Grundtvig Learning Partnership

'Self-assessment of their Needs by Family Carers : The Pathway to Support'

Full Report

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Introduction

From August 2010 until July 2012, ten national nongovernmental organisations (NGOs) have worked together in a Grundtvig Learning Partnership on help to family carers: 'Self-assessment of their needs by family carers: The pathway to support'. This European project was funded with support from the European Lifelong Learning Programme 'Grundtvig' for the promotion of adult education.

Self-Assessment of Family Carers' Needs: Why?

'Family carers' can be defined as 'non-professional persons who provide primary assistance with activities in daily life, either in part or in whole, towards a dependent person in their immediate circle. This regular care may be provided on a permanent or non permanent basis and may assume various forms, in particular: nursing, care, assistance in education and social life, administrative formalities, co-ordination, permanent vigilance, psychological support, communication, domestic activities, etc.'[1].

In Europe, family members are the largest provider of care for older, frail, disabled and chronically ill people of all ages. However, caring for a loved one often comes with a considerable personal cost to family carers, with many experiencing financial, professional, health and social consequences. Recognition of and support for family carers are necessary to help to maintain and/or improve the quality of life of family carers and care recipients, to enhance family carers' social inclusion and to foster quality care for persons with dependency needs.

The objective of the partnership was to identify challenges and formulates recommendations in the field of awareness raising and training aiming at promoting self-assessment of their needs by family carers. Indeed, it is essential that family carers take steps to gain awareness of their difficulties, to define their needs, to ask for adequate support, and to prevent breakdown situations. Absorbed as they are by their commitment to their relatives, family carers often neglect their own issues and the outside support they could seek. Often even, they don't consider themselves as carers but just as parent or spouse, and they have no knowledge of their rights.

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[1] COFACE-Disability European Charter for Family Carers

In order to find practical solutions adapted to the diversity of situations, the partnership has brought together associations from nine countries, with various scopes (NGOs active in the field of disability or Alzheimer disease, family carers' organizations, and general family organizations). It also involved family carers, as adult learners, at all stages, in a participatory approach that has been central to the partnership. Family carers also had the opportunity to gain a better understanding of the various schemes of help to carers existing in Europe, through six transnational meetings in six different host countries.

Many Obstacles to Self-Assessment of Needs

As a first step, partners undertook an analysis of the obstacles to family carers' perception and self-assessment of their needs. A questionnaire was elaborated and disseminated to family carers in the nine partner countries. Finding were summed up in national reports, and shared during one of the transnational meetings.

This survey made it clear that the family relationship and affection make it difficult for family carers to identify themselves as such. Indeed, caring is seen as something natural. The existence or not of a public debate or a legal status for family carers also has an impact on self-identification as family carers. The lack of support or lack of knowledge of the support available, the lack of time and energy, an attention entirely focused on the needs of the persons cared for, and the lack of quality cooperation with professionals also make it difficult for family carers to perceive and express their needs.

The survey also emphasises that isolation is both a major risk factor and the main consequence of this lack of awareness. The issue of how to reach out to family carers who do not engage with NGOs is therefore an absolutely crucial one. Early intervention is also critical to prevent starting a vicious circle of isolation. There also needs to be a gender approach, and an adaption to the needs of subgroups of carers (e.g. young carers, older carers …). Finally, cultural differences from one country to another should not be neglected.

A Wide Range of Best Practices

Based on these findings, partners collected best practices in their respective countries. They looked at the ability of these practices to: promote awareness of relatives of persons with dependency needs of their role as family carers; help family carers assess and express their needs; and reach out to the most isolated family carers.

The best practices collected by partners cover a wide range. Some are awareness raising tools (e.g. research initiatives, national days for family carers, legal status for family carers, etc.). Others are tools for direct intervention with family carers, promoting self-assessment of needs (e.g. self-assessment tools, support services, support groups, etc.). Others have a more indirect role (assessment of the needs of the care recipient, training, respite services, etc.). Finally some tools' focus is to reach out to family carers (e.g. awareness-raising in relevant networks, use of new technologies, door to door approach, etc.).

These best practices were thoroughly analysed and discussed during two transnational meetings. Partners were able to identify key characteristics for awareness-raising and self-assessment tools, falling into the following categories: supportive local, national and European environments; cross-cutting characteristics; characteristics related to the design of the tool; and characteristics related to the impact of the tool. Partners also analysed the impact of these best practices on the relationship between family carers and professionals: the impact is often too limited, best practices still have to be developed with regard to cooperation between family carers and professionals.

Other important findings were that, whereas in some countries a lot has been developed already, in others nothing or little is done. While many of the collected best practices are transferable in other countries, providing that they receive adequate backing by public funding, some of them might be less easily transferable because of cultural differences. Finally, transferability in less advanced countries will also require time (at least for the most accomplished models of best practices).

Practical and policy recommendations

Building on these numerous findings, partners have elaborated and agreed upon several set of recommendations:

- Some recommendations for the design of tools for the self-assessment and expression of their needs by family carers;

- Some recommendations on training provision to be made for family carers and professionals to help family carers assess and express their needs;

- The Partnership recommendations to the European Union, in order to establish social and policy environments supportive of self-assessment and expression of their needs by family carers.

Recommendations for the Design of Tools for the Self-Assessment and Expression of their Needs by Family Carers

Rationale

These recommendations for the design of tools for the self-assessment and expression of their needs by family carer are based on the cumulative work of the Grundtvig Learning Partnership, specifically:

- Guiding principles of the learning partnership[2];
- Findings from national surveys to identify obstacles to family carers' perception and self-assessment of their needs;
- The characteristics identified during the examination of best practice examples collected at national level;
- Recommendations on training provision to be made for family carers and professionals to help family carers assess and express their needs.

It is also based on COFACE-Disability European Charter for Family Carers, including its definition of the expression 'family carer'[3].

Family Carer's Self-assessment of Needs – What is at Stake?

The public policy response to the issue of dependency (from any cause: disability, illness, age, accident, etc.) in most EU countries is at present inadequate or non-existent. The gap therefore has to be filled in many cases by friends and family – usually women. Family members are the largest provider of care for older, frail, disabled and chronically ill people of all ages, saving Governments across Europe billions of euros each year.

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[2] These guiding principles have been elaborated and agreed upon by partners in order to give an ethical framework to the partnership. The COFACE-Disability European Charter for Family Carers serves as a basis for these principles.

[3] See page 3

Family solidarity cannot in any sense absolve a state or public authorities of their duty to provide the necessary appropriate help in life for people who depend on someone else to carry out the activities of daily living. Inadequacies in State support gives little consideration to the wishes and choices of the recipient of care, the wishes and choices of family carers, their needs and the impact that caring has on their lives, or to the risk of abuse and mistreatment. Caring for a loved one often comes with a considerable personal cost to family carers, with many experiencing, financial, professional, health and social consequences.

Recognition of and support for family carers are necessary to help to maintain and/or improve the quality of life of family carers and care recipients, to enhance family carers' social inclusion and to foster quality care. The development of tools that enable the self-assessment of family carers' needs is a step towards recognising family carers as partners in care. These tools will enable family carers to identify as such and to express their needs, and will empower them. It will be easier for them to access information and advice, and to make alternative or contingency plans if they are not willing or are unable to continue to provide care. Self-assessment will also promote greater collaboration between service providers and family carers, and will inform the development of family carer training programmes.

Objectives of the Recommendations

Social and cultural contexts are very diverse in the European Union. Therefore, as such, these recommendations do not intend to propose a family carer's needs self-assessment model *per se*, but rather set out the important considerations that should be taken into account when designing a family carer self-assessment tool. They point out the factors that should be considered in the design and implementation of future tools for family carer self-assessment, regardless of the level of family carer supports and services that currently exists in their country. However, social recognition of the role of family carers and of their difficulties, as well as the existence of strategies, support and public funding for family carers, and of strong associations representing family carers, do constitute supportive environment maximising the impact of self-assessment.

The recommendations presented are aimed specifically at the development of family carer self assessment tools, i.e. a self-administered assessment.

Objectives of the Family Carer Self-assessment Tool

Access to a comprehensive needs self-assessment should allow family carers to better identify and acknowledge:

- Their role as family carer;
- Their skills and competences, and their limitations;
- Any difficulties they may be experiencing;
- Their needs in terms of support (equipment, aids, training, etc.) to help them in their caring role;
- Their needs in terms of health and wellbeing (thus helping to avoid stress, burden and burnout);
- Their needs in terms of balance between caring, work and other aspects of their personal and family life.

Access to self-assessment should also allow them to:

- Understand the changing demands of their caring role, and consider the financial implications of caring;
- Put into words and express their needs so that clinicians and professionals can understand them and provide useful interventions whenever possible or design new ones;
- Be empowered, self-determined and equal partners in care with professionals.

1. Principles to be Respected for Tool Design

1.1. Quality, Accountability, Validity, Reliability, and Neutrality

When developing a family carer self-assessment tool, it is necessary to protect the integrity of the data collected by ensuring the tool adheres to best practice quality protocols including accountability (who is responsible for the self-assessment); validity (the extent to which the self-assessment outcomes can be supported by evidence); reliability (the degree of consistency and accuracy of the self-assessment outcomes) and neutrality (the tool must not influence the responses).

1.2. Transparency and Confidentiality

The self-assessment process may be the first time that the family carer has considered their needs or provided information they have not discussed with the cared for person. Family carers must

understand the self-assessment process and the fact that they are in no obligation to disclose this information and the results of the self-assessment. These can only be shared with the family carer's consent.

1.3. Participatory Approach

The self-assessment tool should be organised and designed around what is important to the family carer. It should appreciate the family carer as an individual, and be focused on supporting them to carry out (or not) their caring role and responsibilities. In practical terms, this means that family carers should be directly involved in the planning, design and implementation of the needs self-assessment tool, and that the self-assessment tools should recognise the characteristics, capabilities, needs and wishes of family carers.

Best Practices Example: a Self-assessment Guide to Families' Needs

The French NGO Association des Paralysés de France (APF) has published '***The Guide to families' needs'***, a self-assessment tool aiming at identifying the needs of a family with a child or adult with disabilities. This handbook lists needs all parents have, who may have unwittingly become a "family carer", without regard to the child's age or type of help they need. The Guide aims to cover all the areas where a carer may require support in providing the best possible care while preserving their own personal, family, social and professional life, and the quality of the cared-for person's life. The Guide to families' needs helps parents to identify and express needs that they may think no-one else has or do not even know they have. The Guide helps them assert and put their needs into words so that they can be heard and understood by the professionals they are talking to without feeling judged. It offers a basis for a dialogue with professionals. The Guide has been produced by parents, for parents. It is easy to use. It sets out the various needs voiced by parents who were interviewed to compile it. For each need, parents can tick the boxes for points they specifically want to include when seeking support. It is a very efficient tool for self-identification as family carers and for self-assessment and expression of needs. The Guide is also easy to transfer to other countries or situations (the Italian family carers organisation Co.Fa.As "Clelia" has produced an Italian version), as well as to disseminate.
Further information: http://interparents.blogs.apf.asso.fr/

1.4. Acknowledge the Diversity of Family Carers

The tool must respect the diversity of family carers with regard to age, gender, and geographical, social and cultural contexts. Each of these 'sub groups' (e.g. young, male, rural, working, or former family carers or those with a disability) may necessitate a separate tailored self-assessment model. For example young family carers may be more willing to engage through the use of technology such as chatrooms or dedicated young family carer websites; whereas older family carers may prefer face to face interaction with service providers.

It must also reflect the diversity of needs of the cared for person and how this impacts on the needs of the family carer. For example, those caring for someone with high dependency needs may find it difficult to leave their home and so may prefer to complete a self-assessment in their own time.

1.5. Simplicity

The self-assessment tool should be written in simple, easy to understand language and should be structured in a logical way. Where possible it should include words and phrases familiar to the family carer and avoid the use of jargon or complicated medical terms. Because the tool is self assessed and not professionally administered, it is essential that all family carers feel comfortable completing the self-assessment.

1.6. Flexibility

The self-assessment tool should be adaptable to different situations and family carers' needs and should allow the family carer to negotiate certain aspects of their self-assessment. The self-assessment tool must also be fair and must not disadvantage particular family carers such as those with a disability, literacy issues or from different cultural backgrounds.

1.7. Facilitate Self Identification as a Family Carer

The family carer self-assessment should not only be an assessment of needs but should also act as a trigger for family carers at all stages of the caring cycle to self-identify as a family carer. This may be achieved by including a series of carefully phrased questions within the self-assessment designed to encourage family members to

recognise the caring tasks they regularly undertake, or emphasising the diversity of carer groups. For example the self-assessment may include a definition of 'family carer' set out in simple language and with detailed examples of a range of typical family carers' situations. The tool should also help overcome family carers' guilt.

2. Implementation of the Carer Self Assessment Tool

2.1. Easy to Implement

Self-assessment is a form of assessment that is completed by the subject (the family carer) without the immediate or direct involvement of professionals. As an assessment method it has the potential to increase the participation and engagement of family carers and may be easier and less expensive to introduce and implement than a professionally administered needs assessment.

Its means that family carers should be able to perform self-assessment on their own. Professionals or volunteers can help family carers to take the self-assessment, but their intervention should not be necessary. The tool can therefore be used informally, at home, in the everyday activities of organisations involved in providing support to family carers, or more formally, based on the advice of professionals.

2.2. Ability to Reach to Family Carers who do not Normally Engage

Every effort should be made to identify 'hidden' family carers who do not normally engage with support organisations or service providers and therefore receive no support in their caring role. Many family carers do not identify as a 'family carer' and therefore strategies using this term may not resonant with them. It is important that a multi-layer approach be adopted to identify and engage with these hidden family carers. As such, cognizance must be given to the following points when implementing the family carer self-assessment:

- A family carer may first become 'visible' through their interaction with professionals, for example when attending hospital, their GP or support services along with the care recipient. It is important to liaise with professionals to ensure they are aware of family carers' needs and are trained to assist and refer family carers where appropriate, and to offer them self-assessment;

In **Luxembourg**, the Assessment and Referral unit of the long-term care insurance is organizing informative evenings for GPs, pediatricians and other health professionals in order to raise their awareness of existing support services and measures. It also disseminates a leaflet with information. Indeed, pediatricians or specialized doctors are on the forefront to announce to parents that the child has a disability, to refer the family to special services, and to advise them to file an application for long-term care insurance benefits, while GPs are responsible for regular medical check-ups during the first years of the child. It is therefore essential that these health professionals be able to take into account family carers' needs and to refer them to relevant services.

- A family carer self-assessment should be offered when an organisation first comes into contact with a carer, or when the family carer contacts them for information, support or assistance;

In French-speaking Belgium, the family carers organisation **Aidants Proches asbl** is running a helpdesk over the phone and the Internet, reflecting the lack of time of family carers for face-to-face meetings. Family carers can easily get a live response to their problem, and psychological support. They can also get help with efforts to care for their relatives through information and referral to the appropriate services. Talking to family carers about their problem allows them to clarify their situation, brings to light needs they had not identified, and satisfies their need to say what is on their mind, whether their request can be met or not. The helpdesk is also somewhere the carer is treated first and foremost as an individual who can say and ask things in a guilt-free setting. Further information: www.aidants-proches.be

In Ireland, **The Carers Association** offers a confidential, friendly and supportive national Care Line 1800 24 07 24. This free listening service is a vital link for the isolated carer. Staff are able to refer callers to their closest Resource Centre, look up information for them, advise them on rights, entitlements and benefits or just chat with carers in a supportive, understanding and non-judgemental way. Occasionally, other support services are enlisted to assist carers who are in crisis. The Care Line acts as a first point of contact for isolated family carers seeking help and support. Staff can ask carers if they would like to continue to

receive information and support from the Association and thereby initiate a longer term relationship. The Care Line often receives calls from carers who are at a crisis point and so is invaluable in supporting them at times of difficulty.
Further information: www.carersireland.com

Such helpdesk or helpline need to be resourced adequately in order to operate on a 24h/day 7 days/week basis. Staff must be fully trained and experienced in dealing with crisis situations.

- Family carers in the early stages of the caring cycle, those living in rural areas, from different cultural backgrounds or with a disability may face additional difficulties in accessing self-assessments. Alternative ways to reach these family carers will need to be considered, such as for instance a door to door approach, communication between peers and mouth of word;

- Family carers organisations must work with schools, employers, government departments, media, etc. to identify hidden family carers and use these as points of contact to engage with them;

- Organisations must not wait for family carers to come to them, but rather must reach family carers by bringing family carer self-assessments into their communities (including at the workplace). By taking this wider approach, community awareness of family carers and caring generally will be raised and information may be passed on by relatives, friends and neighbours of 'hidden' family carers;

Best Practices Example: Awareness Raising at the Workplace

In Italy, the family carers organization **Co.Fa.As. "Clelia"** has undertaken an initiative to raise awareness at the workplace concerning the difficulties faced by family carers. This knowledge sparked a demonstration of tolerance, support and assistance to colleagues who are family carers. This awareness campaign through emails and meetings at the workplace has been a great success.
Further information: www.cofaasclelia.it

- It is important to remember that some family carers will not want to self-assess their needs. Managing on their own is their choice, and it should be respected.

2.3. Accessibility

Family carers should be able to access a needs self-assessment at any time, when and in a format most suited to them. The self-assessment should be free of charge and compatible with their caring role and responsibilities in terms of the time required to complete it.

2.4. Early Intervention

Efforts should be made to identify family carers and offer a self-assessment at the earliest possible stage in the caring lifecycle. The value of early intervention and timely assessments is well recognised, particularly in the area of preventative supports for family carers. By assessing family carers' needs as early as possible and providing interventions to meet these needs, family carer stress, burden or breakdown can be avoided.

> ### Best Practices Examples: Information Booklets and Early Childhoold Support Service
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> In France, local associations of families of persons with brain injuries, **AFTCs**, have published «new starter» booklets for families of victims of brain injuries. One is handed to families when they reach the hospital, after the accident. Another one is also handed in hospitals, addressing what happen after the person with brain injury leaves the hospital. Both intend to explain to families what they are facing and likely to face, including information on the burden of care. Information on help to family carers and useful contacts are provided. Further information: www.unaftc.org
>
> In France too, Adapei 44, a local association for persons with intellectual disabilities and their families, is offering **SAFE**, an education support ambulatory service for parents and other non-professionals caring for a child with an intellectual disability. SAFE is a psychologist-run service that intervenes where there are communication difficulties with the child or challenging behaviour. SAFE works with the family to assess its needs in relation to the child's education, and to set up educational strategies. This early intervention service contributes to raising awareness of the role of family carers. It helps family carers voice and address their needs, working with parents in an age bracket that is key to prevent family carers to lose touch with society and the working world. SAFE is also an information resource and a gateway to other forms of support. Further information: www.adapei44a.fr and www.adapei44a.fr/modules/services/safe_2007-2008.pdf

2.5. Regularity and Reactivity

The needs of family carers are not static but will change overtime as the condition of the care recipient improves or deteriorates. A self-assessment of family carers' needs should not be a once-of event, but rather should be undertaken periodically and at intervals that reflect the changing needs of the family carer.

It should be made clear to the family carer that they can perform a self-assessment at any time. It is important to consider ways of providing regular access to a needs self-assessment for family carers or facilitating ways of incorporating them into organisations' regular activities, such as support groups, family carer training, information seminars, etc.

2.6. Promoting Greater Recognition of Family Carers

Organisations operating in countries where the term 'family carer' is not fully recognised may need to undertake additional awareness raising efforts before the implementation of a family carer self-assessment tool is possible.

Best Practices Examples: Family Carers Weeks/Days and Annual Carer of the Year Awards

In several countries, **Family Carers Weeks or Days** are organised to raise awareness of the general public, media, policy makers, family carers themselves and professionals on the reality of family carers' lives. It can be organised at national level (e.g. Belgium, France, Ireland, UK) or local level (e.g. the town of Carpi, in Italy). It can be promoted by public authorities (e.g. France) or by family carers organisations (e.g. Belgium). Such events help family carers to identify themselves as such, bringing them to an awareness of a collective identity. They also foster the dissemination of the term 'family carer' and place the issue on the policy agenda.
Further information on the national week in Ireland: www.carersweek.ie
Further information on the national day in Belgium www.aidants-proches.be

Now in its fifth year, the annual **Carers of the Year Awards** were created by the Carers Association to formally recognize the enormous contribution of Ireland's family carers, to highlight the invaluable work they carry out in homes and communities around the country and to express appreciation for their hard work and commitment. The event enables The Carers Association to reach family carers in every corner or Ireland. Family carers (who may otherwise never engage with support services) are nominated by family and friends. The ceremony includes a special *Young Carer of the Year Award* to recognize young carers, raise their awareness and make other young people more willing to come forward and seek help. The *Carer of the Year Awards* have enjoyed tremendous success nationally. The event is launched each year by the Minister for Social protection. It receives sponsorship from private enterprises and is hosted by two of Irelands best known personalities. The event raises awareness and profile of

family carers and the issues they face, particularly through the considerable media coverage that the event attracts.
Further information: www.carersireland.com

Also in Ireland, the **national census** identifies family carers by asking respondents if they provide regular unpaid help to relatives with dependency needs.
Further information: www.census.ie/-and-Communities/Census-for-Carers.139.1.aspx

It may also be necessary to change the language used in the self-assessment tool or use a term other than 'carer'. For example parents of children with a disability will identify firstly as parents rather than family carers.

2.7. Ethical Issues

Depending on the context, family carers' needs may not all find an answer. Family carers' attention must be brought to the fact that self-assessment of their needs will not necessarily entail a solution or a response to each of these needs.

However, even if no additional support is provided after taking a family carer self-assessment, the process should help family carers to:

- Feel recognised and valued;
- Recognise themselves as a family carer, and as a partner in care for professionals;
- Be better informed and know who to contact for help;
- Know what additional support services are available;
- Gain more confidence to avail of services and supports;
- Make demands which may lead in turn to advocacy initiatives for a greater recognition of family carers.

3. Content of the Self-Assessment

3.1. Modules of Questions

The family carer self-assessment should provide a comprehensive framework to examine all of the family carer's physical, psychological, social, professional, and financial needs. It could include the following important modules of questions:

- General information;
- Information about the care recipient;
- Family carer's role;
- Family carer health and wellbeing;
- Practical and emotional supports;
- Employment & other commitments;
- Breaks/ respite;
- Financial considerations;
- Rights and formalities;
- Accommodation, equipment and aids;
- Education and training;
- The future.

The appendix provides an outline of these modules and sample questions that may be included.

3.2. Measuring Device

The self-assessment should allow for a weighing of the difficulties and needs (see for instance the Zarit scale for assessment of family carer burden).

3.3. Toolbox

For easier access to support, the self-assessment tool may contain at the end some useful links and addresses, or it may be part of a tool box containing addresses and information on existing quality support.

4. Self-Assessment Outcomes - Next Steps

4.1. (Self) Identification of Family Carers

The self-assessment process will help facilitate the identification and self-identification of Family Carers by giving them a mechanism through which to express their needs. In some cases the self-assessment process may have been the first time that a family carer has engaged with support services and so it is important to ensure that every effort is made to fully support them. However possible, and with the family carers' consent, the organisation or services providing the self-assessment tools should

follow up on the family carers situation, making regular contact made with them and, for example inviting them to participate in relevant training, local family carers support groups or information days. One aim is to put an end to or prevent the isolation of the family carer, for instance thanks to peer support (making sure to avoid the pitfall of collective demoralisation).

4.2. Identification of Family Carers' Needs

The outcomes of the self-assessment will identify family carers' needs, and will allow the family carer to express what, if any, support should be provided to meet these needs. Family carers are free to use or not the results of the self-assessment, and to use them the way they wish to.

For instance, family carers should be able to report on the outcomes of their self-assessment to support services, explaining what needs have been identified in order to receive help on how these needs could best be addressed (for example, by referral to a local support organization, respite hours, training, provision of care equipment, hoists etc.). If the self-assessment shows that the family carer is particularly vulnerable then this should act as a trigger for the immediate intervention of appropriate support services. Family carers should also be able to use the results of the self-assessment to trigger or strengthen partnership with professionals involved in the care.

Best Practices Examples: Holistic Support Services for Family Carers

In France, several local NGOs have developed holistic support services for family carers, such as the **APEI Ouest 44** in Loire-Atlantique, the **CASA** in Poitou-Charentes, or **Handi-Répit** in Val-de-Marne. These services target all family carers of persons with disabilities, or all family carers irrespective of the cause of dependency. They provide several types of support, ranging from individualized support (comprehensive support, addressing all consequences of disability: administrative, financial, psychological, social and other aspects) and collective activities (support groups, information meetings, debates, and leisure activities) to coordination of delivery of services, home care services, respite services and training to family carers and professionals. These services have a clear focus on ending isolation and preventing burnout, providing information, assessing needs and referring towards relevant support schemes, fostering self-identification as family carers and empowerment. Their efforts to reach out to family carers are important (easy access, leaflet and other dissemination tools, local media coverage, networking with relevant social and health services,

etc.). Partnership between family carers and professionals is promoted. These services are funded by local or regional authorities.
Further information on APEI Ouest 44's service: www.apei44-asso.fr/ and
http://livreapeistnazaire.free.fr/plaquette%20du%20service%20aide%20aux%20aidants.pdf
Further information on the CASA:
www.laparoleauxaidants.forumactif.fr

In Luxembourg, **APEMH** has developed SCAF, a service aiming at supporting families in the expression of their needs and of the needs of persons with disabilities, in order to offer comprehensive support and care, ranging from needs assessment and planning and coordination of services delivery to psychological support, parenthood support, and partnership with professionals.
Further information: www.apemh.lu/les-services/scaf

The Carers Association has a network of 16 carer centres located throughout Ireland. Each centre allows family carers to drop-in, and provides advice on rights and entitlements, support groups, respite services and carer training. Because centres are visible in the community, it encourages the identification of family carers and enables them to seek support locally.
For further information: www.carersireland.com

4.3. Identification of Training Needs

The self-assessment process will help to identify what training or learning provision is needed to:

- Provide practical support to family carers in their caring role and responsibilities (first aid, patient moving and lifting, personal care etc);

- Enable them to combine their caring work with part-time paid work;

- Or to prepare them for employment when their caring role and responsibilities comes to an end (confidence building, exploring possible areas of work, referral to accredited training, CV preparation etc).

Efforts should be made to harness the skills and goodwill of former family carers and explore ways of utilizing their expertise, experience and knowledge.

4.4. Cooperation and Learning

The self-assessment process should encourage greater co-operation, networking, and sharing of good practice between family carers, family carers groups, NGOs, statutory bodies and health and social services professionals, by providing a systematic mechanism through which to identify family carers, give them access to self-assessment and respond to their needs.

4.5. Empowerment of Family Carers

The self-assessment process will help achieve greater recognition, empowerment and a better quality of life for family carers. It will empower them to make better informed decisions, make them feel more supported in their caring role and enable them to influence the planning and delivery of services for both themselves and those they care for. The self-assessment process will also increase the knowledge and understanding of all those who work with family carers about their needs.

Appendix

The following table provides an outline of some of the important modules and sample questions that may be included. Please note, these questions are intended only for sample purposes. Not all modules or questions will be relevant. These proposals should be adapted to the situation.

No.	Module	Sample Questions
1.	General Information	• How did you obtain the self-assessment tool (at your request, offer of self-assessment, when searching for information, etc)? • Date of self-assessment. • Length of time in the caring role. • Other information that may be considered relevant including religion, cultural beliefs, disability, literacy, communication difficulties, young family carer etc.
2.	About the Care Recipient	• What is your relationship to the care recipient? • Physical or mental health conditions? • Can the cared for person make their own decisions? • Can the cared for person assist in their own care e.g. make meals, drive etc?
3.	Family Carer's Role	• Details about the care provided e.g. personal care, emotional care, help with activities of daily living, medication, help eating, legal representation, etc. • Do you have a choice about providing care? • Are you willing or able to continue in your caring role? • How much time per day/week do you spend caring? • Do you live with the person for whom you care? • What aspect of your caring role (if any) are you willing to provide? • Which parts of the role do you actively not want to do? • What aspects of their caring role do you find difficult?

No.	Module	Sample Questions
		• Are there aspects of the caring role that you can manage to carry out without help? • Do you understand the extent of the care recipients' condition and possible future care needs? • What is/are the outcomes you would like to see to you in your role? • What is your view of the most important outcomes to achieve for the person they care for? Are these in conflict with the cared for person's views? • Do you work in partnership with professionals?
4.	Family Carer Health and Wellbeing	• How do you describe your own health? • Are you stressed, anxious or depressed? • Do you frequently go without sleep? • Are you suffering from any physical ailment or illness? • Do you suffer from depression or any mental health issue? • Do your caring responsibilities include physical tasks such as patient lifting, moving etc? • Are you receiving any treatment? • Is your own GP aware of your caring responsibilities?
5.	Practical and Emotional Supports	• Do you consider the level of support you receive at present adequate to meet your needs? • Do you receive support from family or friends to help with your caring responsibilities? • Is there someone to whom you can talk openly? • What support, either formal or informal, do you feel is of most benefit to you? • Do you attend any dedicated support group or organisation? • Are others aware of your caring responsibilities? • Do you know where or how you can access information or advocacy support?

No.	Module	Sample Questions
6.	Employment & Other Commitments	• Are you employed outside the home? • If you do not work outside the home, would you like to? If so how can you be supported to do so? • Do you intend to work outside the home after your caring role has ended? If so how can they be supported to do so? • Do you have other responsibilities such as parenting, voluntary work, training etc.
7.	Breaks / Respite	• Do you consider the level of breaks you receive adequate to meet your needs? • Can you get regular access to a break to allow you to do the things you enjoy? • When was the last time you were able to take a break? • Would the care recipient be willing to be cared for by someone other than you? • Are you willing to take a break away from the care recipient? • Do you find it difficult or stressful to be away from the care recipient? If so what would make it easier? • What would happen if you became ill? Do you have someone who could take over their caring responsibilities?
8.	Financial Considerations	• Has caring affected your personal finance? • Do you feel financially secure or is money as source of concern for you? • Are there additional costs associated with your caring? If so what are the main costs e.g. transport, medication, dietary requirements, medical costs? • Do you receive any financial assistance to help you with your caring role? • Are you aware of financial supports or grants that may be available? • Do you know where to go for advice and information on financial supports, money management etc? • Are you concerned about your financial security after your caring role has ended? • Does the person cared for need help with their financial affairs? • Do you have a legal arrangement with the

No.	Module	Sample Questions
		cared for person e.g. agent, power of attorney, custodian etc?
9	Rights and formalities	• Does your caring role entail a lot of paper work and formalities? • Do you receive any assistance to help you with formalities and accessing rights? • Do you know where to go for advice and information on rights and formalities
10.	Accommodation, Equipment and Aids	• Do you live with the cared for person? • Is the accommodation suitable for the needs of the cared for person e.g. accessible shower and toilet facilities, wheelchair ramps etc? • Are there other problems associated with the accommodation e.g parking, anti social behaviour, house repair etc? • Are there equipment or aids that would help you e.g. hoists, commode etc? • Are you aware of the grants that exist to support housing adaptations for people with disabilities? •
11.	Education and Training	• Have you received training to support you in your caring role, for example first aid, patient moving and handling etc? • Would you like to avail of care specific training? If so what areas are you interested in? • Do you have the opportunity to participate in education or training? • Do you require additional training to help you secure employment?
12.	The Future	• Are care needs likely to increase? • Are you willing to continue to provide care? • What would you like to do in the future? • What additional supports could be put in place to help you (please consider meals, respite, equipment, aids, training, alarms, housing adaptation etc). • Do you have any concerns about the future? • Would you like to be contacted by an

No.	Module	Sample Questions
		organisation that may be able to offer assistance to you?

Recommendations on Training Provision to be Made for Family Carers and Professionals to Help Family Carers Assess and Express their Needs

Rationale

These recommendations are based on:

- a tool[4] produced in the framework of European cooperation funded by the Lifelong Learning Programme, the Leonardo da Vinci transfer of innovation project 'CARERS - Content mAterials to Raise Employability and Reinforce Skills of Carers' (www.carers-project.eu). The aim of this project was to offer a programme of training specifically aimed at 'informal carers' and providing answers tailored to their real needs, in their support work as well as for their own emotional well-being;

- the implementation of the above mentioned tool by APEMH, the Luxembourg partner, and APEMH's wider expertise in the field of training and of support to family carers, involving family carers;

- the characteristics identified during the course of the Partnership when analysing best practices collected in the field of self-assessment of their needs by family carers (these features include the empowerment of family carers; the ability to break with the vicious circle of isolation; and facilitating self-identification as family carers, and facilitating the self-assessment of needs);

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[4] In particular:

- Module 1, aimed at 'informal carers' in general. The objective of this module is to provide a general introduction on the theme of dependency and its impact on the life of carers. In particular it provides guidance for "informal carers" in order to help them develop their own skills, identify and respect their own limits, while learning to accept help. It raises their awareness about their own needs and the importance of taking them into consideration;

- Module 6, consisting in a tool box for 'informal carers'. The objective of this module is to provide carers with as much knowledge as possible, and exercises to help them improve their own well-being and learn how to deal with and manage stress;

- The methodological training guide. This is intended as a learning support for the users of the various training modules. It includes practical concepts relating to adult training and establishes a learning framework by proposing non-formal learning methods.

- the Partnership's participatory approach with full involvement of family carers as adult learners.

These recommendations concern:

- on the one hand, learning[5] provision for family carers, to reinforce their skills and empower them to assess and express their needs;
- on the other hand, training provision for professionals on how to help family carers identify themselves as family carers, assess and express their needs.

Some of the recommendations concerns only learning provision for family carers. Some concerns only training provision for professionals. Some recommendations are common to both.

The recommendations below do not have the ambition to propose detailed specifications for the development of learning/training provision. Their aim is to point out to:

- The need for developing learning/training provision to help family carers assess and express their needs;
- Key success factors.

These recommendations are complementary to the broader set of recommendations for the design of tools for self-assessment and expression of their needs by family carers also developed in the framework of this Partnership:

- self-assessment tools are useful material for learning/training provision;
- self-assessment tools' use can be a pathway to attending a learning programme;
- training of professionals on how to help family carers identify themselves as family carers and assess and express their needs will contribute to a wider use and dissemination of self-assessment tools by professionals.

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[5] Some partners were keen to distinguish vocational training from training for family carers, in order to avoid the risk of unwanted professionalization of family carers. As a result of a consensus, the word 'learning' is used for family carers, instead of the word 'training'. At national level, in some countries some might prefer to use the word 'training' anyway. Irrespective of the used terminology, the same is at stake i.e. the recognition of the needs of family carers in this field.

Attending learning provision is part of a process. Initiatives for reaching out to family carers should be further developed and receive adequate support from public authorities, especially in Members States where there is so far no or little recognition of the role of family carers.

1. Common Recommendations

1.1. Learning provision for family carers and training provision for relevant professionals of the health, social and education sectors should be developed and implemented with the aim of enhancing the perception of the role as family carer and self-assessment and expression of their needs by family carers.

1.2. Common objectives should be:

1.2.1. to promote family carers social inclusion and support their health and wellbeing;

1.2.2. to help family carers to identify, put into words and express their needs;

1.2.3. partnership between family carers and professionals.

1.3. Family carers should be involved, together with professionals, in the definition of the learning / training modules. They should help assess what are the real needs of family carers in terms of such learning/training provision.

1.4. Facilitators/trainers should be very well trained, including in the field of systemic analysis (family carers and professionals are part of a system, with interactions).

2. Recommendations concerning Learning Provision for Family Carers

2.1. Learning provision for family carers should be developed and implemented with the following specific objectives:

2.1.1. Greater awareness of their role and needs, and ability to assess their needs;

2.1.2. Empowerment to express their needs and be assertive;

2.1.3. Access to quality support;

2.1.4. Greater ownership of their life and improved self-esteem;

2.1.5. Empowerment to reflective and critical thinking, and self-determination.

2.2. Care responsibilities should be taken into account in order for family carers to take up learning provision:

2.2.1. Quality, accessible and affordable replacement care services must exist;

2.2.2. The schedule of the learning provision must be realistic;

2.2.3. Learning must be provided close to the family carer's home;

2.2.4. Learning should be provided for free or for a symbolic price.

2.3. Family carers need to be convinced that the learning will be useful to them in their everyday life:

2.3.1. Concrete topics should be advertised such as dealing with stress; detecting signs of exhaustion to prevent burnout; managing guilt or bad feelings; detecting signs of crisis; maintaining family harmony (with the cared for persons, with siblings); the "after us" issue; making it easier to ask for help; partnership with professionals; dependency and its consequences; etc.;

2.3.2. Concrete and realistic achievements should be advertised such as stress reduction; access to information and other types of support; decrease of isolation and sharing of experiences; etc.

2.4. The learning provision should be tailor-made and flexible (diversity of family carers and of contexts).

2.5. Interactivity and active involvement of family carers in the learning process should be ensured through:

2.5.1. organizational aspects (size, regularity and continuity of the group; informal and friendly settings);

2.5.2. a methodology based on active participation, practical experiences, cooperative learning, and peer emulation. The learning must be based on everyday situations and feelings (see 2.3.1). Topics must be chosen by learners. Family carers must be able to link what they learn to what they already know, and understand its relevance in helping them. Through exchanges of experiences, family carers will act as resources for their peer. This will support self-recognition of their role and competences;

2.5.3.   listening, support to expression, and respect for the needs and motivation of the adult undergoing education.

2.6.   The learning process should be facilitated through:

2.6.1.   a terminology adapted to the target group;

2.6.2.   search for mutual agreement and understanding on the definitions of subject matters and of key ideas (brainstorming);

2.6.3.   illustration using a practical case, close to family carers' everyday life and experiences, facilitating an awareness of the carer's role and needs;

2.6.4.   informal and continuous verification of the assimilation of knowledge to respect family carers' learning pace.

2.7.   The learning provision should be based on the following tools:

2.7.1.   a module with practical strategies and general advice in order to prevent stress and enable family carers to manage the risk of burnout;

2.7.2.   a questionnaire for the self-assessment of needs (validated by family carers);

2.7.3.   a tool box containing addresses and information on quality support available.

2.8.   The facilitator should have the following specific competences:

2.8.1.   knowledge of the work of family carers and of the impact of dependency needs on relatives;

2.8.2.   good listening skills, and an ability to empathise and avoid any judgements;

2.8.3.   empower learners, and support their expression so as to encourage them to participate actively and express their views, needs and individual aspirations;

2.8.4.   recognize the competence of learners, and make explicit and value their knowledge.

2.9.   The facilitator should have the following general skills:

2.9.1.   be able to coordinate a group, ensure its proper functioning, and promote collaborative work and solidarity;

2.9.2.   establish a secure environment of trust and respect within the group, thereby helping to boost self-esteem and encouraging learners to express themselves freely;

2.9.3.   be capable of reflective and critical thinking;

2.9.4.   be capable of ongoing adaptation and readjustment of the learning approaches and tools according to objectives and needs;

2.10. The quality and relevance of the learning provision should be assessed on an ongoing basis, using an evaluation and satisfaction questionnaire filled in by learners.

3. Recommendations concerning Training Provision for Professionals

3.1. Training provision for relevant professionals of the health, social and education sectors should be developed and implemented with the following specific objectives:

3.1.1.   create awareness of family carers among professionals so that professionals will be better informed to meet family carers' needs;

3.1.2.   foster 'automatic' recognition of family carers and access to quality support as early as possible;

3.1.3.   encourage professionals to be proactive in offering quality support;

3.1.4.   recognition of family carers as equal partner in care and avoid feelings of unease or intimidation between family carers and professionals.

3.2. Professionals should be trained in understanding family carers and their role, including:

3.2.1.   helping family carers to come to terms with the dependency of a loved one;

3.2.2.   enabling family carers to make a free and well-informed choice about whether performing this role at all or not;

3.2.3.   identifying difficulties that family carers may have in communicating their needs;

3.2.4.   identifying risks of vulnerability and suffering;

3.2.5.   supporting family carers and helping them to take a step back from their situation;

3.2.6.   preventing burnout among carers and avoiding crisis situations;

3.2.7.   supporting harmonious family relationship;

3.2.8.   helping family carers to prepare for life after caring.

3.3. Professionals should be trained in how to include family carers as partner in care, including:

    3.3.1.   defining the role of professionals vis-à-vis family carers and vice versa;

    3.3.2.   developing the ability of professionals to listen to families, to communicate effectively with them, and to have a dialogue with them;

    3.3.3.   exchanging know-how and best practices with family carers.

3.4. The training provision should also include specific themes in order for professionals to help family carers to access quality support, including helping family carers:

    3.4.1.   to find and understand information;

    3.4.2.   with the formalities to receive existing aid;

    3.4.3.   to decipher professionals' language;

    3.4.4.   to be assertive.

3.5. The training may be provided with the contribution of family carers.

3.6. This training should be part of initial and continuous vocational training.

Best Practices Example: the EUFORPOLY Project (Europe-Training-Multiple Disabilities)

The EUFORPOLY project (Europe – Training – Multiple disabilities) was funded by the EU programme Leonardo da Vinci.

The focus of the project was the joint training of parents (family carers) and of professionals with less qualification. Parents and professionals from several countries (Belgium, France, Portugal, Spain and UK) worked together from 1996 to 2001.

The starting point of the project was the acknowledgement by family carers, looking for skilled professionals to take over the care of their children, that many of the professionals had no or few qualifications. And yet, there are many requirements in order to prevent the worsening of the disability: constant attention (epileptic fits, positioning, swallowing,…), careful manipulation, and, taking into account the difficulties with verbal communication, observation skills.

The objectives of EUFORPOLY were:

- To recognise persons with multiple disabilities through their competences and specific needs;
- To recognise the needs of carers (parents and professionals);
- To value parental expertise, and to help family carers to acknowledge their role, in order to promote partnership with professionals;
- To collect practical and theoretical knowledge, clinical experiences, and methodological tools, in order to establish a corpus of shared references and to define essential directions and content for quality care.

One of the project's results was the elaboration of a frame of reference for training for parents and professionals concerning multiple disabilities.

EUFORPOLY is a good exemplification of the above recommendations. The approach put family carers and professionals on an equal footing for a constructive project for persons will multiple disabilities. It empowers family carers to reflective and critical thinking, and self-determination. Interactivity and active involvement of family carers is ensured.

The frame of reference enables the development of training provision enhancing the perception of the role as family carer and fostering self-assessment and expression of their needs by family carers. This frame of reference emphasizes training as a need of parents and professionals, and as a partnership tool.

Another result of the project, a compendium of articles, was designed and written a way to make it accessible to persons with few qualifications. It can also be used as training material for training provision for family carers and professionals.

For further information:
http://associationair.chez.com/euforpoly.html

Conclusion: Partnership Recommendations to the European Union

The recommendations are based on the cumulative work of the Grundtvig Learning Partnership 'Self-assessment of their needs by family carers: The pathway to support'. They point out measures and initiatives which are needed at European level in order to establish, across the EU, social and policy environments supportive of self-assessment and expression of their needs by family carers.

1. Fostering EU wide recognition of the role of family carers and of the support they need

The role and issues of family carers are not recognised to the same extent across the European Union. In some Member States, the lack of recognition is such that no or few policies or programmes are developed for family carers, and family carers themselves are not well aware of their role – let alone empowered in any way.

The European Union should foster EU wide recognition of the role of family carers, their contribution, their difficulties and the support they need. This should be done through:

- **Awareness raising** in the framework of the 2012 European Year for Active Ageing and Solidarity between generations, and of the designation of 2014 as the European Year for Reconciling Work and Family Life[6];

- **Awareness raising** through the establishment of a European Day of Family Carers, based on National Days/Weeks existing in some Members States;

- **Policy coordination and exchange of good practices** between Member States on the issue of support to family carers, including on the official status of family carers and carers national strategies. To do so, the EU should use the framework of the Europe 2020 Strategy, of the European Platform Against Poverty, of the Social Protection Committee, and of the European Alliance for Families (including National Reform Programmes and National Social Reports submitted yearly by Member States);

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[6] Further information: http://www.coface-eu.org/en/News/European-Year-2014/

- **Mainstreaming** of the issue across all European disability, ageing, health, and gender equality strategies / initiatives (including when implementing the UN Convention on the Rights of Persons with Disabilities);
- Adoption of an **EU directive** introducing a leave to care for a dependent relative;
- **Collection of statistics and data** concerning family carers in the European Union, including with the support of Eurostat.

2. Encouraging the development of holistic support services for family carers

Holistic support services for family carers are instrumental for self-assessment and expression of their needs by family carers. They reach out to family carers, raise their awareness, provide them self-assessment tools and encourage the expression of their needs, thus contributing in an essential way to their empowerment. They also provide the necessary follow-up to self-assessment of needs: access to concrete support (ranging from information and training to psychological support and delivery of respite services). Such support services are still very little developed across the European Union. Lack of funding is an issue.

The European Union should encourage the development of holistic support services for family carers. This should be done through:
- **Exchange and promotion of good practices**, using the current PROGRESS programme and the future EU Programmes for Social Change and Innovation, and for Rights and Citizenship;
- **Use of the EU structural funds** to finance holistic support services for family carers, in the framework of the 2014-2020 priorities (transition from institutional to community-based care, reconciliation between work and private life, and enhancing access to affordable, sustainable and high-quality social services).

3. Encouraging the development of learning and training provision for family carers and professionals

Education and training has a key role to play to enhance the perception of their role, and self-assessment and expression of their needs by family carers. Learning provision for family carers and training provision for relevant professionals of the health, social and

education sectors should be developed and implemented to create awareness of family carers among professionals, empower family carers, and promote partnership between family carers and professionals.

The European Union should encourage the development of such learning and training provision. This should be done through:

- **Exchange and promotion of good practices**, in the framework of the renewed European Agenda for Adult Learning, and using the current Lifelong Learning Programme and the future Erasmus for All Programme;
- **Use of the European Social Fund**.

List of Partners

Partner Organisations

Belgium

Association de parents et professionnels autour de la personne polyhandicapée (AP³)
www.ap3.be

Bulgaria

Center of Women's Studies and Policies (CWSP)
www.cwsp.bg

Cyprus

Pancyprian Organisation of Large Families (POP)
www.pop.org.cy

France

Association des Paralysées de France (APF)
www.apf.asso.fr

France

Union nationale des associations de parents, de personnes handicapées mentales et de leurs amis (Unapei)
www.unapei.org

Ireland

The Carers Association
www.carersireland.com

Italy

Il Coordinamento dei familiari assistenti "Clelia" (Co.Fa.As "Clelia")
www.cofaasclelia.it

Luxembourg

Association des parents d'enfants mentalement handicapés (APEMH)
www.apemh.lu

Slovakia

Club of Large Families
www.kmr.sk

Spain

Confederación española de familiares
de enfermos de alzheimer y otras
demencias (CEAFA)
www.ceafa.es

With the support of

Belgium

Aidants Proches ASBL
www.aidants-proches.be

France

Alliance Maladies Rares
www.alliance-maladies-rares.org

France

Association nationale Spina Bifida
et Handicaps Associés (ASBH)
www.spina-bifida.org

France

Union nationale des associations
de familles de traumatisés
crâniens et cérébro-lésés
(UNAFTC)
www.unaftc.org

European Networks

Confederation of Family Organisations
in the European Union (COFACE)
www.coface-eu.org

EUROCARERS
www.eurocarers.org

Further information

Further information about this Grundtvig Learning Partnership is available on the COFACE and Eurocarers websites:

- COFACE: www.coface-eu.org/en/Projects/Carers-Project/
- EUROCARERS: www.eurocarers.org/research_qualityframework.php

For any query, please feel free to contact Céline Simonin, International Projects Officer, Unapei (c.simonin@unapei.org).

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