

**USERS
AS
EXPERTS**

Repository of user expertise best practice



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1 Introduction

This document is the first intellectual output, or deliverable, of the Users as Experts project. It is a repository of user expertise best practices, which means that it collects and describes a number of successful previous initiatives and projects that relate to the topic of user expertise.

The document consists of four parts. This **introduction** provides basic information about the project and describes the methods applied during the development of IO1. **The analytical framework** gives a more detailed description of the assumptions underpinning our data collection and analysis, including a provisional definition of user expertise and our criteria for what constitutes a best practice. In the third part, we present our curated repository of **user expertise best practices**. We give a brief description of each practice and highlight possible lessons and limitations. Finally, we make some **comparisons and summarise** the collected practices.

1.1 About the project

Users as Experts is a transnational cooperation partnership funded by the Erasmus+ programme of the European Union. The aim of the project is to find new ways of turning personal experiences into recognised areas of expertise. In particular, we look at how persons with disabilities can use their experiences of inaccessibility to support efforts to create accessible products and services.

The partnership consists of the following organisations:

- **Funka**, an accessibility consultancy with a specific focus on ICT. Project coordinator. Based in Sweden.
- **DIAS**, an accessibility consultancy and research organisation. Based in Germany.
- **Synthesis Center for Research and Education**, a VET centre with a specific focus on social entrepreneurship. Based in Cyprus.
- **Furuboda**, a folk high school with a specific focus on persons with disabilities. Based in Sweden.

The Users as Experts project started in November 2020 and is expected to continue until November 2022. In that time, the partners will produce the following Intellectual Outputs (IOs):

- IO1: Repository of user expertise best practices
- IO2: Methodological toolkit for the identification, professionalisation and certification of user expertise
- IO3: Typology of web accessibility user expertise among persons with disabilities.
- IO4: Model curriculum for a user expertise course in web accessibility

1.2 Methods

In developing the repository of user expertise best practices, we have carried out cocreated data collection combined with some stakeholder engagement.

The data collection proceeded in several stages, with input from all partners. First, we identified existing sources where user expertise initiatives might be found. These sources included several databases of current and previous European and national research projects.

Name	Description
EPALE	Community for adult learning, funded by Erasmus+. Contains a resource centre and case studies repository, where we might find relevant initiatives.
Cordis	CORDIS is the EC's database of project results, probably the first port of call for anyone looking for information about research initiatives.
Erasmus+ Project Results	Platform for all results from Erasmus+ projects
REHADAT	Database of, among other things, research projects on inclusion of people with disabilities in Germany.
Vinnova	Database of projects funded by Vinnova, the Swedish innovation agency (in Swedish).
The Inheritance Fund	Database of projects funded by the Inheritance Fund, a Swedish funding scheme specifically aimed at youth and persons with disabilities (in Swedish).
Nordplus	Database of projects funded by Nordplus (funding scheme operated by Nordic Council of Ministers).
Prosjektbanken	Database of projects funded by the Norwegian Research Council.
Bufdir	Projects funded by the Directorate for children, youth and families (Norway) - in Norwegian, no proper search function.

Name	Description
KEEP	Database of cross-border, transnational and interregional projects in EU
EACEA Europe for Citizens	Database of projects/actions funded by the EU's Education, Audiovisual and Culture Executive Agency (EACEA)
Danske patienter	Overview of user involvement in the Danish Health Care system (In Danish)
Project contribution management of the Federal Office of Switzerland for the Equality of Persons with Disabilities (EBGB)	Database of projects funded by the EBGB
VET Repository / German-language publications	Literature search at the Federal Institute for Vocational Education and Training (BIBB) - Germany
European Agency for Special Needs and Inclusive Education	Database of projects funded by this agency
German education server	Database of Organisations, Networks, Research of inclusive education in Germany and on the european level
ESF Projects	Database of projects funded by the European Social Fund (ESF)

These sources were then trawled for relevant projects and initiatives, using a set of keywords. These included:

- Real users
- End users
- Users
- Expertise
- Experts by experience

- Co-creation
- User-centred design process
- Experts with disabilities
- Experienced involvement

Finally, the collected projects and initiatives were analysed according to four overarching indicators: aims, methods, results, and replicability.

2 Analytical framework

In this chapter, we give a brief overview of the analytical framework employed in Intellectual Output 1 and in the Users as Experts project as a whole.

The provisional definition of “user expertise” suggested in the Users as Experts proposal is the transformation of “lived experiences of persons at risk of exclusion [...] into skills that are sought after in the labour market”. A foundational assumption of the project is that marginalised persons have experiences that can respond to certain needs for expertise. Our example of this, and the focus of the latter half of the project, is persons with disabilities acting as auditors of web accessibility.

The overall theory is not new, though it goes by several different names – most often “experts by experience”. User involvement is also a related term. As part of IO1, the partners carried out a limited questionnaire with stakeholders thought to have worked with user expertise, expertise by experience, or use involvement. This questionnaire asked whether the respondents had carried out projects that relied on the active participation of marginalised target groups, and whether and how those projects used the particular experiences of those target groups.

The results were somewhat skewed towards organisations that work with persons with disabilities – in particular in the field of web accessibility – likely owing to the context in which the partners operate. A sampling of responses is presented below:

Have you carried out projects that rely on the active participation of those target groups?

If we define our employees with disabilities as the target group: Yes, all of our services depend on their work and participation - they are the more experienced screen reader testers, they are much better at assessing interferences between screen reader and other software, etc.

Clients as experts by experience do usability tests (of smart home devices).

Yes, face-to-face and online seminars.

In all the projects I worked on... the active participation of blind and visually impaired people was a prerequisite.

Minimum requirements for testing web content in easy-to-read language according to WCAG 2.1.

The focus of the business is on creating meeting places to learn from each other's experiences, try new things, empowerment and to arrange activities that are accessible to everyone, such as wheelchair dancing.

Have you used the particular experiences of those target groups in these projects? And if so, how did that work?

Yes, of course - as experts, they contribute their findings (they always test against WCAG) and uncover accessibility barriers in the digital applications much faster than we do. In addition, it often becomes clear how important it is that widgets are programmed and implemented correctly. Otherwise our colleagues ask "What is this? What can I do here?" and show us and our customers how essential correct programming is.

The support takes a lot of time. First, the person's trust has to be won (independent of the goal of the test, but in order to create a personal relationship/basis of trust). In the next step, the technology may need to be explained in much more detail and reservations/fears may need to be reduced. For example, if someone want to test a smart-controlled device, he or she may first need to be trained in how to use the smartphone and must understand what "the internet" is and can do. So it is not just a matter of translating the operating instructions of the devices to be tested into a language that the client can understand.

In particular, we did not conduct our online seminars as frontal instruction, but designed them in such a way that participants could contribute their own experiences. For each seminar, for example, we create a forum thread in which we provide the course material, but which participants can also supplement with their own knowledge and experiences. Supplementary contributions from participants during the online sessions are also posted there afterwards.

Yes, mostly through (regular, partly questionnaire-based) user tests that were noted as milestones in the project plan.

All activities are based on the target group's wishes and needs. As an organization, we have not been invited or noticed that other organizations / projects have been interested in our members' experiences to create increased accessibility.

The target group's interest controls which kind of operations we start. Then it is the case that we who lead the business ourselves have various disabilities, so in principle everyone ... belongs to the target group itself.

3 User expertise best practice

This chapter presents the first results of our efforts to build a repository of best practices of user expertise. With the analytical indicators – aims, methods, results, and replicability – as a starting point, we describe a collection of initiatives from across Europe. As the Users as Experts project progresses, we may add to this list as we become aware of further initiatives.

3.1 EX-IN

Experienced Involvement (EX-IN) is a model for the deployment of persons with experiences of psychiatric treatment as support staff in psychiatry systems. It began life as a project carried out between 2005 and 2007, with funding from the Leonardo da Vinci research programme. In that project, a consortium consisting of former psychiatric patients, support and advocacy organisations, educational institutions, and mental health care practitioners from Germany, Norway, Sweden, the Netherlands and Slovenia, came together to develop a training course for “Experts by Experience” in psychiatry. (EX-IN, 2021)

After a process of co-creation, the first pilot courses were carried out in 2007 and 2008. A few years after that, EX-IN was reconstituted in Germany as a charitable foundation. The EX-IN foundation maintains and promotes quality standards, methods, and curricula for “Experts by Experience” in psychiatry, primarily in Germany, but also elsewhere in Europe.

At its various locations around Germany, the EX-IN foundation currently offers three separate courses:

- Training course for Recovery Companions (*GenesungsbegleiterInnen*)
- Training course for Next-of-kin Companions (*AngehörigenbegleiterInnen*)
- Training course EX-IN trainers (*TrainerInnen*)

The course for Recovery Companions teaches people who have themselves experienced psychiatric crises to give support and guidance to others currently in that situation. The course for Next-of-kin Companions does something similar, but for relatives of people experiencing mental health crises. Finally, the course for trainers teaches participants how to lead the first two courses.

3.1.1 Key lessons

In terms of longevity and sustainability, EX-IN is a clear success. Since its beginnings as a project in the 2000s, the EX-IN foundation has established itself as a reference point for user expertise in psychiatry in German-speaking countries. Today, EX-IN courses are offered regularly at nearly 30 different locations in Germany, Austria, and Switzerland – and the companions trained through those courses are a valuable and much-appreciated resource in a variety of different psychiatric care institutions.

What explains this apparent success? A key factor seems to have been the co-creation model applied since the project's earliest stages. Persons with experience of psychiatric care and their next-of-kin were involved in the planning, design and development of the methods and curricula, which ensured a clear connection to the actual needs of the target group throughout.

At the same time, the project is clearly situated within the available scientific literature on psychiatric practice, and it also takes the views and experiences of practitioners into account. The original project leaders have admitted that bringing together people with so many different experiences was "a major challenge", but argue that in the end, this opened up new perspectives for everyone involved. (Heuchemer, 2016, p. 6)

Another success factor is the relatively limited scope of the initiative. EX-IN does not claim that their "companions" can function as substitutes for accredited psychiatric help; rather, the companions are intended as complements to existing care regimens. This, it appears, has helped set realistic expectations for what EX-IN can accomplish.

3.1.2 Possible limitations

Despite tracing its roots to a transnational project, the current use of EX-IN's courses and methods is mostly confined to German-speaking countries. As such, it is unclear how well the approach would work in other cultural contexts.

Another possible limitation is the lack of a clear professional path for those training as EX-IN companions. Although the companions are seen as a valuable resource by many practitioners, their participation in psychiatric care regimens usually takes place in an ad hoc manner.

Finally, EX-IN has thus far not made much use of digital solutions to further the spread and uptake of their methods. A new project called Trialog im Netz (Dialogue on the Web, TriN) is attempting to address this gap.

3.2 EXPERIENCE

Our Strength Is Experience (EXPERIENCE) was an Erasmus+ strategic partnership in the field of adult education that ran from 2017 to 2019. It brought together civil society and adult education partners in Slovakia, Hungary, Romania and Turkey. The main objective of the project was to help persons with disabilities become experts by experience, who could then counsel others in similar situations on the transition from education to employment. (EXPERIENCE, 2020)

The project sought to address the barriers to employment facing many persons with disabilities. While there are support systems in place across the EU, these systems are often understaffed. Moreover, how persons with disabilities might transition from education to employment is poorly understood by many, even within these support systems. The solution proposed by the project, then, was to make use of the experience of persons with disabilities themselves, allowing them to function as counsellors within those support systems giving advice to others facing that transition.

In pursuit of these aims, the project partners did the following:

- Workshops with experts and labour market representatives to identify needs, good practices, and recommendations
- International exchanges of experiences between support system professionals
- An online training platform for experts by experience based on the identified experiences and recommendations
- Pilot testing of the platform according to a blended learning methodology
- Recommendations for further implementation of the training programme

3.2.1 Key lessons

The EXPERIENCE project was structured in a way similar to the present Users as Experts project: that is, an initial collection of previous efforts in the field leading on to the development of new guidelines and training packages. This approach appears to have worked well, resulting in a robust set of material now freely available at the project website. Moreover, the validation carried out at the end of the project showed a high degree of satisfaction with the training, which bodes well for the future use of the results.

By creating the training programme as an online platform, available as an open educational resource on the project website, the project partners have ensured that the results can live on even without their active participation. This is of particular use during the current situation, with the ongoing pandemic making it difficult to carry out in-person training sessions.

Furthermore, the extensive efforts to validate the project outputs with stakeholders – including national conferences carried out in all four project countries – helped raise awareness of the materials created under the EXPERIENCE umbrella. This, too, is something that can be replicated.

3.2.2 Possible limitations

The EXPERIENCE project has a fairly high degree of complexity in its design. As such, it presupposes that those implementing its results will have some familiarity with labour market policy, supported employment initiatives, and civil society organising. This may have an inhibiting effect on actual uptake.

Furthermore, there does not appear to have been any effort to generalise the project findings to the European level. Rather, the project sits within a more specific, south-southeastern European context. This is not necessarily a drawback, as it could increase usefulness in that particular context, but it is worth keeping in mind when trying to implement the results elsewhere.

3.3 Experts by experience (FI)

Experts by Experience is an initiative by Mielen, a mental health NGO based in Tampere, Finland. Mielen's main focus is on what they call "recovery orientation"; in other words, helping persons in care navigate their own recovery proactively and independently. The Experts by Experience initiative started in 2001, with people recovering from crises related

to mental health, substance abuse, or other life events as its main target audience. The stated aim of the initiative is to make use of the lived experiences of this target audience in therapeutic practice. The purpose is both to give persons currently in care a more personal perspective on what recovery can look like, and to provide employment opportunities to persons formerly in care. (Mielen, 2020)

In practice, the solution offered is a training programme comprising about 100 hours of education over eight months. The programme teaches participants how to fit their life stories into therapeutic practice, so that they cohere with and enhance ongoing treatments. Since the participants have had traumatic experiences of their own, their well-being is monitored throughout using the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) to prevent triggering effects and relapses.

Once trained, Mielen's Experts by Experience get to participate in placements to test their skills. After this, they can pursue paid employment in a variety of mental health care settings.

3.3.1 Key lessons

The longevity of the Experts by Experience initiative speaks to its success. Today, trained Experts work as support staff within mental health care services, lecturers relating their life stories to varied audiences, and as service user representatives in decision-making processes. A 2017 impact study of the initiative found that it is appreciated both by the Experts themselves, and by persons in care. In addition, the study found that there were clear economic benefits to the initiative, since the Experts by Experience provide early intervention support.

A possible source of strength for the Experts by Experience initiative is that it is rooted in both the scientific literature and therapeutic practice.

3.3.2 Possible limitations

The same impact study mentioned above also indicated that the training programme, extensive though it is, could only go so far. There is a significant component of "learning by doing" for the Experts by Experience – that is, they get better at providing support the more practice they get. For others attempting to make use of lived experiences as expertise, two conclusions can be drawn from this; one, that you should not be overly reliant on teacher-to-student education, and two, that any successful training programme must provide for extensive practical application of the skills learned.

3.4 Fachkraft "Leichte Sprache" (DE)

The Fachkraft "Leichte Sprache" (Simple Language Professionals) is a project by the Netzwerk Leichte Sprache (The Simple Language Network), in cooperation with the charity organisation Caritas Augsburg and with funding from the German Federal Department of Labour. The target audiences of the project are people with learning disabilities and persons producing "simple language" material. The aim of the project is to ensure that "simple language" texts are useful to those who need them the most. (Netzwerk Leichte Sprache, 2021)

The proposed solution of the project is to train persons with learning disabilities to become proof-readers for simple language texts. The assumption is that since persons in this group actually use and benefit from simple language, they will be well-placed to judge whether a simple language text actually meets their and their peers' needs. Over the course of twelve months, participants will learn how to audit simple language texts and advocate for simple language within office settings.

The project started in early 2020 with a pre-study. Individuals from the target groups participated in the pre-study. One of the results of that study was to specify the professional title of those who have undergone training as "Büropraktiker*in" (office practitioner). Twelve participants were recruited for a pilot version of the course that was due to start in August 2020. However, this was postponed due to the ongoing covid-19 pandemic.

3.4.1 Key lessons

The Fachkraft "Leichte Sprache" project is a clear example of how user expertise methods can benefit persons who stand at a remove from education or employment, by turning their particular experiences into sources of strength. This is further enhanced by the involvement of the target audiences themselves from the very beginning of the development process.

Finally, the project keeps the particular needs of the labour market in focus, ensuring that the training programme results in something of real use to both the participants and potential employers.

3.4.2 Possible limitations

Because of the delays incurred following the outbreak of the pandemic, there is so far little proof of concept for the training course approach. There is a possibility that the programme will have to be adjusted to properly cater to the needs of the participants. Furthermore, the project is placed within the German context, and scant attention appears to have been paid to future internationalisation. However, there are no inherent obstacles to such an internationalisation.

3.5 Illico

Illico is an Erasmus+ project carried out by a consortium of partners in the civil and higher education sectors in Ireland, France, Bulgaria and Finland. The project started in 2018 and is slated to run until the end of 2021. Its target audiences are people with intellectual disabilities and their next of kin. The aim of the project is to empower persons with intellectual disabilities and enable their inclusion and self-determination in society – and, in a more practical sense, to further the process of deinstitutionalisation. (European Commission, 2018)

To achieve this, the solution pursued by the Illico partners is fourfold. The first step is to carry out research on what is referred to as "peer mentoring" – that is, support and guidance being provided by someone who has similar life experiences to the supported person. The second step is to develop video trainings on independent living by and for the

chosen target audiences. The third step is the assembly of a toolkit for developing support networks, which can be implemented in a variety of political and national contexts. Finally, and on the basis of the preceding steps, the fourth step is to lay out techniques for peer mentoring – in essence, a model methodology.

3.5.1 Key lessons

The first two steps of the project appear to be completed and have resulted in a series of online seminars and a set of video training sessions.

One particular point of interest with regard to this project is that it covers disparate geographic and political contexts. The countries represented in the consortium have different systems of welfare and social care, and are at different stages in the process of deinstitutionalisation. This may help produce results that are valid and useful across Europe and elsewhere.

In addition, the focus on user involvement and co-creation is a considerable source of strength for the sustainability of this project.

3.5.2 Possible limitations

As with many other current initiatives, the covid-19 pandemic appears to have had an adverse effect on this project in the form of delays. This issue is compounded by a somewhat lacking approach to dissemination: in their brief information about the project on their respective websites, each of the partners link to a separate website and indicate that more information can be found there. However, as of July 2021, that website is either inaccessible or non-existent. This makes it difficult to gauge precisely how much progress has been made in the project.

3.6 Knowing what poverty really means (BE)

The “Knowing what poverty really means” project trained people who have had personal experiences with poverty and social exclusion to assist Belgian federal public services to reach out to those in need. Those recruited provided their personal experiences in situations of poverty to help develop services that can better respond to the needs and expectations of vulnerable people in Belgium. The project received funding from the European Social Fund (ESF) and was carried out between 2009 and 2015. (European Social Fund, 2016)

The main objective of this “innovative experts by experience” initiative was to integrate the human dimension of poverty within the federal public services and improve access to the federal public services for all citizens, particularly for those people in vulnerable situations.

This initiative aimed to achieve these objectives by:

- Improving the user experience when asking public services for help.
- Providing the most relevant information about the services available.

- Guiding vulnerable people through “the system” so that they can access the services that best suit their needs.
- Contributing knowledge and experiences to different public sector departments to encourage the implementation of actions to combat poverty and ensure relevant issues are tackled more effectively at political level.

In total, 28 experts were employed by the public sector and 4 coordinators were appointed to help develop the project, organise its activities and supervise the experts. All the experts received extensive 2-year vocational training course including both part time training and part time work experience. This training was also tailored according to the different roles and areas of work of each expert.

3.6.1 Key lessons

The initiative was a success in Belgium. In 2015, after 7 years of implementing the project, the service was expanded to support vulnerable people who wish to access healthcare provision. It has had a direct impact on the ground, providing 28 vulnerable people with access to training programmes and work experience. Indirectly, many more have benefited.

The project is now considered as an established practice in policy to combat poverty in Belgium. The term “expert by experience” championed by this initiative has now been officially recognised and adopted within the functional architecture of the Belgian public services.

An “expert by experience” network has also been created which enables the experts to exchange information and to draw from the lessons learned from the experiences of others. According to information launched by the project, "a good number" of the experts of experience are still working in the same service, after the initiative has finished.

3.6.2 Possible limitations

There is no information available to indicate that this practice has been expanded to other countries outside of Belgium, suggesting limited impact and uptake at European level. Little information is provided with regards to the number of experts still working in this field and the real impact the service has had in combatting poverty in Belgium. More concrete success indicators such as the number of users who continue to work as experts in paid positions in the public sector or the number of vulnerable people who have benefited from the service, would be helpful to better gauge the success and sustainability of the project.

There is no information or website with updated or current information on the project.

3.7 Food Research Collaboration (UK)

The “Learning from 'experts-by-experience' as a form of participation in food policy” project aims to identify the benefits and limitations of engaging with experts-by-experience for local authorities and food partnerships. It was carried out between 2008 and 2015 and was funded by the European Social Fund. (Food Research Collaboration, 2021)

In food policy, this concept has been used in participatory research and as a tool to provide input to the development of policies. Particularly at local level, experts by experience have been used for a wide range of issues such as local food environments, obesity, and urban food policy. Moreover, different groups have been involved as experts including young people, older adults or those facing specific social situations such as food poverty.

Whilst the active involvement of citizens makes policy development more inclusive and effective, it can also present a series of political and ethical challenges. Typical issues that arise with this type of public participation include:

- Representation: who do the experts represent?
- Legitimacy of knowledge: formal vs lay expertise
- Use of knowledge: in what way can and should the knowledge be used?
- Burdens placed on participants.

Additional issues have arisen with the use of the practice in specific areas, such as food poverty. Their use in this area raises questions such as what does it mean to be labelled as an “expert-by-experience in food poverty”?

3.7.1 Key lessons

The active involvement of different groups as experts has been used on a wide range of issues, suggesting the positive result achieved previously by the Food Research Collaboration with this approach in the UK.

3.7.2 Possible limitations

The coordinators of the project make it clear that there are some negative implications of using experts by experience in policy development, particularly highlighting the ethical and political challenges.

Also, there are no real results or information on impact available on this initiative. It is therefore difficult to discover the conclusions of the project and a detailed overview of the positive and negative aspects of using experts by experience in policy development.

This project was limited to the UK, suggesting a very national approach in the use of experts by experience in this policy domain.

3.8 No Labels No Walls Overseas

Today, a great many young people find themselves outside of the societal norms and expectations. The “No Labels No Walls Overseas” project will investigate and further develop youth work practices that promote inclusion, wellbeing, and social participation of younger members of society that find themselves in a vulnerable position. The target group of the project activities include youth workers, both professional and voluntary, who are helping and supporting young people with disabilities and young people experiencing mental health. This group includes people in more vulnerable positions due to physical,

mental, ethnical, educational, economic, health and social obstacles. The project is funded by the ERASMUS+, Learning Mobility of Individuals Key Action and will take place during 2021. (European Commission, 2021)

Peer support practices, such as the Guided Peer Support (GFP) model have great potential to support vulnerable people. GFP uses meaningful and concrete cultural workshop activities to empower marginalised people. Activity groups are run by young people who are trained to help their peers on various life aspects such as social skills and practical life skills. During the activities, the participants are encouraged to explore their strengths, providing them with new opportunities to succeed in life and better integrate in society. The leaders are people who directly work with young people, and some may have experienced the same obstacles as the young people they help and support. These “experts-by-experience” work as peer-tutors in the GFP based youth work practices. In this model, the professionals have a supporting role and do not play a central role in the learning sessions.

The project also aims to train youth workers to be able to use digital tools to create a supportive environment for young people and their support networks. It also aims to use these digital tools to actively engage youth workers, peer tutors and young people in a process of continuous learning and collaboration on a national and international level.

Furthermore, the project aims to continue developing way to provide entrepreneurship opportunities and entrepreneurship guidance in the field of culture for youth participants. Vulnerable youth and youth with mental health backgrounds often have challenges in finding employment and a place in society. Project partners aim to create environments where participants can become empowered, highlighting entrepreneurship opportunities in the social and health sectors, and demonstrating that culture belongs to everyone, including more marginalised groups.

The project consortium aims to achieve these goals through a staff exchange programme whereby representatives from each of the partners get to spend time and work with another organisation in the consortium with the intention of learning from each other’s practices by participating and doing. The focus of each of the exchanges includes:

- Staff exchange 1 (Sweden): methodologies and practices of culture and entrepreneurship, fostering wellbeing and inclusion.
- Staff exchange 2 (Finland): digital platforms and how they can support cultural creation of marginalized groups and youth with mental health challenges.
- Staff exchange 3 (Sweden): peer support and co-creation practices, exploring the potential of collaborative and inclusive learning and mutual support.
- Staff exchange 4 (Finland): co-organisation of the No Labels No Walls (NLNW) international online festival. The festival focuses on inclusion and citizenship through arts and culture.

The project will aim to improve and diversify the youth work practices of partners, implement more entrepreneurship training activities for these groups and better integrate

new marginalised target groups in the activities. One of the joint expected impacts is the implementation of more and better online practices. The highlight of which will be the creation of an online platform for continuous learning and development between the two partners.

3.8.1 Key lessons

A very strong element of this project is the fact that the consortium is taking a tried and tested peer to peer training methodology (Guided Peer Support) that has proven to be very cost-efficient and effective, and they are adapting it to different context and situations. This will help the consortium to identify the potential and possible limitations for this model with the view of a wider use in municipal context on an international level.

The transnational testing of national digital practices and applications is also extremely positive as it is expected to lead to the development of new digital practices in Europe.

The project will also generate a lot of mutual learning, capacity building and exchange of good practices that are replicable or adaptable and can be implemented within the partner organisations and beyond as an outcome of the project. The focus on equipping youth with an “entrepreneurship attitude” is also interesting as an approach to help them to become more independent, decisive, and skilled.

The involvement of partners with a wide outreach in their respective countries. For example, Kukunoria, a central association in Finland, reaches over 70,000 individuals by providing opportunities for professionals and peer-to-peer activities to experiment with new skills and methodologies.

Finally, the participants who become “experts-by-experience” will receive valuable experience in international collaboration. For some, this may be the first time, providing them with inspiration to follow new career pathways and receive guidance in both their personal and professional lives.

3.8.2 Possible limitations

One of the main limitations with this project is that it is very new. The project began in January 2021 and does not end until 2023. This means that tangible results from the project will not be made available until a later stage, limiting the impact that they will have on the Users as experts project.

The involvement of partners from two Nordic countries (Sweden and Finland) limits the scope and possible learning opportunities for a project of this nature. Whilst the project description highlights the aim of extending the GFP model to other European countries, the learning outcomes of the project would have benefitted a great deal from additional members in the consortium from other parts of Europe who may address the subject from a different perspective.

The objectives for the project can also be seen to be extremely ambitious. There are a lot of activities that will be carried out and the expected impact seems to be very high level. Also, the successful training and subsequent incorporation of vulnerable youth groups into

employment is extremely challenging. Therefore, the management of expectations of the “experts by experience” should be considered to ensure that they are aware of the difficulty of the task at hand and do not become frustrated.

3.9 Peer Support

The PEER Support project aimed to develop and establish a new professional role within the Swedish healthcare services: Peer Supporter. The Swedish Partnership for Mental Health (NSPH), funded by the Swedish Inheritance Fund, has produced a national programme including guidelines and a framework for Swedish education on peer support, as well as training the first peer supporters in the country between 2016-2019. (NSPH, 2019)

The idea behind the project is that people who have suffered mental health problems in the past can use their experience and be trained to work as supporters in healthcare support and rehabilitation services. The Peer support model is a research-based method that has been tested successfully in other countries such as the USA, the Netherlands and England for several years. Swedish and international research shows that peer support gives faster recovery and self-power development, better self-image, reduced self-stigma and increased hope for the future, more close relationships and feel more understood, accepted, and liked. PEER is an acronym for personal, experience, expert, resource.

The main objective was to establish peer support as a new, quality assured professional role in Sweden and further develop knowledge and generate awareness about the potential benefits of peer support. The project has developed a national platform and framework for this professional role. In the longer term, the project aims for peer support to become an integral part of the services offered by the Swedish healthcare system, being offered at different phases of a patient’s contact with the system.

The training programme was provided in four pilot counties: Stockholm, Skåne, Västra Götaland and Västerbotten. After the training programme was carried out, the newly trained peer supporters were employed within health care services or social psychiatric units in their respective counties. A reference group was created with the CEPI research group at Lund University to ensure the quality of the project. Their focus was on the quality of the training programme and of the subsequent peer support services provided.

3.9.1 Key lessons

The Peer support model is a tried and tested methodology that has proven to be successful in different countries. Research shows that it has generated results including faster recovery and self-power development, better self-image and reduced self-stigma.

Also, results from the project showed that this method served as an important bridge between patients and the staff. For example, patients may be more willing to talk about their vulnerability and life situation with a peer supporter in comparison to a member of staff in the inpatient ward. This leads to increased equality and more openness about what is discussed, helping to establish a solid relationship with the patient.

The positive effects of peer support can also be seen through the companies that use it. The companies involved in the project mention that they have become better at seeing the business from a user perspective. They mention things like increased knowledge and understanding.

Finally, it also seems that the control measures introduced were an important part of the project, ensuring the quality of the project using a reference group.

3.9.2 Possible limitations

No direct data or indicators can be found for the results of the project. For example, concrete quantitative indicators such as the number of peer supporters employed across the four counties during the project would be beneficial to help gage the success of the initiative.

Interviews with the project manager after the project had finished highlighted that authorities and decision-makers in Sweden are anxious and have not dared to expand the initiative to even more cases just yet. Furthermore, it seems that this was a funded initiative, and the project was not able during this time to make it an integral part of the Swedish healthcare system.

3.10 The Missing Link

Experts through experience nowadays play a crucial role in enabling societal participation for different groups affected by exclusion. In various countries there are already training programmes for these experts who work professionally in various paid and voluntary areas. This project aims to improve training programmes and employment opportunities in this area. The project was financed by the European Commission's Lifelong Learning Programme. (Missing Link, 2011)

The project focused mainly on the training of the experts through experience by developing a "train the trainer" programme for experts by experience, experts by training and those working in tandem. A tool was also developed providing examples of tandem working which aimed to get participants to reflect on the effects of working in tandem for excluded persons and to stimulate reflection on the complimentary roles of experts by experience and experts by training. The project also helped the expert by experience to work on their life stories as a crucial element in their learning process, helping them to monitor their own growth and empowerment.

Another key part of the project is the focus on employment. A methodology was created to address employers regarding the employment of experts by experience. On-the-job training programmes were also created for experts by experience.

Finally, the consortium focused on the evaluation of this approach by developing special research instruments to describe the result of the evaluation of the training programme and its effects on social inclusion. It also served to describe the foundation of this approach and the underlying knowledge behind it.

A European Charter on increasing social inclusion by engaging experts by experience was developed at the end of the project and still available online to be signed, publicly.

3.10.1 Key lessons

The project develops synergies between professional education and employment combining the dual focus on peer-to-peer training and an active contact with potential employer to facilitate an encourage the employment of experts by experience.

The development of a European Charter is a powerful tool for generating awareness on the use of experts by experience in this instance, for increasing social inclusion in Europe.

The use of the life stories of the experts by experience as a training tool as part of the “train the trainer” programme used in this project is extremely interesting.

The detailed evaluation approach is an extremely positive part of the work carried out in this project.

3.10.2 Possible limitations

The project is somewhat dated and information about the impact and results for the project is limited.

3.11 Trust the experience, not the dealer

The three-year project will share knowledge and best practices, to develop an international model of “next level” experts by experience on the damage that gambling can cause. During the project, a pilot group of participants, consisting of experience-based experts, will be trained. Although the project approaches experiential expertise through gambling addiction, the training package is designed to be applicable to other topics as well. The project is funded by Erasmus + and is implemented in cooperation with three countries: Finland (Sosped Foundation), Ireland (Extern Ireland) and Norway (Spillavhengighet Norge). (European Commission, 2020)

In all three countries, there's a demand for knowledge, new approaches, effective models, and concrete tools that support our public health professionals and treatment (expert by experience, working side by side with professionals), tools that help organisations and individual experts by experience to influence in society and structure and training for those individuals who have suffered harms (in this case gambling) and want to continue their work of helping others in a bigger scale.

Through exchange of expertise and good practices the project aims to create a high-level training, competence, and ability of all three organisations to support, educate their target groups, spread the knowledge to society and public health by trained experts by experience and in the end- spread this next level training to other areas, such as mental health issues and other addictions.

The activities to be carried out in the project will focus on:

- Creating a structure and training for the “next level” experts by experience.

- Providing an operating model for international use.
- Researching more about the phenomenon globally (including treatment, differences in regimes etc.)
- Creating a structure and training that can be copied in other areas (for example mental health issues, other addictions) developing a certain type of standard in the field of experts by experience.

As part of the training developed, material will be produced on experiential self-care, public speaking and social impact. The material will be compiled into one training package, which will be made freely available and used in the training of experienced experts.

The project can be considered as innovative for different reasons. Firstly, the experienced experts are behind the project itself. They identified a need for the project and have taken this idea forward. Furthermore, the international nature of the project will provide an understanding of gambling addiction and its prevention in different contexts. Although gambling is organised differently in each project country, the disadvantages of gambling are similar.

There are no results available for this project yet as it started only towards the end of 2020.

3.11.1 Key lessons

Peer-to-peer models have generated positive results in Finland in developing services, changing attitudes, and creating an understanding of challenges which people meet during their lifespan.

A very interesting aspect of this project is that the training programme and knowledge whilst initially targeting the subject of gambling, will be able to be used in other areas such as mental health issues and other addictions, highlighting its potential for transferability.

3.11.2 Possible limitations

It is still very early on in the project and so no concrete results, or impact can be assessed.

4 Conclusions

4.1 Key lessons summarised

Many of the initiatives we have found were started quite recently, which makes it difficult to assess the impact of the projects in the medium and long term. Nevertheless, there are a few factors among the key lessons for the different projects that may be particularly useful to consider for setting up similar initiatives.

1) The importance of commitment to substantive training and support

It can be noted that the three initiatives that have been going on for the longest time and have been extended beyond the initial projects all involve substantial amounts of training for the experts by experience (1-2 years training programmes), as well as a well-defined structure and infrastructure for how the experts can put their knowledge to use after they have been trained. It would therefore seem that for an initiative to be successful in the long run, there needs to be an important commitment both on the side of the experts (to go for a substantive training), and on the side of the trainers/facilitators (to provide continuous support for the application of the expertise). This is also in line with the ambition of the Users as Experts project, where one of the objectives is to create a curriculum for a vocational training course to turn user experience into expertise

2) Managing co-creation

It was difficult to find enough details on the co-creation process of the different projects to be able to discern how the processes converge or differ and what factors are important to consider for making co-creation a success. Only a few projects clearly stated that persons with experience were involved in designing the training and/or other project activities. In a few instances, representatives of the users are the initiators of the project itself. However, most of the projects make some sort of reference to exchange of views and mutual learning, either between the users with experience and outside experts or in a peer-to-peer setting. To be able to fully utilise the potential of the user experts as well as empower the users themselves, it therefore seems important to design the project in a way that leaves a lot of space for the users to make a contribution to the design and execution of the activities as co-creators, not just participants.

3) Clearly defining the remit of the user expertise

Most of the projects and initiatives are focussed on providing user expertise based on experience to other persons currently facing similar situations. Notably, several of the initiatives focus on experiences in the health sector and aim at peer-to-peer support to persons in vulnerable situations. A few of the projects aim at providing services to professionals based on the expertise stemming from experience. While the intended receivers/customers of the user experts vary depending on the topic, the examples we found show that it is important to have a clear view of what the user experts are able to provide, in order to avoid confusion and possible disappointment. In several of the projects, the user experts work alongside professionals to complement their services, either in a voluntary or in a paid capacity. In other words, the user expert is a category of

professionals per se, they are not replacing or acting in the same capacity as the trained professionals in their field and they may still need support from other professionals in their role as user experts. It is therefore important to define the role of the user experts in a way that makes it clear both to themselves and to whoever uses their expertise what the role involves and what the limitations are.

4.2 Table summarising the characteristics of each of the examples

	Geographical scope	Long-term (beyond single project)	Professional development (employment opportunities)	Clients when using acquired expertise
EX-IN	Germany, Norway, Sweden, Netherlands, Slovenia	Long-term	No	Peers
EXPERIENCE	Slovakia, Hungary, Romania, Turkey	Project	Yes	Peers
Experts by experience	Finland	Long-term	Yes	Peers
Fachkraft "Leichte Sprache"	Germany	Project	No	Peers
Illico	France, Ireland, Bulgaria, Finland	Project	No	Peers
Knowing what poverty means	Belgium	Long-term	Yes	Peers, professionals
Food Research Collaboration	UK	Project	No	Professionals
No labels no walls overseas	Sweden, Finland	Project	Yes	Peers
Peer support	Sweden	Project	Yes	Peers
The Missing link	Netherlands, Bulgaria, Germany, Portugal, Belgium	Project	Yes	Peers, professionals
Trust the experience, not the dealer	Finland	Project	No	Peers

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