less.

› **Recommendation:** Clowning organisations and artists in particular need to relieve themselves of the pressure of succeeding in co-creation and adapt the process to each specific context. Co-creation needs resources. The first stage of the co-creation process - focused on forming a solid partnership and shaping a shared goal - requires the most resources. Then, regular co-creation activities take place more organically within this framework.

› **Recommendation:** Take into consideration who is coordinating the co-creation process, and their needs, so the artists can be an equal participant in a process of co-creation. Budget time specifically for co-creation processes. Co-creation enhances impact for the target groups. While positive effects of clowning for the target groups have happened without co-creation, artists, staff, and family members alike indicate that co-creation has multiplied or deepened the effects.

› **Recommendation:** Consider all the relevant stakeholders who can bring added value to co-creation: families, institutional staff, the target groups themselves, and plan to include them. More resources for co-creation processes have been made available by the partners in the dedicated website section for the [Co-Creation Map](#).

## THE ROLE AND WELLBEING OF ARTISTS IN THE HEALTHCARE / PEDAGOGICAL ECOSYSTEM

Artistic interventions work as complementary to the medical, therapeutic and caregiving acts. In the case of dementia, due to the nature of the work with older people, clowns occasionally support the caregiving staff with routines such as physical exercise, assistance with moving around, nutrition, etc. In ASD classrooms, the intersections between the clowns' activities and regular therapy for ASD have sometimes been confusing.

› **Recommendation:** As healthcare clowning becomes more intertwined in the healthcare landscape, the recommendation for organisations is to consider the implications and have clear discussions to negotiate roles and boundaries with medical staff and artists. Working with the target groups has been both rewarding and, in some cases, emotionally draining.

› **Recommendation:** While the organisations do currently offer psychological support to the artists in general, it is recommended to have regular evaluation of the psychosocial needs of the artists, to ensure their wellbeing.



See more information about the **CO-CREATION MAP**

## LEARNING TOOLS

**Learning and evaluation tools** such as post-visit reports and direct observation by others, help the artists and the organisations to better evaluate and understand the impact of their work by accessing relevant information that can otherwise elude them. Giving time and tools to facilitate reflection and self-reflection helps artists adapt their approach to the needs of participants, making the creative process more relevant and increasing the artist's confidence.

► **Recommendation:** If the resources allow our recommendation for the organisations is to intentionally give the artists the space and time for reflection in their work beyond ClowNexus, and maybe offer some additional resources to facilitate guided reflection (e.g. reporting forms with open questions, 3rd party observers etc). Through encouraging monitoring, evaluation, research, and documenting tools, ClowNexus has created an important pool of resources for the Arts and Health field.

► **Recommendation:** Create opportunities beyond ClowNexus for knowledge-sharing that can lead to a stronger collective impact.

## CLOWNING FOR THE TARGET GROUPS

The profound connection that the clowns can establish with people with dementia and children with ASD is the fertile ground in which positive effects can grow. Both audiences need continuity of clown visits. Recurrence of visits by the same clown has been associated with positive medium or long-term effects, both in the case of people with dementia, where memory loss is progressive, and for children with ASD who need more time to establish relationships.

► **Recommendation:** Strive to create long-term programmes for the work with audiences such as older people with dementia and children with ASD, if the resources and context allows. Focus on building strong relationships with institutions, as they are necessary to ensure continuity. Regular visits of the same artists with the same target group are essential. Getting to know the beneficiaries before the visits, from staff and families, was essential for the artists to integrate each person's needs in their play and to protect their mental wellbeing, as well as for caregivers and families to understand the potential of healthcare clowning.

► **Recommendation:** When possible, try to facilitate personal exchanges between artists, staff, and family members, where every party is encouraged to both speak and be curious. The direct exposure of institutional staff and families to artistic experiences increases their own understanding of the beneficiaries' condition and has positive effects for their own wellbeing. The staff and family members directly involved can also learn humour and art practices and integrate them in their own routines.

► **Recommendation:** While it is evident that the person most in need of support is the resident, artistic interventions could more often and more precisely target carers and families as direct beneficiaries (e.g., creating specific interventions to reduce stress at work among staff or creative approaches to reduce anxiety among family members). Now, the impact on them is indirect, they are more witnesses to what is happening than active participants.

► **Recommendation:** Given the fact that most of the time, mothers are hospitalised with children, they should be seen as direct beneficiaries, with specific activities to relieve anxiety, stress, and depression.

## AWARENESS RAISING

All audiences highly appreciate materials that bring the voices of the artists and the tangible reality of the institutional staff, beneficiaries, and families, such as the documentary film, clown portraits and Most Significant Change stories. Through their skills, artists can raise public awareness, promote acceptance, and stimulate positive change for vulnerable audiences.

► **Recommendation:** Artists can become advocates for people with dementia or a child with autism as well as for other target groups, and for healthcare clowning. Even when stakeholders were impressed by the impact of artists on target audiences, they could not always understand how these changes happened.

► **Recommendation:** In addition to evaluating and disseminating the impact of healthcare clowning, it is our recommendation to also create opportunities to show and discuss the methods that generate the success. By this, people will fully internalise the impact, and more importantly, the potential of this profession.



# ClowNexus

## ENDLINE EVALUATION

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December, 2023