

PAPER FOR EUROCARERS WEBSITE

Informal care and volunteering assistance in Europe; a comparison between countries in the North Sea region by Roos Galjaard (Bureau PAU), Elise van Opstal (city of Aalst) and Maud Diemer (CMO STAMM)

<https://northsearegion.eu/in-for-care/>

Abstract:

Countries with plentiful publically-funded care and services are increasingly shifting the focus towards family or social responsibility and promoting informal care. This transition in the social care systems is not without risk; it may cause increasing (health)care inequality, problems combining work and care or costs in relation to sick leave. Furthermore, it is widely recognised that informal caregivers face a number of challenges including psychological issues such as stress, anxiety and/or depression.

To address these challenges, the EU-funded project 'In For Care' was launched in early 2017. The 10 project partners represent regions from around the North Sea that share high welfare status and comparable health systems. The project's aim is to improve voluntary work processes and informal care in social service delivery. The project's core method – the quadruple helix approach – is used to enable user-driven innovation in services, implementing new technology (collaboration tools) and demonstrating valuable matchmaking between informal and formal networks.

This paper presents an overview of informal care and volunteering assistance in the participating countries, whilst identifying bottlenecks and challenges as well as specific strategies for coping with the latter. It explores and compares the various interventions in the partner regions aimed at strengthening cooperation between informal carers and professionals, but also looking into how to support young informal carers, create informal care-friendly policies and using service design and co-creation as innovation support measures.

1. Introduction

Informal care constitutes a significant proportion of total long-term care (LTC) provision in European countries. Estimates suggest that as much as 80% of all long-term care in Europe is provided by informal carers (Hoffmann & Rodrigues, 2010). The available estimates of the number of informal caregivers ranges from 10 up to 25% of the total population in Europe. The average varies significantly between countries, groups of countries depending on how informal care is defined and measured. In the future informal care is likely to become even more important due to demographic changes, healthcare advances, LTC policy and cost-containment pressures leading to a favouring of community care options over institutionalisation where possible (Riedel, 2012).

Countries with large-scale publicly funded care and services are increasingly shifting the focus towards family or social responsibility as well as promoting informal care. The organisation and regulation of services are increasingly being devolved to local and regional authorities, based on the assumption that if the provision of services is organised close to the recipient, this will lead to more appropriate solutions and lower costs (SCP, 2014).

This transition in social care systems is not without risk; it may cause increasing (health)care inequality, problems with combining work and care or costs in relation to sick leave. Furthermore, it is widely recognised that informal caregivers face a number of challenges, including poor understanding of the local health and social care systems, lack of experience and/or formal education in care, limited societal support, lack of specific tools to manage the whole care cycle, skills deficits to support the cared for with daily life activities, lack of technical support with respect to care aids, problems with coordinating care affecting other 'care' employment, psychological issues such as stress, anxiety and/or depression.

To address these challenges, the EU funded project 'In For Care' was launched in early 2017¹. The 10 project partners represent regions around the North Sea with high welfare status and comparable health systems. The aim of the project is to improve voluntary work processes and informal care in social service delivery. It acknowledges the need to increase knowledge of how the public sector can innovate in this regard. A quadruple helix approach is the core method used in the project to enable user-driven innovation in services, implementing new technology (collaboration tools) and demonstrating valuable matchmaking between informal and formal networks.

This paper presents an overview of informal care and volunteering assistance in the participating countries, identifies bottlenecks and challenges as well as specific strategies for coping with these challenges. 'In For Care' interventions aim to strengthen cooperation between informal carers and professionals, but also support young informal carers, create informal care-friendly policies using service design and co-creation as innovation support measures.

2. Informal care and volunteering assistance: bottlenecks, challenges and coping strategies

At the start of the 'In For Care' project, a comparison was made between the quantitative and qualitative aspects of volunteering and informal care in the participating countries: Belgium, Denmark, the Netherlands, Norway, Sweden, and the United Kingdom (In For Care, 2017).

In Belgium, the Netherlands and the United Kingdom informal care is rather similar. Family members such as spouses are caregivers with self-care and community-based care being quite common. In countries such as Denmark, Norway and Sweden care is still seen more as a public responsibility, provided by the state. However, because of ageing populations, governments are increasingly shifting the focus towards family or social responsibility and towards promoting informal care.

All the countries involved in the 'In For Care' project aim to provide higher quality care services to patients and for this to be more cost-efficient. Integrating professional healthcare and informal care has proven to be difficult for numerous reasons. These difficulties are slightly different in each country, but all of them seem to stem from how the population perceives the healthcare system already in place; the way healthcare has been institutionalised in the past.

An important bottleneck to the improvement of the collaborative relationship between organisers of formal healthcare and informal carers is the fact that citizens who have already been providing informal care have a hard time finding information on specific regulations and measures from the government. Either there is no system in place at a municipal level which deals with informal care such as in Norway or the carers do not see themselves as such as is the case in Sweden thereby missing out on opportunities for financial allowances and support. This exemplifies the need for the quadruple helix model as used in the 'In For Care' project.

Obviously, more volunteers working in care greatly reduces the costs of care for the state, but at the same time the increase in demand for informal care puts greater pressure on the existing informal carers. In the UK, research has shown that the time and effort of caring not only take a toll on the carers' physical and mental health, but even lower their income. Spending over 20 hours a week on care decreases income among carers in comparison to non-carers. In the Netherlands those who are supported by their management and colleagues at work while performing informal care experience the combination as less negative than those who do not receive this support. The effects of using one's free time to care for another person on the quality of life is something all countries should take into account and employers need to be made aware of the support they can potentially provide to employees in this position. Furthermore, it is beneficial to companies and government bodies to ensure employees remain physically and mentally healthy as an increase in hours spent as a carer can result in more stress, more days off in sick and therefore increased employer costs.

¹ The project In For Care is partly funded by the North Sea Region Interreg Programme 2014-2020. More info can be found on the website: <https://northsearegion.eu/in-for-care/>

With the number of care recipients increasing, more volunteers will need to be recruited to distribute the load, but due to ageing populations and other factors, countries such as Belgium and the Netherlands struggle to do so.

3. The quadruple helix approach enhances cooperation between public authorities, the care industry, academia and citizens

In the North Sea Region the 'In For Care' project engaged stakeholders in the field of informal care and volunteering for (public) service provision. In order to shape innovative solutions, they opted for the 'design thinking' method. 'Service design' is a method that helps develop the interaction between the service provider and its clients to improve the quality of the results or product. If successful, it is more user-friendly and relevant to clients, whilst being sustainable and competitive for the service provider. This trial method solves challenges on the basis of the user's perspective. The focus is on understanding the users' needs and how these experiences help finding the problem that needs to be solved. Based on this knowledge, new solutions can be developed and tested to create value for both users and organisations.

'In For Care' partners organised workshops in cooperation with various stakeholders to:

- Assess needs (empathise)
- Understand needs (define)
- Create ideas for new services, connected to the needs (ideate)
- Develop solutions for new services (prototype)
- Test new services in real life (test)

18 workshops were organised throughout the North Sea Region connecting various stakeholders. 889 people participated in workshops, co-creation activities and hackathons. Building on an innovative solution with quadruple helix stakeholders was useful during the process for broadening perspectives. It also motivated and stimulated stakeholders to participate and engage in developing ideas.

Transforming co-creation ideas into working solutions (prototyping) is a giant step. While developing ideas is easy, designing working solutions is not. The proof of the pudding is in the eating. To really create a working, innovative solution, you need to put it into practice. Involving stakeholders in the test, engaging them to cooperate and to invest time in the service innovation, requires a thorough communication effort.

A crucial step when setting up a service design through connecting formal and informal networks is to provide the departments and staff involved with good information about the process and engagement.

In the setup for a user-centred innovation and a co-creation process for a wicked societal challenge, it is important to pay attention to involving and engaging organisations. Even more so as it concerns the cooperation between formal and informal networks for which we are designing a service. The various organisations involved need to recognise the added value as well as make it fit their organisation.

Informing and engaging the formal (care organisations) and informal networks (neighbourhoods, volunteer organisations, etc.) about the service design process as a result of the co-creation sessions, asking how they see this service fit within their organisation. Personal interactions with sufficient time and space, collecting a great deal of feedback to provide adjustments to the final process. It is important for the organisation to understand the added value and also to work on the basis of their commitment and strengths. The personal approach ensures they feel more involved and know who the contact person is, making further support and cooperation communication easier.

The quadruple helix cooperation methods were assessed to be useful by the project partners because they gained insights, mapping the needs of the stakeholders.

4. First results from the 'In For Care' project: enhanced cooperation between formal and informal networks

At the start of the project some concern was noted with regard to the fact that not all countries had a system in place through which informal carers could easily find the information and support they needed. Networks which function as a bridge between public authorities and local informal carers are crucial for getting information across from one party to the other.

In order to enhance cooperation between formal and informal networks, not only decision makers and professionals in the field should be invited to meetings and co-creation sessions, but also end users, healthcare academics, SMEs and policy makers. Together they have come up with new strategies and solutions using the quadruple helix approach described in Chapter 3. Multiple new strategies and solutions have demonstrably benefited all those involved in informal care. The quadruple helix actors taking part in the project have been able to experience the effects of successful initiatives and have been inspired to try to apply similar ideas in their own regions.

For example, a pop-up community centre opened in Turnhout, Belgium. It is called 't Geburt and was specifically intended to enhance social cohesion in the neighbourhood and, with that, local residents' willingness to become volunteers. But it was also created as a place for people to get help with their bookkeeping without having to visit the municipality's offices. Social cohesion and the recruitment of new volunteers benefited from low-threshold activities such as coffee mornings, card games, walks around the neighbourhood and a movie night. The community centre functions as a bridge between the local network of citizens and volunteers and the existing, municipal-level network for formal care. The community centre provides the municipality with an easy way to reach out to locals, providing help with paperwork or recruiting volunteers. Another example from Belgium is situated in Aalst, where formal and informal networks meet at an informal care drop-in called De Palto. For the 'In For Care' project, Aalst looked for ways to support informal carers and develop new services. They cooperated with IDROPS, a social innovation agency for profit and non-profit organisations. Together with three local service centres and a core group of informal carers who play a central role in organising De Palto, they welcomed other informal caregivers. The drop-ins are organised in different places across the city on a monthly basis. Informal carers meet there to exchange experiences in a relaxed atmosphere. In addition, they can get information on informal care, home care and other relevant services as well as listen to talks on specific diseases. The Municipality of Aalst is also working on a digital version including a chatbot for requesting information.

Different tools, methods and practices have been tested by all project partners. The usefulness of some has started to stand out as they show potential for being implemented in various countries. In Kristiansand Region and Grimstad, Norway, the **FRIDA** tool was tested by local volunteer centres to improve volunteer management. The tool aims to help volunteer centres improve their day-to-day work and bookkeeping, but can also make it easier for public authorities and formal health services to reach informal carers. Preliminary results from the tool's analysis indicate that it successfully enhances cooperation between formal and informal networks, however further research is being conducted by the University of Agder.

The Municipality of Hoogeveen, one of the project's Dutch partners, is currently running a pilot in which specialised consultants are being deployed as part of a multi-disciplinary team to focus on matters concerning overburdened caregivers. 12 teams, each associated with a doctor's practice in Hoogeveen, now have the extra benefit of a caregiver's consultant. As well as a GP, the multi-disciplinary teams also include a doctor's assistant, a district nurse, a social worker, a municipal social support consultant and a geriatric specialist from the regional hospital. These teams aim to identify and visit vulnerable elderly people subsequently providing the support and care they need, all in close cooperation with general practitioners. The added value of caregiver's consultants is that they don't focus exclusively on the elderly. Following indications from the GP they can trace and identify those who are or threaten to be overwhelmed by caregiving responsibilities and guide them towards suitable forms of help and support. The consultants offer individual counselling, information, advice, emotional support and when necessary, respite care. They can also refer the caregiver to other internal or external services (e.g. voluntary homecare, day care, guest houses and care farms). During the pilot the research division of the University Medical Centre Groningen investigated the following theories:

- Multi-disciplinary teams in general practices are an efficient way of tracing overloaded caregivers.

- The consultant for caregivers alleviates the GP's and other care professionals' workload.
- Using specialised consultants can help alleviate the burden experienced by overloaded caregivers.

The research was conducted using interviews and questionnaires. The analysis and results will be published on the project's website.

In Värmland secondary school students were involved as volunteers in a digitalisation seminar for the elderly. The seminar was intended to both boost interest in using digital tools and services in informal care as well as for the elderly to gain the necessary skills to use these tools. The seminars were a collaboration between the public authorities, the over 65s, young volunteers and a telecom provider. The project gained valuable insights not only into the needs of the elderly with regard to digital tools, but also into how to reach and recruit young people for such activities.

Abertay University in Scotland collaborated with the Fife Society for the Blind in its technology roadshow programme which promotes co-design and co-creation between end users, technology experts and the university.

UC SYD in Denmark is developing a physical training app which helps informal carers stay healthy during their otherwise burdensome work.

The activities have resulted in more awareness about informal care and its challenges, driving a change in mind set, increasing the willingness of local governments, SMEs and the care industry to collaborate. Inclusion of all target groups has proven to be essential for creating tools and services which effectively innovate service provision in relation to care.

What stands out from all these different tools and initiatives is that they introduce the option of connecting to a formal healthcare network closer to the informal carer than it has been ever before. At the same time, it is easier for municipalities to reach informal carers or potential volunteers through improved communication and a presence at community centres. Furthermore, political bodies have shown interest in expanding the development the initiatives in order to further improve the effectiveness of healthcare services provision and to change policies accordingly.

A specifically vulnerable group within 'In For Care' are young informal carers, who receive full attention from CMO STAMM, one of the Dutch partners in the project. The next chapter explores how to improve service provision to this specific target group.

5. The improvement of service provision to and support for young informal carers

CMO STAMM, an innovation centre for social issues in Groningen and Drenthe (NL), put together an expert team specialised in the needs of young informal carers. Cooperation is improving thanks to dialogue sessions with the team and professionals, volunteers and young people. The expert team communicates with municipalities referring young people facing problems when caring for an ill family member. Secondary schools are also involved so information can be passed on to them and this makes it easier to reach out to young people in order to make them part of the network so they can receive all the help and support they need.

Young informal care givers are children who grow up in a family with a chronically ill, mentally or physical disabled, addicted or psychologically troubled family member (0 – 23 years old). Although these children don't call themselves informal care givers and don't provide care in a manner comparable to adults, they grow up with other worries and responsibilities than their peers. For example, they don't have time for friends because their mum needs help cooking dinner, they can't participate in leisure activities because there is no time. The risks inherent in growing up in such a family include: dropping out of school, having no social network of their own, health issues, etc.

Co-creation is essential to 'In For Care'. All the activities address young people, which means involving them as volunteers, giving them responsibilities according to their own talents and age as well as looking for solutions with them (equal voice as adults). In the Province of Groningen there is an Expert Team Young Informal Carers that consists of 12 local practitioners working in different municipalities who collaborate

with each other to raise awareness about young informal care. The aim is to optimise support for these young people according to their own needs. Some bottlenecks from a professional point of view:

- professionals in informal and formal care focus on the person who needs care and therefore don't realise what the impact might be for young people living with that person
- the group of young care givers is relatively invisible and they often want to stay that way because they don't want to differ from their peers.

What are their needs according to the experience and scientific research in the Netherlands?

- leisure time for themselves
- understanding for their home life from their teachers, friends, etc. For example: don't immediately assume that a pupil didn't want to do their homework, but first ask why they didn't
- some young care givers want contact with peers living in a similar situation, others don't
- it is important for interventions or support to match a young carer's needs without problematically stigmatising them and focusing on the whole family.

About the method: A meeting sphere session is a digital way of collecting views and opinions from people anonymously. Every person can answer questions on their own laptop (see images on the first page) and a facilitator collects all answers on a large, shared screen. The method is a relatively quick way to collect individual answers (anonymously), to transfer all the answers to a ranking system and then present the results in a chart, which can be used for further debate or brainstorming. The questions asked were:

- a) to what extent do they agree with the statements?
- b) what is the best way to reach young care givers?
- c) what are their needs?

Remarks made by the young participants:

- Schools should know whether pupils have problems at home, because this explains concentration issues and the way home life may even affect school results. According to the participants almost no one at their school knows about the care giving situation. If they could have had more time for their assignments then they wouldn't have been immediately academically demoted a level as a result of poor marks.
- Young people often don't know what care giving means (even the participants' friends) although it's clear that these friends are also care givers. Participants say that they often have to explain their living circumstances.
- All participants believe that activities for young carers are necessary to relieve their burden, because this takes their mind off things (they are busy enjoying the activity instead of worrying about the family member).
- It's important for young people to be aware that they are a young care giver because then they will be aware of supporting systems around them, such as activities.
- According to the participants very young carers need someone to listen to their concerns that isn't a friend or family member. Friends often forget the young carer's circumstances at home and are not capable of taking them into account. This makes it good to have someone else to talk to.
- Many young carers don't like being addressed as young carers because they don't want to feel different from their peers.

During the work session, attention was paid to all the participants' knowledge and experience. Furthermore, practical examples were given which revealed that you can get the necessary done by getting out from under your organisation's shadow and making new connections. One of the participants told the group how bringing carers together who did not know each other resulted in new relationships and even yielded new volunteers. The following recurring points are notable in all the experiences:

- Carefully listening and giving someone the feeling that they matter (and also showing this)

- Not judging, but rather connecting and being sincere
- Thinking outside the box, spontaneity and addressing challenges self evidently
- Bringing people together, having connective abilities, being goal oriented.

5.1. Transition to adulthood

The transition from adolescence to adulthood is considered a significant developmental stage in a young person's growth. Most young people receive family support to help them with the difficulties associated with this stage. The transition to adulthood is marked by new roles and responsibilities in such interrelated domains as education, employment and family formation.

Providing informal care affects - for instance - the choice of whether or not to leave home. Young adult informal carers who care intensively (more than eight hours per week) find it difficult to leave the person in need of care and also realise caring tasks will need to be done by others, maybe other family members. The young adults who care less intensively (less hours) do not experience these barriers as much. A study by Becker and Becker (2008) shows that young adult informal carers aged between 18 and 25 in the United Kingdom face the greatest challenges when it comes to leaving home at a time of their own choosing.

It is also easy to understand that young informal carers will encounter obstacles when working in combination with their informal care activities (Becker and Becker (2008) and Cass et al (2009)). Young informal carers will have specific demands, such as flexibility in taking time off or shorter travel times, which in turn can hamper finding and working a job. Those not yet active on the labour market (for example, because they are studying) might find it hard to find a part-time job in addition to their studies and caregiving tasks. This may be a disadvantage when entering the labour market in the future due to the lack of experience and confidence.

A study by Becker and Becker (2008) also shows that some young adult informal carers experience difficulty starting intimate relationships. They often choose friends and partners who have sympathy or understanding for the situation. If this is insufficiently present, this can sometimes be a reason to end the relationship. Most young people have had several relationships before they start a steady relationship and get married (Knijn, 2012). Young people who do not provide informal care do not have to take their home situation into account and their partner does not have to be confronted with a person in need of care. In general, the role of informal carer impacts social life. It is less easy for these young adults to spontaneously do something fun and sometimes their friendship come second. Their friends may also not be able to deal with the situation properly.

Which informal care support do young adult informal carers need in order to cope with the limitations they experience during their transition to adulthood? Young informal carers mainly need support aimed at their target group i.e. young people aged between 18 and 34. This means that they do not want to belong to the target group of older adults or to the target group of children. It is important for there to be room to share experiences. They would like to talk and hear how others have tackled or experienced something. As the literature shows, the timing of these events influences the course of people's lives and is related to a person's life outcomes (Billari & Liefbroer, 2010). At the same time young adult informal carers indicate they also experience a lot of positives from providing informal care such as close relationships with their family and the realisation that you have to enjoy the little things in life.

6. Conclusions

Estimates suggest that as much as 80% of all long-term care in Europe is provided by informal carers (Hoffmann & Rodrigues, 2010). Countries with large-scale publicly funded care and services are increasingly shifting the focus towards family or social responsibility as well as promoting informal care. This transition in social care systems is not without risk; it may cause increasing (health)care inequality, problems with combining work and care or costs in relation to sick leave. Integrating professional healthcare and informal care has proven to be difficult for numerous reasons, but all of them seem to stem from how the population perceives the healthcare system already in place; the way healthcare has been institutionalised in the past.

An important bottleneck to the improvement of the collaborative relationship between organisers of formal healthcare and informal carers is the fact that citizens who have already been providing informal care have a hard time finding information on specific regulations and measures from the government.

The increase in demand for informal care puts greater pressure on the existing informal carers. Spending over 20 hours a week on care decreases income among carers in comparison to non-carers. The effects of using one's free time to care for another person on the quality of life is something all countries should take into account and employers need to be made aware of the support they can potentially provide to employees in this position. This trial method solves challenges on the basis of the user's perspective. The focus is on understanding the users' needs and how these experiences help finding the problem that needs to be solved. Building on an innovative solution with quadruple helix stakeholders was useful during the process for broadening perspectives. It also motivated and stimulated stakeholders to participate and engage in developing ideas. To really create a working, innovative solution, you need to put it into practice. Involving stakeholders in the test, engaging them to cooperate and to invest time in the service innovation, requires a thorough communication effort. In the setup for a user-centred innovation and a co-creation process for a wicked societal challenge, it is important to pay attention to involving and engaging organisations. Networks which function as a bridge between public authorities and local informal carers are crucial for getting information across from one party to the other.

In order to enhance cooperation between formal and informal networks, not only decision makers and professionals in the field should be invited to meetings and co-creation sessions, but also end users, healthcare academics, SMEs and policy makers. Inclusion of all target groups has proven to be essential for creating tools and services which effectively innovate service provision in relation to care.

What stands out from all the different tools and initiatives in In For care is that they introduce the option of connecting to a formal healthcare network closer to the informal carer than it has been ever before.

In the case of young informal care givers it is important to note that these children do not call themselves informal care givers and do not provide care in a manner comparable to adults, they grow up with other worries and responsibilities than their peers. What they need most is leisure time for themselves and understanding for their home life from their teachers, friends, etc. For example: don't immediately assume that a pupil didn't want to do their homework, but first ask why they didn't. Some young care givers want contact with peers living in a similar situation, others don't. It is important for interventions or support to match a young carer's needs without problematically stigmatising them and focusing on the whole family.

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