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**ENABLIN+ External Evaluation
August 2017
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Executive Summary

ENABLIN+ is an international partnership project funded by the European Union's Life Long Learning Programme from 1/1/2014-30/6/2017 (Contract 541981-LLP-1-2013-1-BE-LEONARDO-LMP). It aimed to address the needs of children and young people with complex and intense support needs (CISN), their caregivers and supporters. The project developed a system of interdisciplinary in-service training and associated resources, through which parents and professionals of various backgrounds learned together, the aim being to improve inclusion, promote de-institutionalisation and enhance quality of life of the children and young people with CISN. The project partners, from the Netherlands, Belgium, France (including the Island of Réunion), Portugal, Italy, Bulgaria and Romania, were also diverse, including universities and private organisations, both commercial and non-profit.

This report is an external (independent) evaluation of the ENABLIN+ project, conducted by Professor Juliet Goldbart and Dr Claire Pierson (Manchester Metropolitan University, U.K.). The evaluation assesses the success of the project in meeting its stated aims and identifies both areas of good practice and challenges in achieving outcomes, providing recommendations for future collaborations.

The evaluation engaged with participants through online interviews and questionnaires. The lead member of each of the eight project teams participated in an online interview and reported back on the achievement of project deliverables. The views and experiences of project team members (nine in total) and external participants (23 in total) were collected through questionnaires.

Findings:

1. The project partners completed a needs assessment, identifying examples of good practice then developing a set of training modules across the relevant languages, oriented to support needs assessment, staff attitudes, beliefs and conceptual systems, enhancing children's communication capacities, daily life activities, behaviour regulation, activation and participation in learning and inclusive schooling. The results were disseminated in newsletters, professional articles, and, most significantly, in a training book and DVD, available across all the project languages.

2. In relation to the original aims of the Enablin+ project (see Introduction), the aim of “promoting quality of life of children and young people with complex dependency needs” is a major societal project. As recognised by several participants, this will take longer than the lifespan of the Enablin+ project. The resources and training delivered by the project and aimed at a wide range of stakeholders, however, are likely to make a significant contribution.
3. **The training materials (book, DVD, conferences and workshops) have succeeded in providing resources accessible to and appropriate for a wide range of practitioners and for families.** The collegiate approach to the development and implementation of this training has been noted by several participants. This suggests that family carers as well as professionals, service providers and policymakers can feel empowered by the materials developed.
4. Differences in current education policies and practices across countries mean that progress towards social and educational inclusion is interpreted in different ways. As with enhancement of quality of life, it is unrealistic to expect rapid change, but both project team members and external beneficiaries report the value of the project in contributing to these ends.

There were a number of highly positive processes and outcomes identified by the evaluation, including:

5. The process of **sharing knowledge, experience and practice** both with partners from a variety of European countries and with a mix of professionals, academics, policy makers and service users was emphasised by almost all participants to the evaluations as one of the core benefits of taking part in this project. The sharing of such knowledge was viewed as mutually beneficial to all who took part.
6. The project was deemed to have **created innovative and useful materials** including training materials, workshop notes and a website. Participants noted they have used these to develop their own practice on a regular basis.
7. **Raising awareness** of the issues which affect children with complex and intense support needs was viewed as a contribution of the project to wider society. Whilst this

cannot be measured in the short term, this should be a longer term benefit of the project which will contribute to quality of life outcomes.

8. Whilst it was noted that the project aims were highly ambitious, they were viewed as **clear and well-articulated**.
9. The **dissemination of project outcomes both through events and online dissemination** was highlighted as a positive outcome.

There were also a number of areas raised for consideration, including:

10. Given the number of partners involved in the project, **funding for translation should have been a greater part of the costs**. In addition, precise **definitions and terminology relating to CISN should have been discussed and agreed at the start of the project**
11. More structured processes for managing a large and geographically diverse project would have facilitated the achievement of outcomes. This might have included a **designated project manager**.
12. A minority suggested that project aims were perhaps too ambitious and could have been more modest. Publication of academic papers has been slow, relative to other outputs.
13. Whilst project outputs were mostly well disseminated, one partner highlighted that more consideration of how the outputs were to be utilised would have been helpful.

Conclusion

To sum up, the project has achieved those aims that it is realistic to expect within the lifetime of the project. The project teams have also completed the great majority of the planned deliverables and outcomes. Notable outputs include the book of training and background materials: Enabling Activity and Participation, and its associated DVD.

In addition, the process of collaborative and interdisciplinary working has modelled good practice.

Authors

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Conflict of interest statement:

Juliet Goldbart attended the partner meetings in Milan and Evora and presented at the associated workshops/conferences. The content is included in the Training the Trainers book produced as one of the main deliverables of the project.

Claire Pierson has had no engagement with the project outside the external evaluation.

Introduction

ENABLIN+ is a unique and innovative international partnership project funded by the European Union's Life Long Learning Programme from 1/1/2014-30/6/2017 (Contract 541981-LLP-1-2013-1-BE-LEONARDO-LMP). It addressed the needs of children and young people with complex and intense support needs (CISN), their caregivers and supporters. The project developed a system of interdisciplinary in-service training and associated resources, where parents and practitioners of various professional backgrounds learned together; the aim being to improve inclusion, promote de-institutionalisation and enhance the quality of life of the children and young people with CISN.

The Enablin+ project is led by Dr Jo Lebeer, University of Antwerp, and has eight partners:

- University of Antwerp, INCENA Inclusion & Enablement project (Belgium)
- Bureau Nijland & Kroes (Netherlands)
- CESAP (France)
- Babes-Bolyai University, Department of Applied Psychology (Romania)
- ASFA Association Saint-François d'Assise (Réunion, France)
- Karin Dom Foundation (Bulgaria)
- Fondazione Don Gnocchi (Italy)
- Universidade de Evora (Portugal)

The balance of public and private partners is worthy of note; there are three university partners, four private non-profit organisations and one private consultancy.

The stated aims of the Enablin+ project were:

1. "To promote quality of life of children and young adults with complex dependency needs by increasing social and educational participation, facilitating activities, learning and development; by raising awareness of those supporting them, that it is possible and worthwhile to activate them, and by creating a shift of mind in this sense.

2. To enhance the quality of support as well as contribute to de-institutionalisation and inclusion, by increasing self-efficacy of parents and professionals working with children and young adults with complex dependency needs, in accompanying them towards a more inclusive and active life
3. To develop interdisciplinary in-service training modules for professionals and parents working with this target group, to enhance competencies in cognitive activation, increasing autonomy, activities in daily life, communication, behaviour regulation and in inclusive education
4. Professionalizing staff of mainstream schools in welcoming children with complex dependency needs
5. Strengthen parents-professionals cooperation
6. Empower parents and professionals.”

(Enabling and Including Young People with Complex and Intense Support Needs, Enablin+, Lifelong Learning Programme Application Form p.30, 2013)

Overview of the Evaluation Methodology

The aim of this external evaluation was to assess the extent to which the Enablin+ project had met its stated aims, the challenges to meeting those aims experienced by the project partners and the benefits of the project, its impact and future directions.

The evaluation plan was presented to the Enablin+ project team at the team meeting in Evora, Portugal (19/02/17) and agreed (see Table 1).

Table 1: Evaluation Plan

1. Identify the expected deliverables from each of the work packages.
2. Interview a leading team member from each of the project partners, to explore impact, barriers and challenges in more detail. *This was amended at the request of several team leaders who were not confident in their ability to address complex issues in a “real-time” interview in English. As an alternative, the interview questions were emailed to the team leader who could then respond in their own time. See Appendix 1.
3. Use the list of deliverables derived in 1. (above) to produce a questionnaire (see Appendix 2) to identify from project team members:
 - a) The extent to which deliverables had been achieved.
 - b) Modifications to the original objectives and the reasons for these.
 - b) Some quantitative data, e.g. number of participants at training events
 - c) Reasons why any objectives or deliverables were not achieved or were not fully successful.
 - d) Perceived impact of the project for different stakeholders; team members, professionals, families, children with complex needs.
 - e) Perceived barriers to implementing findings of the project.
4. A second questionnaire (see Appendix 3) aimed at a wide range of potential project beneficiaries, e.g. family members, professionals, service providers, was developed to identify the impact of the project within the beneficiary’s family, service, profession and/or region, their perceptions, experiences, benefits and the challenges experience in relation to the project.

Data Collection

The data collected were primarily qualitative. Data collection tools were devised as identified in Table 1, and comprised an online interview for project partners and two open-ended questionnaires. The first questionnaire was designed for project team members. The second was designed to elicit information from external participants to the project (including professionals, service users, policy makers and service managers).

All data were collected electronically and stored on the researchers' password protected computers. Ethical approval was granted by Manchester Metropolitan University Faculty of Health, Psychology and Social Care Ethics Committee.

Interviews:

Structured email interviews, in English, were sent to the identified lead person (or their nominee) for each of the eight partner organisation. All eight were completed and returned. Interviews were used to determine how the project deliverables were met, the benefits of these deliverables and any challenges incurred.

Questionnaires:

The two questionnaires were sent to the lead person for each of the partner organisations (or their nominee), with the request that the first be distributed to all Enablin+ project team members in their organisation, and the second to a range of people who had engaged with the Enablin+ project as potential beneficiaries. This was intended to include service users (including family members), service managers, policy makers and professionals. The ENABLIN+ project team were responsible for disseminating the questionnaire and translating it into the host country/region language where required.

Data Analysis

Interview and qualitative questionnaire data were analysed using Thematic Network Analysis (Attride-Stirling, 2001). Thematic Network Analysis is a robust and highly sensitive tool for the systematization and presentation of qualitative analyses, increasingly used internationally in

health and social science evaluations (e.g. Dickenson, 2009; Flacking & Dyckes, 2017; Goldbart & Marshall 2014, Skovdal, 2011). Thematic networks are web-like illustrations that summarize the main themes from qualitative data using firstly a global theme which is then broken down into smaller organising and basic themes.

Limitations of the evaluation

There are three main limitations identified within this evaluation.

First, all data were collected in English. As professional translation services were not available within the scope of the evaluation the evaluation team relied on translation by project team partners and project team members into English.

Second, all data was collected electronically. This means that while interviews and questionnaires were open-ended, the researchers did not have the opportunity to ask follow up questions of participants.

Third, the completion rate for the questionnaires was low for some partner organisations. This was partly due to the small size of some of the teams, but also a resource and time issue.

In addition, but unavoidably, the data for this external evaluation were collected before the final completion of the Enablin+ project. Thus, some deliverables were incomplete but have been completed subsequent to the finalisation of this report.

Evaluation Findings

The following findings are divided into four parts, based on the online interview and two questionnaires which were distributed to stakeholders. Findings 1 and 2 are based on the views of project partners and project team members, whilst findings 3 is based on the views of external participants including professionals, service users, policy makers and service managers. See Appendix D for a full breakdown of respondents by partner organisation.

Findings 4 comprises responses to questions to team leaders regarding the completion of the identified deliverables for each of the Enablin+ project's work packages. This was Part 2 of the e-interview.

Findings 1: Perspectives of leads of partner organisations

The eight project partners to ENABLIN participated in email interviews in May and June 2017. These interviews asked about the project aims and objectives, steps taken to meet these aims and further actions needed to complete any outstanding work. Thematic analysis of these interviews (see research methodology) revealed three Global Themes with supporting Organising and Basic themes emerging from the interview data. Results are presented in the table below with more descriptive information provided below Table 2 (below).

Table 2: Findings 1

Global Theme	Organising Theme	Basic Theme
1. Challenges →	Time →	To complete project
		To see change
	Money →	Translation costs
		Project management / staff continuity

	Ambitious nature of project →	Measuring output
		Awareness of usage for outputs / rationale
2. Developing and Sharing Knowledge →	Changing practice →	Training
		Resources
	Sharing good practice →	Between small and large scale projects
		Interdisciplinary
	Mutual empowerment and collaboration	Policy makers
		Service users
		Parents
		Professionals
Academics		
3. Inclusion →	Promoting inclusion and deinstitutionalisation	
	Raising awareness	
	Quality of life and support to achieve this	

Discussion of Themes – Findings 1

1. Challenges:

Challenges in completing project aims and goals were a key priority for project partners. Core to these challenges were practical aspects of the project which could be considered for future funding applications. There was awareness that more **time** was needed to complete all outputs from the project and to see the change in society that the project envisioned. As one participant noted:

‘Some objectives (1, 2, 8) were rather general and too ambitious. It would take years to change that, because these objectives depend on too many people.’

Participants highlighted that more funding should have been allocated to translation costs with such a diversity of languages; translation also took up time which could have been used to meet project objectives. For example, one respondent identified that they could not use the training DVD as there were not subtitles in their language at this point. In addition, funding of project management was mentioned, particularly as this could have structured management between project partners, on the project as a whole and lessened the impact of staff (dis)continuity on project management.

A further challenge lay in the **ambitious nature of the project** itself. It was emphasised that more methods to measure the impact of outputs would help in evaluating the success of the project, for example, measuring readership of newsletters or usage of DVD's. This challenge was also structural to the project itself. It was stated that some partners were not sufficiently aware of the rationale for particular outputs and how these outputs could be utilised, for example the project website and training DVD. For example, one respondent stated about the project website:

‘We only use it when we present the project to a partner to indicate the existence of the project ENABLIN+.’

2. *Developing and Sharing Knowledge*

Project partners were proud of the fact they have had a role in changing practice through the development of training materials and resources:

'...it required a lot of time and effort, but we have a course now which is innovative, it created some enthusiasm and awareness and we have materials which are suitable for training during a number of years.'

The project was viewed as particularly useful in **disseminating knowledge and practice** between large and small scale organisations in terms of practice and experience and that this knowledge was interdisciplinary in nature. One note of caution was however that definitions of terminology, and therefore needs, between countries is often different so that on occasion the difference between populations was lost when developing broad outputs. For example:

'We were able to share a knowledge of the accompanying practices in the different participating countries, but while recognizing that the context of each country on the question and this must be taken into account. We regretted that the heterogeneity of the populations presented in different counties, which did not always correspond to what, for us, specifies the characteristics of PIMD: this leads to a different view of the needs and expectations of these people and modifies the vision of the accompaniment necessary to support their inclusion in ordinary environment.'

Respondents emphasised that knowledge was shared between groups in this project – as such knowledge was mutually empowering rather than being shared and developed in a top-down manner. This was noted as true collaboration between partners and academics, parents, service users, professionals and policy-makers.

3. *Inclusion*

The theme of inclusion was constant throughout the interviews. The project contributed to raising awareness of the need for inclusion and deinstitutionalisation throughout the project partner countries. Further to this however, was recognition that the goal of inclusion must be measured in the longer term and could not possibly be achieved within one project cycle.

Again, it was noted that **enhancing quality of life** was key to the project. It was thought that the outputs of the project could work to support this, but that measuring changes in quality of life as a goal of the project would be impossible at this point. Consequently, outputs could be viewed as *supporting* the enhancement of quality of life.

Findings 2: Project team member's views

Nine project team members completed questionnaires (see Appendix D for details). This included team members responsible for interpretation and translation, administration, data collection, project development, event organisation, communication, dissemination and team supervision. The questionnaire included questions about the project aims, the challenges and benefits of being involved in the project and the impact on policy, practice and stakeholders.

Table 3: Findings 2

Global Theme	Organising Theme	Basic Theme
1. Benefits →	Good Practice →	Training
		Intervention techniques
	Knowledge Sharing →	Between countries
		Reflecting on inclusion
2. Challenges →	Practical →	Language
		Law and policy
	Project related →	Over ambitious aims
		Project management
3. Impact →	Good practice →	Training
		Potential to influence practice and policy
		Interaction between participants
	Future →	Dissemination
		Evaluation
		Social change

Discussion of Themes – Findings 2

1. Benefits

Project team members focussed on the **good practice** and **knowledge sharing** which had taken place as part of the project. It was noted that training other professionals and disseminating knowledge and good practice was a very beneficial aspect of being involved in the project. In addition, reflecting on what inclusion means and learning of instances of good practice were part of the wider benefits of working on the project. As stated by one respondent:

'The project is creating a strong network between European leaders in the field and the project was able to promote the TTT course with a model which includes and involves the families of the children with CISN.'

2. Challenges

In some cases the challenges and benefits overlapped, for example - several respondents noted that one of the challenges of this project was working with project partners in a range of countries – these practical challenges included **language** and translation barriers, cultural differences and **legislative, policy and practice differences**. However, it was also noted that learning from different contexts and experiences was one of the key benefits of this project.

'Working on a European level and all ENABLIN partners following the same rules and regulations, as well as using the same therapies, medical practices etc.....virtually impossible seeing as each country has different laws and legislations, cultural differences and barriers.'

All those who participated agreed that the **project aims** were well defined and clear. Two noted that whilst the aims were clear they were perhaps over-ambitious. Whilst all aims had been met in part or fully, respondents did note that more time was needed to fully realise aims of social change and dissemination of materials.

Managing a team who are 'disparate' in terms of geography and language was a challenge but team members were mostly positive about what had been achieved by such a diverse team.

'The biggest challenge is the coordination between all the partners, being a European partnership it was necessary a lot of communication and adaptability in order to conclude the tasks that we were responsible for (especially if workpackage leaders) ad to help other partners conclude the deliverables they were responsible for.'

3. Impact

The project was noted by project team members to have **impacted on practice and policy** and also has potential to have wider future impact. One respondent noted that involvement in the project would help their team 'evolve' in that they could better understand the issues and what needs to be done to further inclusivity.

The development of training materials was highlighted as a key contribution to practice of the project. One concrete example was given that teachers and therapists in Milan are now using good practice from the 'Train the Trainer' course.

Respondents highlighted that project outputs included quality intervention based on good practice and international standards. Dissemination of good practice and materials and cooperation between organisations and the potential to influence policy and practice in the future.

'Many people have appreciated the richness of training content and thought.'

Almost all participants note the need for further **future dissemination** of training materials and instances of good practice highlighted through the project.

'I believe it will be a very important contribution because our project results will influence policy making through public dissemination.'

It was noted that a **further evaluation** may be needed in 1-2 years in order to fully appreciate the impact of the project in terms of dissemination, reach and societal impact.

'...more distal objectives cannot be fully achieved during the formal time of the project. Only a follow-up evaluation (within a year for example) could offer an idea about the impact of the work done.'

Findings 3: External beneficiaries' questionnaires

Twenty-three questionnaires were completed by a mix of 11 professionals (including teachers and therapists), seven service users (including parents), four service managers and one policy maker (see Appendix D for further details). The questionnaire asked about their experiences of participation in the project, expectations and how these were met, perspectives on project materials and website, how the project could change practice and what the respondent believed the project could do in the future.

Table 4: Findings 3

Global Theme	Organising Theme	Basic Theme
1. Benefits of the project →	Engagement	Between partners from different countries
		Between different types of practitioner
	Good practice	Strategies for dealing with different situations
		On improving quality of life
	Outputs	Easy to understand
		DVD's / workshop notes / website
2. Challenges →	Barriers to participation	Language
		Online interaction
	Engaging particular groups	Schools
		Wider society

	Culture	Differences in policy and law
		Differences in thinking about needs and practice
3. Future Directions →	Continuing dissemination	Training materials and DVD's
		Examples of good practice
	Developing new knowledge and frameworks	Human rights
		Strategies
	Integration	Of knowledge and practice into daily life of children
		Longer term goal for project

Discussion of Themes – Findings 3

1. *Benefits*

Participants again highlighted that one of the most important aspects of the project was being able to hear the experiences of others from other contexts and countries and about good practice in new forms of intervention. This enabled reflection on own practice for future development.

'The thing that remained most impressive to me and that I learned from this project is that there isn't a standard approach to a patient but it is necessary to use a multidisciplinary and multimodal approach (not only to every single patient but also to every patient single need).'

Outputs from the project, in particular the DVD and training/workshop materials were noted as being easy to understand and of high quality and participants noted using these in their practice. For example, one respondent:

'I find the project materials very useful in order to review and deepen more what was learned in those days. Especially what was discussed in parallel workshops (not having obviously been able to take part in every one). I also found it very useful the material directly provided during the project as it allowed to better follow the plenary sessions, facilitating assimilation and critical analysis of what was seen and heard.'

2. Challenges

Again, language was highlighted as a barrier to participation in the project. One participant noted that more online interaction perhaps via the project website could have helped break down language barriers.

Schools were noted as a group which are often difficult to engage and parents who responded to the questionnaire noted that the findings of the project must filter through to make a difference in the lives of children with severe learning disabilities. For example:

'As a parent, I feel that only in part were the project aims met, seeing as disabled children in normal schools still have a marginal part and usually stay outside the classroom. Rarely do we find support teachers and caregivers that are really competent in their job, some are, but not all...and this is what makes the difference between theory and practice, therefore between a good quality of life and a poor one.'

The wide range of countries and contexts taking part in the project, whilst a positive, also presented challenges with regard to differences in cultural and policy contexts and attempting to develop common consensus.

3. Future Directions

Respondents emphasised that the materials developed throughout the project must continue to be disseminated and instances of good practice documented. In addition, future collaboration and cooperation is needed to incorporate findings into everyday practice and the integration into daily life of children:

'Personally I would focus on the consolidation of the international network created to foster current knowledge sharing and new skills acquisition (also through an international research project).'

'To continue our cooperative work in the search for the best way to get the principles of inclusive school to the education community.'

Human rights frameworks were highlighted by a number of respondents as a means to develop new ways of thinking about integration and developing new strategies founded through a rights-based lens.

'Create methodologies to achieve all kinds of people, founded in civil rights and promoting best practice in full citizenship for persons with disabilities.'

Findings 4: Progress on project deliverables

Appendix D presents the extent to which the originally identified project deliverables have been met, their reach, and any challenges to their completion.

Apart from the final reports (including the present), there has been very significant progress in completing a lengthy and substantial number of outputs and actions. Of the 27 (omitting the two final reports), 17 are reported as completed; five have been completed in some languages or formats, and the final five are in progress.

Progress seems to have been relatively slow in the successful submission of academic journal articles. This is unsurprising, as the process from writing, through submission to acceptance is slow, and submission is dependent on data available only late in the project.

It is notable that, where reported, the reach of outputs has been substantial. Attendance at Train the Trainers conferences and workshops has been good, and website hits appear high. This would seem to support the importance of this project in addressing a shortage of information and resources in the area of complex and intense support needs. In addition, there is a high level of diversity in the reported beneficiaries from the project. A wide range of professionals have been involved, in addition to family members, service providers and, to some extent, policy makers.

The challenges to completion of deliverables reflect those reported in the questionnaires and interviews. A lack of funding for translation has been particularly problematic. The availability of staff time for the project has been challenging, exacerbated by staff turnover. Finally, the diversity of definitions of CISN and the heterogeneity of systems and policies across the contributing countries have also been problematic.

Conclusions and Recommendations

This evaluation has provided evidence of project partners', project team members' and external stakeholders' views and experiences of the ENABLIN+ project. It has also addressed the extent to which the projects' deliverables have been completed. From this, we have sought to examine the challenges and benefits of the project and its impact on policy and practice. Finally, views on the future directions for the work completed and future projects were elicited.

- In relation to the original aims of the Enablin+ project (see Introduction), the aim of “promoting quality of life of children and young people with complex dependency needs” is a major societal project. As recognised by several participants, this will take longer than the lifespan of the Enablin+ project. The resources and training delivered by the project, however, are likely to make a significant contribution.
- The training materials (book, DVD, conferences and workshops) have succeeded in providing resources accessible to and appropriate for a wide range of practitioners and for families. The collegiate approach to the development and implementation of this training has been noted by several participants. This suggests that family carers as well as professionals, service providers and policymakers can feel empowered by the materials developed.
- Differences in current education policies and practices across countries mean that progress towards social and educational inclusion is interpreted in different ways. As with enhancement of quality of life, it is unrealistic to expect rapid change, but both project team members and external beneficiaries report the value of the project in contributing to these ends.

There were a number of highly positive processes and outcomes identified through the evaluation, including:

- The process of sharing knowledge, experience and practice both with partners from a variety of European countries and with a mix of professionals, academics, policy makers and service users was emphasised by almost all participants to the evaluations as one of the core benefits of taking part in this project. The sharing of such knowledge was viewed as mutually beneficial to all who took part.
- The project was deemed to have created innovative and useful materials including training materials, workshop notes and a website. Participants noted they have used these to develop their own practice on a regular basis.
- Raising awareness of the issues which affect children with complex and intense support needs was viewed as a contribution of the project to wider society. Whilst this cannot be measured in the short term, this should be a longer term benefit of the project which will contribute to quality of life outcomes.
- Whilst it was noted that the project aims were highly ambitious, they were viewed to be clear and well-articulated.
- The dissemination of project outcomes both through events and online dissemination was highlighted as a positive outcome.

There were also a number of areas raised for consideration within the project structure, including:

- With the number and linguistic diversity of partners involved in the project, translation costs should have been written into the initial grant more extensively.
- More structured processes for managing a large and geographically diverse project would have facilitated the achievement of outcomes and mitigated against the impact of staff turnover.
- Several respondents noted that project aims were perhaps too ambitious and could have been more modest or more time for project team members made available.

- Time might have been saved by use of freely available resources that existed at the outset of the project e.g. *Training materials for teachers of learners with severe, profound and complex learning difficulties*, a free online course funded by the Department for Children, Schools and Families (England) at <http://www.complexneeds.org.uk/> (accessed 16th August 2017).
- Differences in terminology and definitions could have been addressed specifically at the outset of the project.
- Whilst project outputs were mostly well disseminated, one partner highlighted that more consideration of how the outputs were to be utilised would have been helpful.

From these findings the evaluation team propose a number of recommendations:

- A strategy for ensuring that final completion and dissemination of project outputs and knowledge continues after the project ends would be beneficial, maximising the impact of the project on children and young people's lives..
- It would be appropriate to reflect on the success of the project at a future date when longer term quality of life and inclusion-related outcomes can be evaluated.
- In developing of future projects, language and terminology issues, and in particular translation costs, merit additional consideration.
- There is a strong desire for maintenance and development of the project's international networks and frameworks for further good practice outcomes. One mechanism for this could be engagement with the Profound Intellectual and Multiple Disabilities Special Interest Research Group of IASSIDD – see <https://www.iassidd.org/content/profound-multiple-disabilities>

References

Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, 1, (3), 385-405.

Dickenson, J. (2009). An exploratory study of patient interventions and nutritional advice for patients with chronic obstructive pulmonary disorder, living in the community. *International Journal on Disability and Human Development*, 8(1), 43-49.

Flacking, R. and Dykes, F. (2017). Perceptions and experiences of using a nipple shield among parents and staff – an ethnographic study in neonatal units. *BMC Pregnancy and Childbirth*. 17.1 Published online 3 January 2017. DoI: 10.1186/s12884-016-1183-6.

Goldbart, J. and Marshall, J. (2014). Using Thematic Network Analysis: An Example Using Interview Data from Parents of Children Who Use AAC. In M.J. Ball, N. Müller and R.L. Nelson (Eds.) *Handbook of Qualitative Research in Communication Disorders*. (pp. 297-310). Abingdon: Psychology Press.

Skovdal, M. (2011). Examining the trajectories of children providing care for adults in rural Kenya. *Children and Youth Services Review*. 33(7), 1262-1269.

Appendix A – Email interview for Project Team Leaders

EXTERNAL EVALUATION E-INTERVIEW FOR TEAM LEADERS (or nominees)

This interview is in two parts.

Part 1 will ask about you, your organisation and your participation in the Enablin+ project.

Part 2 will ask about the deliverables for which your organisation was responsible. *See

Appendix E for a compilation of responses from all eight team leaders.

Part 1

Name of respondent:

Name of your organisation:

Your role in the organisation:

Type of organisation: University / Independent research organisation/ Independent training organisation / Service provider / Training provider / Other Circle all those that apply

How have you contributed (personally) to the Enablin+ project?

How would you describe the main role of your organisation in the Enablin+ project?

Is this the first EU education project your organisation has been part of? If NO, please list the others.

.....

What was the aim of your organisation in taking part in the Enablin+ project?

.....

Has the project met that aim? Please tell us a little about this:

.....

What are the primary objectives of the Enablin+ project?

.....

Have these objectives been achieved?

.....

If you have any questions or comments about this questionnaire please email the project team – Claire Pierson – c.pierson@mmu.ac.uk or Juliet Goldbart – j.goldbart@mmu.ac.uk

Appendix B – Questionnaire for Enablin+ project team

Thank you for taking time to answer these questions. Please read the participant information sheet before answering.

Demographic Information

(please underline the correct answer or fill in your answer in the space)

Age – under 18 / 18-24 / 25-39 / 40-49 / 50+

Which country do you live / work in? _____

When did you get involved in the project? – at proposal stage / from start / part way through

Please describe your role on the project

Evaluation Questions

Were the project aims clear? – yes / no – please explain

To what extent were the project aims met? - not at all / in part / fully – please explain

Did the aims of the project fit with the aims of your organisation? - yes / no – please explain

What were the challenges of this project?

What was the most enjoyable/ beneficial part of the project for you personally and for your organisation?

Will the ENABLIN+ project change any aspect of policy or practice in your organisation? – yes / no - Please explain

What has been the impact of the ENABLIN+ project on stakeholders who use your services? Stakeholders might be - the people who use your services, policy makers in your area, service delivery organisations e.g. Schools

What are the next steps after this project?

If you have any questions or comments about this questionnaire please email the project team – Dr Claire Pierson – c.pierson@mmu.ac.uk

Appendix C - Questionnaire for Enablin+ project beneficiaries

Thank you for taking time to answer these questions. Please read and sign the participant information sheet before answering.

Demographic Information

(please underline the correct answer or fill in your answer in the space)

Gender – male / female / other

Age – under 18 / 18-24 / 25-39 / 40-49 / 50+

Which country do you live / work in? _____

What was your involvement in the project? - professional e.g. teacher, therapist / service user e.g. family member, carer / policy maker / service manager

How did you get involved in this project?

Evaluation Questions

Have you attended any ENABLIN + project events? – yes / no
If yes, which ones?

What was your expectation of participation?

Did the project meet your expectations? - yes / no. Please explain

What have you learned from the project?

Service users - Will this project change anything you do with your child? – yes/no
How? _____

Professionals / policy-makers / service managers – Will this project change any of your policies or services? -yes / no How?

Were there any barriers to engaging with this project? – yes / no
If yes, please explain

What was the best thing about the ENABLIN+ project?

Have you seen the project website or newsletters? – yes / no
If yes, what did you think of them?

Have you used any of the project materials? E.g. DVD, workshop notes – yes / no
If yes – what do you think of them?

What was the impact of this project on you or your organisation?

What are the next steps after this project?

Do you have any other comments?

If you have any questions or comments about this questionnaire please email the project team –
Dr Claire Pierson – c.pierson@mmu.ac.uk

Appendix D – Respondents to interview and questionnaires

	Interview	Questionnaire - Internal	Questionnaire – External
Partner 1 – Belgium	Completed	0	2
Partner 2 – Netherlands	Completed	0	1
Partner 3 – CESAP France	Completed	1	1
Partner 4 – Romania	Completed	0	0
Partner 5 – ASFA Reunion	Completed	0	2
Partner 6 – Bulgaria	Completed	0	2
Partner 7 – Italy	Completed	4	8
Partner 8 – Portugal	Completed	4	7
Total	8	9	23

Appendix E: Progress on project deliverables (as of June 2017)

Del. No.	Title	Description	Completed	What are the benefits?	Challenges for completion
1	Who are they? Assessing the needs of children with intensive and complex support needs	The report will describe the needs of children and youth with complex support needs in the various partner countries	Yes (for the EN and FR version) No (for the version in other languages)	<p>Belgium: Full text (English and French version) in pdf is published on the website. There are no printed copies. Report was announced in newsletter 2, which was sent to thousands in different partner countries. We have no idea how many times the report has been downloaded. In fact, we lacked a “marketing strategy” to make the publication better known</p> <p>Netherlands: We use the report for parents to learn how the diagnostic tools can be used.</p> <p>Reunion: We use the report as a base for training and to explain what ENABLIN is.</p> <p>Bulgaria: using report as a tool for analysis and further planning of training and support needs. More than 80 professionals and 40 parents filled in the questionnaire for needs assessment. This is a good overview for our country.</p> <p>Portugal: The report gives a European landscape about the different stages of inclusion and enables us to see what are the most pressing needs for parents and professionals.</p>	Belgium: With the limited translation budget, we decided to make a summary in Dutch, Italian, Bulgarian, Romanian, Hungarian and Portuguese. It needs more time for completion.
2	Assessing the needs of children with intensive and complex needs	An article in the scientific press summarizing the report of delivery 1 to be published in Alter and another English journal (Disability & Society)	No – it is in progress.		<p>* What has prevented this progress? We decided to write an article together but it is very difficult because of the heterogenous data and response rates.</p> <p>* What is needed for you to complete the</p>

					<p>article and when will it be finished? Time. * Where do you plan to submit it? Certainly a ICI journal, possibly Alter, or Disability and Society</p>
3	Newsletter 1	<p>Newsletter 1 will report the works about needs assessment and various initiatives of partners. Put on the website</p>	Yes	<p>* Have you had any response to the newsletter? Not that I know of * How many paper copies have been distributed? In Dutch a 100; distributed on seminars, workshops, local conference *Can you measure the number of "hits" on the electronic newsletter? Dutch newsletter - 2700</p>	
4	<p>Children and youth with complex and intense dependency needs: needs for continuous support systems regarding inclusion and activation Good practices and methodologies which really work</p>	<p>This report will be based on the results of the questionnaire/ interviews/ videosamples Part I Current support systems in seven European countries Part II Examples of innovation and good practices regarding inclusion and activation Part III A selection of relevant methodologies in supporting care & education of children with complex and intensive support needs</p>	<p>Have you completed your component of the "good practices and methodologies" report?</p> <p>Belgium: No France: Yes Reunion: Yes Bulgaria: yes Portugal: yes</p>	<p>France: We are not using the report it was realized for the benefit of the ENABLIN project - we do not use it particularly, * Has the book & DVD been produced? Yes/No A DVD is available * How will you use the book and DVD and who is the target audience? Bulgaria: Waiting for approved summary in BG. After that it will be made available to the public. We will use DVD and book in trainings. Reunion: Impact – to develop knowledge about competences of children with special needs and good practice. Using it in training courses and conferences. Portugal: We use the book and DVD in training courses and will use it in Master and doctoral course in Psychology and with trainees in psychomotricity.</p>	<p>Belgium: Not completed due to drop out of staff and management. What is needed for you to complete the report and when will it be finished? Time; editorial assistance; perhaps cut part III which is totally incomplete * How will you use the book and DVD when they are finished and who is the target audience? The DVD is ready and is a separate deliverable; the idea is to attach the DVD in a training manual. Furthermore, to insert some of the texts of the report on continuing support systems and examples of good practices into a book,</p>

					if we succeed with the deadline. The target audience consists of professionals working with children with CISN, in a management position, in policy making, in direct educational planning and monitoring, in training positions. But parents might benefit as well
5	Children and youth with complex and intense dependency needs: needs for continuous support systems regarding inclusion and activation	This is an article based on the report delivery 4, to be published in Alter and another English journal (Disability & Society)	No		<p>* What has prevented this progress? The report was not ready, so the article couldn't be made.</p> <p>* What is needed for you to complete the article and when will it be finished? Time, one more year to the project would be better to finish all deliverables properly; have an editorial assistant who is fluent in English and who is able to write a consistent academic paper</p> <p>* Where do you plan to submit it? End of 2017</p>
6	Needs assessment for in-service training of people working with children and youth with complex and intensive dependency	List of required transversal as well as profession-specific competencies for various professionals working with CISN - what key contents does an	Yes	<p>Belgium: A preliminary report on training needs in various partner countries has been started; country training needs from BE are stated. A list of competences is ready in French, but needs translation into EN.</p> <p>France: There is no single key content. It depends on each training</p>	<p>* What is preventing completion of your country summary on training needs? - an editor who puts all data together in a fluent and coherent text - data from other partner countries - translated list of</p>

		in-service training require?		<p>Reunion: need partners inclusion, good practice competencies</p> <p>Bulgaria: support should be provided for professionals, parents and other staff working with children in terms of training. Theoretical and practical and supervisions in – sensory stimulation, feeding, positioning and physical activity, communication, development of cognitive skills, adaptive skills, functional skills, inclusive environments, independence and quality of life.</p>	<p>competencies from French to EN</p> <p>* When will this be completed? 31/7/2017</p>
7	Enablin+ website	The project's website will contain :home page, objectives, activities, partner's presentation, project's documents, forum, calendar	<p>Yes</p> <p>Bulgaria: BG texts provided but not uploaded.</p>	<p>* How are you using the project website?</p> <p>France: We use it when we present the project to a partner to indicate the existence of the project ENABLIN +</p> <p>Netherlands: to inform people in Holland about the project – also twitter and Facebook. Invitation to pilot training.</p>	<p>Portugal: we are not using it as we should. We are finding it difficult to receive feedback about the Portuguese translation and updates. We noticed differences between different partners content.</p>
8	Curriculum for In-service Training for Support to Children with intense & complex support needs	Modules about: (1) quality of life and support needs assessment of CISN (2) how to improve communication (3) basic attitudes and concepts regarding learning, development and inclusion (mediation and instruction) (4) education (special and inclusive); (5) difficultly understandable behaviour, prevention and regulation; (6) learning basic	<p>France: No</p> <p>Portugal: Yes but in editing.</p> <p>Netherlands: Yes started in Dutch and translated to English</p> <p>Reunion: No</p> <p>Bulgaria: Yes</p>	<p>Netherlands: We use it as part of our training offer.</p> <p>Reunion: We will use it when it has been translated.</p> <p>Bulgaria: We have piloted the common training module successfully with 2 pilot trainings and plan to conduct more trainings using this model.</p>	<p>* Is the Common Training Model being used in your organisation?</p> <p>France: We used the first part of the joint project, the one we tested in France and proposed in the WP</p> <p>*When will it be available in your country's language/s?</p> <p>As far as the whole joint project is concerned, we do not yet know whether we will be able to use it in its entirety. Indeed, the</p>

		<p>self-care skills (nutrition, toileting, other); (7) how to organize a continuous support system, prevention of burn-out, ethical issues (8) other relevant topics. Describes content, scientific backgrounds, format, scenario, suggested time-schedules, teachers, methods</p>			<p>theoretical references are not yet all available in French. However, the project will be proposed as a reference tool for the trainers of "CESAP Training", to whom it will be proposed to make reference as far as possible.</p> <p>*How do you expect the Common Training Model to be used after the Enablin+ project has finished?</p> <p>The ENABLIN project is not fully completed. But from now on, we regularly use the part proposed by CESAP in the framework of a training session for the reception of new professionals.</p> <p>Portugal: our org. used the common training model as the framework to support ENABLIN+. It will be replicated in other training courses, schools, institutions and associations. We are preparing a research article on teachers' level of stress considering the extension of compulsory education to eh special needs education.</p>
9	Teaching videos Support to	Set of videos to be used for teaching, about	Yes	A first prototype, and incomplete, was used at the training pilot in May 2016 in Belgium; a more	

	Children with intense & complex support needs	various relevant topics in care and support, e.g. sleeping difficulties, behaviour management, communication enhancement, feeding problems, mobility, learning and activation, inclusive education		<p>complete, but yet incomplete prototype was used at the dissemination conference in Febr. 2017 in Evora; a complete version has been shown on the EACD conference in Amsterdam on May 18th 2017</p> <p>* Who is using it, and how? For the time being, only Enablin+ staff</p> <p>* Who do you think will use the curriculum and DVD in your country? The various training centres, linked to the Enablin+ partners, then larger dissemination to whoever is training the target group</p> <p>* How will it be used? The DVD will be part of a paper manual; this is needed to explain and frame the video fragments</p> <p>* Is the DVD already being used? No</p> <p>* Who is using it, and how?</p> <p>* Who do you think will use the curriculum and DVD in your country?</p> <p>* How will it be used? We have not yet considered this question</p> <p>Bulgaria: There is is no translation to BG.</p> <p>Portugal: Use it in training courses</p>	
10	Policy document: Caregivers and support needs for children with intense	Policy document is the result of a committee which summarizes the results of WP1, 2, and 3 with	Yes	<p>Netherlands: Disseminated by email</p> <p>Response: people agree but it is difficult to fight the current system. It takes time.</p>	

	and complex support needs	recommendations to policy makers in health, welfare and other relevant ministries.			
11	In-service training "Supporting children with intense and complex support needs towards activity and inclusion"	In 2015-16 a try-out of some of the modules (ideally all the modules, but not necessarily all the modules by all partners) ; programme announcement on websites of partners, on common websites, in leaflets	Yes	<p>* Which modules have you tried out (piloted)?</p> <p>France: We have set up training sessions inspired by the proposed training, without following exactly the same organization. For example, module n ° 1: «who are the BICS children and what their needs are» corresponds to the formation of CESAP training «to discover or rediscover PIMD» In the end, within the framework of the project, we proposed a module intended for new professionals discovering PIMD. This module has been tested within our organization. It responds well to the questions that people ask themselves, the duration is suitable and allows them to be part of deepening mechanisms</p> <p>6 sessions have already taken place. There will be 4 per year, with approximately 15 to 20 people - Professionals: physicians, physiotherapists, psychometricians, rehabilitation workers, "AMP" (Professionals working directly with people for daily care) and administrative and logistical staff</p> <p>Reunion: we have piloted the first course. Feedback: better understanding about needs of children.</p> <p>Portugal: We have adapted versions of modules – quality of life, basic attitudes and concepts, inclusion and mediation, education. We had 15</p>	

				participants including teachers, psychologists, sociologist, sociocultural animation. Feedback was very good.	
12	Experience with In-service training "Supporting children with intense and complex support needs towards activity and inclusion"	The report will summarize the evaluations of the experience with the pilot trainings, and their effect on the trainees and possibly also on children. First a confidential part will be made to be discussed in the partners' meeting; then an article will be made	Yes A presentation of the pilot module was made at the Milan seminar (WP5) We took stock of the first experimental sessions with a precise return of the evaluations of the participants	* What changes in the modules have resulted from the pilots? Few changes have been made because these modules meet the needs of professionals and allow them to confront their problems with PIMD	Report complete
13	Train-the-trainers course "Support for children with complex and intensive support needs" and abstract book	International course, open to public participation of trainers of professionals from all disciplines	Yes		
14	Training materials: Train-the-trainers course "Support for children with complex and intensive support needs" Teaching manual based on delivery 8, common core training	The DVD will contain powerpoints, teaching videos, abstract book of the « train-the-trainer course	Yes		Completed August 2017.
15	Project	Leaflet describing	Portugal: yes		

	leaflets	project			
16	Newsletter 2	Describe results of partner meeting 2 & 3, local events, stories of kids, examples of good practice, and announce pilot IST course for 2015-16.	Netherlands: Yes	Netherlands: paper copies not distributed, 750 online hits.	
17	Newsletter 3	Newsletter 3 will describe results of partner meeting 4 ; local events, stories of kids, example of good practice, Report of TTT conference Milan + announcing Evora event.	Yes	<p>* Have you had any response to the newsletter?</p> <p>France: The newsletter n ° 3 has been translated into French by our colleagues from the Association Saint-François d'Assise (Reunion Island), but is not yet available on the ENABLIN +. The contribution of CESAP is well represented in newsletter n°3 (English version)</p> <p>* How many paper copies have been distributed?</p> <p>France: Number 2 was distributed to more than 600 copies during the associative days of CESAP</p> <p>Bulgaria: we are still waiting for the approved BG version.</p> <p>Portugal: 150 copies distributed.</p>	
18	Children with complex and intense support needs: how to enhance inclusion and activity	A series of articles, to be published in the scientific press (possibly: Alter, IASSID journal, DMCN,)	Portugal: Yes	Portugal: Submitted to Journal of Intellectual Disabilities, Frontiers in psychology. JID – accepted, Frontiers – under review.	
19	Who are they? Assessing the needs of children with intensive and complex support needs	Mini-conference, back to back with 1st partner meeting Antwerp	Yes	<p>* How many people attended the mini-conference in Antwerp? 72</p> <p>* What professional groups and countries were they from? BE, NL, FR, RO, BG, IT, PT</p> <p>SEN coordinators, Medical</p>	

				doctors, Educators, Team coordinators, Special needs psychologists, Early intervention worker, Social worker, School principal, Policy maker (administration), Professor, Speech therapists * How many parents/family members attended? 6 * What was the feedback on the course? It was not a course, it was a ½ day kick off seminar . No written evaluation was done	
20	Children with intense and complex support needs: how to train parents and professionals	Back to back partner meeting in Netherlands	Yes		
21	Children with intense and complex support needs: good practices towards activity and inclusive learning	Back to back partner meeting with EVORA.	Portugal: Yes	22 attended conference – researchers, doctors, professors, psychologists, orthopaedics. Feedback was generally positive	
22	Children with complex and intense support needs: how we can improve support	Follow up of partner meeting in Cluj-Napoca	Yes	We did not make any report but various contributions to the general report and documents produced in connection with this report. * How many people attended the seminar in Cluj-Napoca? Over 20 people	
23 a, b	Children with complex and intense support needs (+ specification of partial topics)	Abstracts which will be presented at international large conferences such as IASSID, EACD	Yes		Lack of finance prevented some conference presentations
24	Progress report Enabling+	Official progress report for the EU Commission, confidential and			

		public part			
25	Final report	Official final report	In preparation		
26	Enabling Children with complex and intense support needs	Back to back final partner meeting in Evora, public 1 day conference	Yes	168 attendees – students, doctors, professors, psychologists, orthopaedics, teachers, social workers. Feedback was generally very positive.	
27	Enabling+ Quality assurance plan	Report			
28	Enabling+ External Evaluator's report	Report			
29	Newsletter 4	Report of Evora meeting + Announce publications	No Bulgaria: No Portugal: Yes but updating		<p>* When will your team complete your section of Newsletter 4?</p> <p>July 2017</p> <p>* What are the barriers to its completion?</p> <p>The time credit for the ENABLIN project is largely exceeded</p>



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