In defence of professional care

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Introduction

Amour is an award winning 2012 French-language film starring Jean-Louis Trintignant and Emmanuelle Riva as Anne and George. They are in their eighties, both retired music teachers with a daughter who lives abroad. They enjoy their life together, talking, playing music and visiting concerts until Anne suffers a stroke which paralyses her on the right side of her body. Following the fashion of the day Anne does not want to go to a hospital or a nursing home, and George makes a promise that she can stay at home. He takes care of her himself. The film shows how utterly uncomfortable and embarrassing this is for both parties, despite their love or possibly because of their love. She doesn't want to depend on her husband to help her go to the toilet, change her diaper and spoon feed her. He clearly misses his intelligent, book reading, piano playing wife and he was not cut out to be a home carer. At one point he even lashes out at her when she refuses to swallow her drink. At the end of the movie he smothers her with a pillow after which he takes his own life.

Family care can be a rewarding experience but it can be a terrible burden as well. The German book *Mutter, wann stirbst du endlich?* (Mother, when will you finally die?) relates the experiences of Martina Rosenberg who moved in with her parents after a sojourn abroad. A nice arrangement, she thought. That way her parents would get to know their grandchildren and vice versa. But when her parents are struck by one ailment after another – old age is not kind to many of us, it strikes us with blindness, deafness, arthritis, diabetes, strokes, rheumatism and senile dementia – when that happens Rosenberg and her husband find themselves in a role that they didn't sign up for; with a burden that is too heavy to bear.

Dutch journalist and psychologist Yvonne Kroonenberg wrote a book about family care. She talked to many middle aged people who care for their ageing parents and though her book contains a number of pleasant, happy anecdotes she mostly describes the sadness of it all. Elderly people who used to be independent have to cope with a weekly or daily invasion of adult children and children in law who go through their administration, read the incoming mail, rearrange their kitchen, put things where they are not supposed to be and take away their car keys because they are a danger to themselves and others on the road. Of course there are wise, cheerful elderly people who can cope with all of that but there are also people who become grumpy and who snap at their children. The adult children on their part mostly feel sorry for their parents. Hence they can put up with occasional complaints, but they also feel that they are entitled to a bit of gratitude. After all, they spend time on their parents that they might have spent on their work or their children. Or perhaps on their friends,

the gym and the church choir. Family care can be a tricky business charged with all sorts of complicated emotions.

Despite that, policy developments all around us steer us firmly in the direction of ever more family care. Present day ideology dictates that vulnerable citizens – be they elderly patients suffering from Alzheimer's, people with intellectual disabilities, people with psychiatric conditions or people suffering from a multitude of old age ailments – should be empowered and manage on their own as long as possible. If it is absolutely impossible to cope on one's own one should lean on one's nearest and dearest: partners, adult children, parents, brothers and sisters. If these are not available - if they are not around, non-existent or utterly unwilling - one should resort to neighbors, friends and acquaintances, usually referred to as "community care". Or one might choose to engage a volunteer to provide unpaid assistance.

It is a development that doesn't just occur in the health care system. We can see it in social work as well. Social workers are asked to organize family group conferences, to cooperate with family carers, to empower their clients' networks and to train volunteers to perform their own jobs. We can see it in the UK, where they call it "the big society". We can see a little bit of it in Belgium where they speak about "responsabiliseren" and we see very much of it in Italy, where anthropologist Andrea Muehlebach wrote a beautiful book about the fate of present day vulnerable citizens who go to social services for an intake and are then immediately referred to their family, to the local parish or to the countless workers who lost their job during the recession and who now try to give their life meaning by volunteering. In the Netherlands our policy makers call it "the participation society", referring to the fact that everybody has to **participate**: help out, lend a hand, offer time and energy rather than just pay taxes and leave the actual care to professionals, as used to be the case in the traditional welfare state.

In this talk I want to discuss with you what this development means for the three different groups involved: **for the vulnerable citizens**, **for their nearest and dearest** (family members, friends, neighbors and members of the larger network) and **for paid professionals**, social workers first and foremost since many of you belong to that tribe, but many of it also applies to paid professional home carers.

Empowerment for vulnerable groups

I will start with the vulnerable groups and then first discuss the least problematic development: the plea for empowerment, or the do-it-yourself ideology. We all know about phenomena such as hospitalization and medicalization. We know that people who never have to cook, clean, take care of themselves, take care of their children will soon lose the capacity to do so. Social workers know this especially well. Since 2015 I have interviewed a lot of social workers and many of them told me that this was the first thing they learned during vocational training: you have to make yourself superfluous. Your client needs to stand on his or her own feet again. Seems a sensible principle.

Still I think the trend toward empowerment and the do-it-yourself ideology may go too far.

To see that, it is good to relate the empowerment logic to two different phenomena many of us know from our own lives. The **toddler log**ic and the **employee logic**. Who among you have a toddler in the house? Well many others can no doubt remember the time when their children were that age.

The toddler is generally known for his desire to do everything himself. Particularly things he can't really do yet: climb the stairs, get dressed, prepare a sandwich, cycle on a little bike without trainers. Parents know that they have to honor these wishes, at least most of the time. Despite the fact that it is much faster to just pick up the toddler and take him up the stairs or put him in a children's seat on your own bike. Children have to practice all these things; there is no other way to learn. Empowering them is obviously the right thing to do.

But there is another empowerment logic. The employee logic. When I first started teaching – we are talking about the nineteen eighties now – my university was in a period of transition. Lecturers older than me had always had secretaries. Not one on one, mind you, but, say, five lecturers for one secretary. Secretaries could Xerox your exam sheets, they did your grading administration, typed articles and conference papers and if you were very lucky, they could also sort of organize your day: work out what files you needed for which appointment, and put them on your desk in the proper order. When I started working, these days were over. My generation of lecturers got to be empowered from day 1. If we wanted something typed we could borrow a type writer. If we wanted to send a fax, we were sent to the fax machine where we had to follow a list of instructions on the wall. Once computers were introduced we were sent to courses to learn Word perfect and Word so we would never require typing assistance.

Does this sound familiar?

I am sure many of you recognize the employee logic. Once upon a time we had secretarial support and then management took that away and gave us computer systems instead. Make up your own roster in the system. Keep track of your own hours. Register your own appointments. Have a new password for every system, which you are bound to forget. Very often we get a new version of the system every two or three years so we, poor employees will never really get the hang of it. That's empowerment in the employee logic.

On occasion I find myself dreaming about a secretary who would help me with my administration, look up files, and keep my office neat and tidy. I know that I would become dependent on my hypothetical secretary. Less empowered in fact. But I would like it all the same.

I think we have to ask ourselves what clients experience when they are being empowered. Are they like struggling toddlers who, one fine day, will really manage on their own? Or are they employees who never had an innate desire to be empowered but had to deal with it anyway? If it takes an elderly woman two hours to get dressed on her own, is it still justified empowerment to let her do this herself? What if it takes three hours? One of the Dutch journals for social work recently published an interview with a young mother who had been struggling for months with debts piling up after she lost her job and could no longer afford the rent. Like many other people with debts she closed the curtains so as not to see the debt collectors pounding on the door and she no longer opened her mail. When she finally found the courage to go to social services she was empowered immediately: she was instructed to chart all her debts, file them in different maps and call all the creditors herself. I am not sure that this is the rewarding toddler empowerment logic. I have a feeling that this client would have been very happy to get some actual help instead.

Network support for vulnerable groups

If vulnerable citizens are definitely unable to cope on their own they are supposed to find help in their network: family, friends, neighbors. In the Netherlands this is often presented as **a patient preference**. Policy makers claim that people do not want cold, distant, institutional or otherwise professional care. They supposedly prefer the warm, loving care of their close relations. And politicians who argue this are not completely off base. Dying at home, for example, is for many people the best way to go. If the doctor tells you that you have three weeks or even three more months to live, chances are that you would want to spend this time with your loved ones at home. You would put up with the inconveniences and the embarrassment portrayed in ***Amour***. But very often long term care and social work take much longer than three months. Old people may get ever more ailments and live with them for ten or fifteen years. People with intellectual disabilities will never get better. Many of them need lifelong care. Many chronic psychiatric patients will never quite manage on their own either. Physical disabilities such as cerebral palsy cannot be cured.

When you face the prospect of long term dependency that changes the odds. The disability movement has fought for years to accomplish independence for people with disabilities. And independence meant for many of them: **being independent from their family**. Two years ago I did a lecture for clients with an intellectual disability and for the social workers and other professionals who took care of them. There were many clients in the conference hall who understood what was happening. They were afraid that the new developments would deprive them of professional help and force them to lean on their parents again. This was not what they wanted; they were afraid that their parents would fuss over them; they wanted to remain on their own and rely on professional help.

Likewise many fragile elderly people dread the idea of having to rely on their adult children. In the early nineteen fifties this was common practice in the Netherlands and when public retirement benefits were finally introduced the then prime minister received numerous grateful letters, thank you cakes and little presents from elderly people, who were tremendously relieved that they would no longer have to depend on their offspring.

In the nineteen seventies many people chose to move to then existing retirement homes before they got really fragile or ill. They met other elderly in retirement homes, enjoyed the luxury of an in-door hairdresser or gift-shop, they could choose to dine together in the home cafetaria, throw bridge parties and run in-house libraries. And once old age really set in, medical help and other assistance were close by. To many people (especially those who lost their spouse) a retirement home was a sensible choice.

However, gradually retirement homes were transformed into nursing homes where you could only be admitted if you were really fragile or sick. Governments started to emphasize that most people **prefer** to remain at home.

We have to realize that in many cases these preferences are what we might call **interdependent preferences**. You do not just have them; you develop them because of other people's preferences. Let me explain that.

Suppose you are a seventy-five year old widow. You try to make up your mind about what to do after your husband's death. Starting a new life in a nice home for the elderly where you can play Scrabble, attend lectures and do some sports with other old ladies does not seem like a bad idea. In fact you think it might be better in many respects than staying in your home where the absence of your husband is tangible. But then you learn that other seventy-five year olds choose to stay in the neighbourhood and make do with family care and home nursing as long as they can. This changes the odds for you. It is less likely that you will find new companions in the old people's home. The home will probably be filled with ninety-something year olds who are deaf, blind, bed-ridden or struck with Alzheimer's disease. Individuals do not just base their own preferences regarding care on quality information and subsequently choose an arrangement that suits their preferences. In many cases they have to make an educated guess about other citizens' choices and then adapt their preferences before making their own.

Moreover, norms will evolve. If you emphasize over and over again that warm personal care is better than professional care adult children will feel that they ***have*** to take on caring obligations. Elderly people who choose professional care over family care get some explaining to do. Are their children nasty grownups who are only interested in making money? Did they have an unhappy childhood and are they now paying back their parents in kind? Preferences with regard to care are highly dependent on other people's preferences and on societal norms.

With regard to social care there is a classic study, entitled *The Client Speaks* (published in 1970). Social work clients were asked why they had sought professional help rather than turn to their family, friends or neighbors. The researchers, John Mayer and Noel Timms, found that there were all sorts of reasons. Some clients wanted to spare their family additional burdens because their family had enough on their plate as it was. Others were afraid that family or friends and acquaintances would tell about their woes to everybody. Some were sure that their family members would not understand their marital problems because they had too good a marriage themselves. Yet others had family members who would always advise them to toughen up and they simply could not do that anymore. Or family members who would always take their side unquestionably whereas they felt they needed objective advice to see their spouse's point of view. *The Client Speaks* is 45 years old but these reasons seem to be valid still. Together with Gercoline van Beek from the Utrecht School for Social Work, I have interviewed social workers in the Netherlands to learn about their ideas and feeling with regard to the changes in the welfare state. Our respondents had doubts about referring every client to his own network for various reasons.

One of them said:

> The good thing of this development is that you get to look broader. Who can step in? It is not self-evident that a social worker steps in because you are temporary. You should always realize that. So if there is family help available that's a good thing. But you should take a long and hard look at the family because they must be able and willing. You can't force them. I think it's dangerous to ask people to support their brother or sister when they basically fight all the time. (…) You can't build a society on volunteers who do not help voluntarily. It's quicksand. People who do not help voluntarily will not hold on and can do damage.

Respondent Marianne works with youngsters. She said:

> If you walk away from home because of the troubles there, you get to hear that you have to work things out with your parents, because it's your own network that's so important. For sure that's important, but sometimes that is the wrong approach.

Social workers have seen many clients who do not have a network or who lost their network because of their own actions. Social worker Eva explained:

> Our whole intake procedure … starts right away with questions about people's own network. Who can do what for you? Whereas I think people come here because they don't have a network or because they already asked their network and that didn't help. Otherwise people wouldn't come here.

Willemien helps clients with substance abuse:

> It would be really great if [you could refer them to their network] but what you see is that many of them don't have a social network left … because of their problems. I mean they may have stolen from family members to buy drugs you know, stuff like that .. makes your whole network break down.

In her experience clients also have network members that are not helpful but rather the opposite because they take drugs themselves and lure clients back into the scene. In a number of cases network members have cognitive disabilities and cannot provide proper guidance to others.

Recently retired Else remembers her clients from ethnic minority groups. She thinks it would have been unwise to refer them to their families.

> Many of my former clients had been cast aside by their families because they filed for divorce, because they had been raped or had been found guilty somehow. They were not accepted by their own network so that would have been difficult.

Family care, network care , or community care is not always good for vulnerable people.

Burdens on others

It is not always good for family members either. There are numerous studies pointing out that caring for a disabled or chronically ill family member can be terribly burdensome. Of course it can be rewarding as well; it can offer a chance to discover talents and strengths you never thought you had. But to many people it is first and foremost a heavy load to carry. Adult children find it difficult to divide their time between their ailing parents, their own children and work obligations. Parents of children with a severe learning disability feel guilty toward their healthy children who sometimes do not get the attention they need. Parents of grown up children with a psychiatric condition are sometimes completely stressed out when psychiatric hospitals refuse to admit their son or daughter because he is not considered enough of a danger and then just toss him on the street and expect his network to take care of him.

It is hard to combine long term care and obligations at work. Even the most benevolent boss or manager can lose his patience when you can't get to work too many times. Buses have to ride, planes must fly, trains must run, groceries have to be sold and classes must be taught. You can't always expect co-workers to step in for you.

Thus at one point or another we are bound to ask ourselves: how did we manage this before the welfare state; when we did not have publicly funded professional care? And the answer is staring us in the face. We managed because married women in those days did not have a paid job. Put two and two together: women are the ones who lose their jobs because of the changes in the welfare states. Paid home carers are mostly women. So are social workers and other professional carers. If they lose their jobs they can make themselves useful taking care of their own and looking after their communities, free of charge! Eureka. If we were to go back to the old days our problems would disappear.

Thus the ongoing changes in the welfare state jeopardize the accomplishments of decades of women emancipation.

Consequences for professionals

We have had the vulnerable groups. We discussed their unpaid carers. Now for the third party. What do the changes entail for paid professional carers; social workers and others? Our respondents told us that many of them are afraid to **lose their jobs**.

One of them said:

> everybody is afraid to be sacked. (…) One colleague after another on the verge of tears. When is the next round of dismissals? That's what's happening. Next year we will have new cutbacks.

Another observed:

> You are dismissed very easily. People all had to re-apply for their job. I have seen social workers with 25 years of experience who did not get hired for the new teams. That's what's happening.

Respondent Yvonne explained why many social workers were afraid to criticize policy developments:

> Every whistleblower loses his job, that's the human condition I think. [I had some questions about the way things were handled.] But if I say something to the official from the municipality, he is like: take it or leave it. You know, there's a new round of tenders coming up. If you don't approve, if you don't want to play my game, fine by me. I can get plenty of others in your place.

Social workers also felt **a loss of professional pride**. Some of them fear that their professional training will be useless shortly since a large part of their work is taken over by informal carers and volunteers. Ayse wondered why people would bother to go into social work in the first place:

> I mean … if everyone and the next person can call themselves social workers .. Look .. I had to go through four years of college education. There's a guild for physiotherapy, you get acknowledgement for being a qualified nurse and so on, but with us, now, they seem to abandon that system.

In the words of Tineke:

> That everybody can be a social worker and that everything should be solved with a practical solution, preferably by volunteers, I find that really terrible.

Eva told her new interns:

> That profession that you were taught to do, that doesn't exist anymore. That profession is gone.

End of quote.

I am not a social worker, but I can relate to both responses. I teach public administration at the university. If my university dean told me that my classes would henceforth be taught by students themselves or by practitioners on a voluntary basis I would be devastated. I would be terribly afraid to lose my job and I would feel really offended by the suggestion that it could be taken over by a bunch of amateurs.

What I would ***not*** do is offer to continue teaching without pay. I love my job, I really like my students but that thought would not even cross my mind. This is completely different for professional carers and social workers. Research in the Netherlands showed that a large percentage of volunteering in the care sector is done by people who used to work in health care or social work or even still work there. A 2004 article in the *British Journal of Social Work* observes

> that workers apparently accept lack of professional recognition and poor economic reward as an inevitable feature of social services work, allowing funding bodies and employing organizations to take advantage of sexist cultural assumptions that care work is naturally 'women's work' and that female workers do not need an independent living wage.

End of quote.

In a similar vein, our respondents told us that they would be willing to work without pay. Tineke teaches an assertiveness course and she enjoys that tremendously, watching her clients improve in just a couple of weeks. Following the reigning ideology of the participation society she has been asked if this course could not be taught by a volunteer, possibly a former student of the course. Tineke does not think that would be a good idea, as every course is different and former students might go on way too long about their own troublesome past. Yet she says "don't tell my boss, but if I would have to do it for free, I would be willing to do that." Else is nearly crying when she talks about the decline of her profession but upon retirement she asked her boss if she could stay on. "I would have worked without pay, I would have my pension, so I didn't need pay. Seemed like an ideal offer to me."

If social workers cling to this attitude we may end up in the nineteenth century, the prehistory of social work. Social workers in those days were middle class ladies who went round visiting the poor on behalf of charity organizations. Unpaid community care, just as present day governments would like to see it.

Why professional (social) care?

Why do we need **professionals** in long term care and social care?

My colleague and I asked our respondents whether they possessed specific knowledge that lay people do not have. In medicine that would have been the established answer to justify professional care. If you compare people who get an appendectomy by a trained surgeon with people who are operated by their spouse or their next door neighbor the former will do better.

Did our respondents have similar reasons to justify professional social care? Most of them did not. For sure they had learned about life, about society, about problems during vocational training but they did not feel that this constituted extremely complex knowledge that lay people would never be able to master.

According to our respondents the biggest difference between professional carers and lay people was a matter of ***attitude***.

Social workers and professional carers chose their career because they wanted to help others. They wanted to help vulnerable people. That is quite something for eighteen year olds choosing a profession or for elderly students who feel called upon later on.

There are many people who choose a career because they want to work **with** people. Many people enjoy working in teams or working with clients. I know quite a few students who did not choose to study chemistry, physics or mathematics because they feared this would confine them to a laboratory and they wanted to meet other human beings. The music teachers in *Amour* no doubt enjoyed the contact with their students but they chose their career first and foremost because they loved music, as others like history, geography, sports, carpentry, electronics or even, first and foremost, money.

Choosing your career because you want to **help** vulnerable others is something special indeed and it is typical for professional carers and social workers.

Wanting to help others is part of the helping attitude. Another part is **the ability to be content with very little or even no progress at all**. Most people need to see progress or results in their work. I get rather frustrated when I have students who don't pick up advice that I have given three or four times. I need to see results. So does the carpenter or the brick layer who wants to see the house finished. Med students usually choose a specialty where they can really make people better. Like surgery, pediatrics, or gynaecology. Despite the fact that we have an ageing population geriatrics is not a popular specialty because old age cannot be cured and many patients are bound to deteriorate despite your efforts. Professional carers in long term care and social workers can cope with that. They can take care of patients who will not get better or who will get worse.

People with cognitive disabilities who can learn very little and sometimes lose what little they learned.

Multi-problem families who struggle with financial problems, addiction, psychiatric conditions, and youth problems cannot be cured, my respondents informed me. Sometimes you have to be content if you manage to stabilize the situation. It is a rare talent if you can be satisfied with little progress and it is a talent that society needs.

The third part of the helping attitude I derived from our interviews is **non-judgmentalism**. Our respondents said that their core expertise consisted in not being judgmental. Stand in the client's

shoes and start from there. This was something that they felt was crucial to social work. Of course many clients are partly to blame for their misfortune but it does not help to point that out and non-professional helpers would probably not be able to resist a tendency to pass blame. I think that is a correct impression. Most of us, ordinary people, are inclined to blame people: for financial problems, for addiction, for not raising their children properly, for messing up their studies, their work, their marriage, their life. It is important that society contains places where people who had bad luck but who also messed up can go to. To start over, to get help. Places where the question whether or not they ***deserve*** help is considered irrelevant.

Long term care and social work: not everybody can do it and it is ludicrous to ask all of us ordinary people to learn it. Society needs you. We need you, and by all means: make sure you keep getting paid for what you do.

Thank you.