

'A strong voice for those in need of care in Berlin'

Following Saarland, which introduced the function of a care commissioner in May 2013, and Bavaria, which established the office of a patient and care commissioner in November 2013, the state of Berlin has also had a care commissioner since June 2024. Although the final appointment has not yet been made, Prof. Dr Sinja H. Meyer-Rötz has temporarily taken over the newly created position, with which the Senate Administration has implemented an important point of its coalition agreement to explicitly appoint a contact person for people in need of care and their relatives. 'This task is a top priority for me and a matter close to my heart,' explains Prof Meyer-Rötz in her first monitoring report (1).

Im Interview:
Professor Dr Sinja H. Meyer-Rötz, Care Commissioner of the State of Berlin

>> Professor Meyer-Rötz, what exactly are your tasks?

My top priority in this role is to put the interests of people in need of care and (caring) relatives at the centre of my work. This includes drawing the attention of politicians, the administration and the public to the numerous and complex challenges and problems associated with the need for long-term care.

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Why focus on those in need of care and (caring) relatives and not on professional care?

Care is multifaceted. Of course, professional care in retirement and nursing homes as well as in outpatient care services is extremely important and the people who work there deserve our great respect. Nevertheless, care is still largely located in family or family-like structures. In Berlin, for example, every second person in need of care is looked after exclusively by family members. To illustrate what informal care does: in 2023, a total of 87 per cent of people in need of care in Berlin were cared for at home! The entire German care landscape is facing a multiple crisis scenario that is being exacerbated by demographic shifts, structural care disruptions and economic imbalances.

With over 5.69 million people in need of care in 2024 - and this figure is forecast to rise to 7.6 million by 2055 - the system has fundamental weaknesses that require comprehensive reform beyond short-term repair measures.

Berlin is no exception. According to the Berlin-Brandenburg Statistical Office, 211,999 Berliners were in need of care as defined by the long-term care insurance system as of 15 December 2023, which corresponds to 5.6 percent of the population. This means that the proportion of Berliners in need of care has risen sharply - by more than 26,000 people compared to 2021 and by more than 53,500 people compared to 2019. In addition, demographic modelling assumes that the number of cases of Berliners in need of care will continue to rise steadily in the coming years.

We are 'only' talking about the carers themselves, not about the large number of people who provide the necessary care in families or family-like structures.

There is still no standardised definition of who exactly counts as a carer. This would be a very important task for care science and care research. Due to various definitions, there is currently no valid data basis for making a reliable statement on the number of carers in Germany or specifically in Berlin. For the time being - as of 2023 - we estimate that there are around 280,000 carers in Berlin. This means that a total of almost 500,000 people in the capital are now directly affected by care because they either need it or provide it informally. This means that the current forecasts of the Senate Department for Science, Health and Care for the year 2040 have already been exceeded.

In reality, this figure will be much higher, because in modern societies, one-to-one care no longer works in most cases.

Caring relatives were and are mostly female and have either used their free time for this work or given up part of their gainful employment, which will cause problems for them personally in old age because it minimises their pension entitlements. In addition, the proportion of single households in the metropolis of Berlin is more than 50 per cent and the closest relative who could provide care may not live in the same district or even in the city itself. This is where caring communities are needed, which usually consist of many more than one person, which means that the aforementioned figure of around 280,000 carers is likely to increase significantly.

Unfortunately, however, there are neither precise figures nor descriptions of how such caring communities are organised.

That's true. I hope that the ever-growing field of nursing science will help us here too.

What is your role here?

You could argue that people in need of care and carers, like other social groups, are actually quite good at representing themselves. However, this is not true because both groups already have enough to do organising and financing their own lives. That is why I point out in my first monitoring report, which has just been published, that those in need of care do not have a strong voice. Otherwise, they would have founded associations or interest groups long ago, but these do not exist.

Why is this the case?

People in need of care are often severely restricted and also emotionally burdened by their need for care, which means that they are unable to fulfil this representative role, with which they can stand up for themselves and their interests. The same also applies to carers and family members, who are confronted with so many things that they are often unable to find the time to lobby on their own behalf. This starts with securing care as such, for which many applications have to be submitted - a reduction in bureaucracy would be a real blessing here. In addition, there are emotionally very stressful issues, such as dementia in a carer or grief after the loss of a partner. Being confronted with challenging behaviour virtually every day can certainly lead to falling through the cracks of the support system. And you are supposed to find the time, energy and leisure to dedicate yourself to an advocacy organisation?

That's why your office exists.

Exactly. This office ensures that I am a strong voice for those in need of care and their carers. I want to ensure that the interests of both target groups are recognised in politics, in administration and in public and that what informal care needs are clearly named and addressed. Here in Berlin alone, we are talking about around half a million people who are in need of care themselves or are affected by care in the form of affiliation and belonging. With just under four million people currently living in Berlin, that is a very relevant and large target group. I am therefore pleased that the Berlin Senate Administration has decided to create a separate office to fight for the rights of people in need of care and family carers instead of incorporating this somewhere else, as is the case in other German federal states. Incidentally, I am also in favour of converting the Federal Ministry of Health into a Ministry of Health and Care, as this would increase the chance of care being considered everywhere from the outset - the same applies to all state ministries, of course. This would clearly emphasise the importance of care. I very much welcome the fact that Berlin is taking a very innovative, stringent and equally open, honest and transparent approach.

'I am pleased that the Berlin Senate Administration has decided to create a separate office to fight for the rights of people in need of care and family carers.'

You have been the Berlin Care Commissioner since June last year. What have you done in these twelve months to be and become as effective a care commissioner as possible?

I used the first few months intensively to network within the Berlin care landscape, of course. I've known many of the players for a long time because I didn't just become active in the care landscape in Berlin yesterday. But it's different to be travelling in this new role and in this office to establish collaborations. There are already regular meetings with some of these cooperation partners, because we have realised that we not only have many of the same or similar focal points and meeting spaces, but also need a common resonance space to exchange ideas on topics and develop them further. The second was that we established a point of contact for the public for my new office and have since been available by phone, email and via a contact form on our website. We have also established a complaints management system and set up a structure for regular monitoring, the first report of which has just been published.

As you have just mentioned, your office of care representative also acts as a complaints centre. What recurring shortcomings do people in need of care and relatives report, and how does this feedback loop translate complaints into concrete recommendations for action?

In order to be able to tackle care-related issues as promptly as possible and on a small scale, a new format was established for 2025 called Bezirksimpuls Pflege. As part of the district impulse, I will visit the respective established support and political structures, district councillors and stakeholders, as well as good practice examples and lighthouse projects, once a month and discuss with them the further development of care issues, as well as the obstacles and problems brought to my office. Since the city of Berlin has twelve districts, I'm practically done in 12 months.

What concerns do Berliners contact you with? Which topics are mentioned particularly frequently?

Often it's simply about supply bottlenecks, but not always, as one might assume, about the mere availability of care services, but about much more trivial, mostly structural obstacles. Let's take a well-known district of Berlin, where there are quite a few tower blocks. In some of these ageing residential silos with seven, eight or even more storeys, the lifts occasionally break down and are often only repaired - if at all - after weeks or months. People who live higher up often cannot find an outpatient care service because their providers know exactly what to expect. They therefore no longer accept orders from certain postal addresses because they have a completely understandable problem: They first have to find a carer who is willing or strong enough to go there and walk up to the seventh or even tenth floor and back down again. That takes time, which nobody pays for. If even physically impaired carers are deployed, they will not be available anyway, because a 55-year-old carer with physical limitations or obesity, for example, might not be able to climb up to the tenth floor in - let's say - 35 degrees in summer, even if they wanted to. This is why such architectural and structural problems lead to supply bottlenecks that should actually be solved at a completely different level of municipal welfare, because property developers and local authorities simply have to manage to create accessibility in such buildings.

You talk about structural housing problems that lead to people in need of care not being able to find a care service. But what does a person in need of care do alone on the 10th floor without a lift?

There are people who have been unable to leave their home for months simply because the lift doesn't work. Incidentally, this is also a problem for rescue services, which are provided by the fire brigade in Berlin: They then run up to the 10th floor with a stretcher and back down again. We just had another case involving a two-year-old child with multiple disabilities. The father, himself seriously ill with cancer, had to regularly carry his child, along with a special wheelchair and oxygen bottle, down seven flights of stairs to doctors' surgeries and therapies for around six months and then back up again. We receive very desperate calls about such cases.

What can you do?

We try to exert pressure on the respective housing or letting companies, which is not originally our job. In the case I just mentioned, our efforts did succeed in getting the lift in the building in question repaired within three weeks.

Older people who don't even need care yet can't get out of the second or third floor with a mobility impairment.

That's right. Let alone from old flats in Berlin, where many of the stairs are worn out or simply no longer in such good shape. Then it becomes difficult. But this shows quite clearly that care has a problem that affects society as a whole and is structural.

Not to mention the existing supply bottlenecks.

This applies to Germany as a whole, but also to Berlin in particular. Think, for example, of care situations on the outskirts of the city. The south of Köpenick, for example, juts out into Brandenburg like a municipal peninsula. It is even more difficult to organise nursing care in such peripheral areas than elsewhere, because outpatient nursing services are simply not available due to a low customer density. It is simply not worthwhile for them to take on long journeys for around ten minutes of basic care. This means that many older people cannot find outpatient care services there. By contrast, we find a different problem in Marzahn-Hellersdorf, a Berlin district with large satellite tower blocks and extremely limited parking space. This was simply not planned for in the past due to different residential structures and living conditions, because not everyone had their own car. The emergency services simply switch on the building lights and block the road, but where is the ambulant care service supposed to park? Incidentally, the same applies to Berlin-Mitte with its enormous parking space problem. As you can see, my office is confronted with very different problems and I therefore have to talk to many different stakeholders, many of whom have nothing to do with care per se.

Where do you see the structural problems in Berlin being particularly pronounced?

Staff shortages and unequal distribution of care are actually everywhere; in this respect, Berlin is comparable to many other German cities. What is currently noticeable in our city, however, is a clear power imbalance in the market. People are afraid to complain to the care service themselves or even take legal action if they receive poor or inadequate care because they are afraid of being cancelled and then not even receiving 'bad' care. This is simply due to too much demand and too little supply of appropriate services, which in turn correlates with the general problem of skilled labour. For my office, this means taking a close look and listening carefully to complaint calls so that this real power imbalance doesn't take up too much space and we can help at an early stage so that consumers and all their rights don't fall too far behind. It is a very important issue to ensure that sufficient support structures can be provided in order to relieve the burden on carers. It may make a lot of sense for Berlin to create a completely different funding modality for this purpose.



Prof. Dr. Sinja H. Meyer-Rötz

took over the newly created position of Care Commissioner for the State of Berlin on 1 September 2024. She is also an honorary professor at the Alice Salomon University of Applied Sciences Berlin (ASH). Prior to this, she had worked as a group leader in the Senate Department for Science, Health and Care since 2020. After completing her gerontology degree in Vechta, Ms Meyer-Rötz obtained a Master of Health Administration from Bielefeld University and successfully completed her doctorate at the University of Duisburg-Essen in 2015. During her relevant career path in health management and in the public sector in Berlin, she taught at the universities in Vechta and Göttingen.

And this in an extremely precarious budgetary situation.

This is made even more difficult. As many good employees in the many support structures are only ever given annual contracts or often enough only multi-month contracts, it is absolutely understandable that this has an impact on staff recruitment and retention. As a result, we are also losing some of the experts who work here, and with each and every person who leaves, another support structure is weakened and may eventually be lost altogether. In Berlin, we need to support and relieve the more than 80 per cent of home care settings and thus make an important contribution to people remaining in their own homes, which is what many citizens want.

How?

Carers and family members need good advice as well as the same level of guidance and support, which we must ensure on the part of the state and the city. Only by making use of counselling and support services at an early stage will we be able to reduce the often enormous burden on relatives and carers and, above all, significantly postpone nursing home admissions. For me, this means that the development and expansion of support structures for relatives must be our top priority, because being cared for at home is the most sought-after, but also the most economical care setting - not everyone can and wants to afford inpatient care, for example - and care model. Incidentally, a Berlin strategy for supporting family carers has been in place since 2018, which is based on an 'action plan for family carers' (2) developed by the specialist centre for family carers together with the administration and other stakeholders back in 2015. We need to renew this strategy and adapt it to the current foreseeable trends and convince politicians that they need to send a clear signal to support family carers as much as possible.

Is it your job to initiate or suggest such actions and strategies, which would actually be the original task of local politics? You don't have any power at all, do you?

That's right. My office does not currently have any powers of intervention. However, we are currently working on this in the background and are examining whether and how this role should be legally anchored in the current legislative proposals. We think this is very important.

Interview

However, nobody would like to be told that another strategy - we are thinking in particular of corona - is lying in a drawer and will never be brought out.

As always in life, it depends on the tone. That's why I think the influence I have at the moment is rather soft. Nevertheless, the monitoring report that has just been published contains clear demands, for example to not only adapt the Berlin strategy for supporting family carers to the current situation, but also to make it future-proof.

'Politicians must send out a very important signal: We care about everyone, including and especially vulnerable groups in our society. '

This is certainly not unimportant in view of the current mood in the country.

Politicians must send out a very important signal: We care about everyone, including and especially vulnerable groups in our society. In Berlin, for example, it would also help to set up a support structure like the care helpline in Hamburg. I am campaigning for us in Berlin to look into whether such a structure could also be set up in Berlin.

Which would have what task?

For example, when it comes to domestic conflicts involving a person in need of care or the absence of a carer due to illness or an accident, where do you call? The police? The fire brigade? The emergency doctor? Of course, these institutions will help because they have to, but this usually triggers parallel hospital admissions, which only occur because there are simply not enough low-threshold support services available.

Let's take an example: What happens if a family carer falls in the shower in the morning, breaks their femoral neck and has to care for their wife who is suffering from dementia?

What then often happens is the parallel hospitalisation just mentioned. The husband is admitted because of his fractured neck of femur, the wife with dementia because of a derailed diabetes or a high blood pressure situation, both perhaps even triggered by acute stress, but actually incorrectly coded, just to secure a care situation.

Well meant ...

... but completely wrongly channelled into an expensive system, whereby acute hospitals do not have the primary task of admitting people who need long-term care, let alone long-term care, on an emergency basis. That's why we need to find other structures for such cases, such as the establishment of permanent 24/7 short-term care, where people in need of care can also be admitted at night in acute situations. Of course, the provision costs a lot of money, but the hospitalisation probably costs even more and at the same time the people mentioned are completely wrong there. Demographically, we are faced with an ever-increasing number of older people in need of care: We need to have answers for this population and prepare ourselves, because otherwise the baby boomers will 'clog up' the hospitals, which actually have a completely different care mandate. We therefore need hospitals and doctors to understand what is happening in care and what structures are in place. And we need nursing staff to understand what goes on in hospitals, doctors' surgeries and medical care centres. Everyone will then realise that it is not acceptable to burden the other side just because we have structural problems on one side. And then we have to think about how we can dovetail the systems much better. Academised nurses could take over a great deal here, because many of these acute care cases don't require a doctor in the first place. A well-trained carer who can assess exactly what the problem is can help. This would allow us to rethink the entire system, starting with the rescue centre, and adapt it to the requirements we face.

Is there any economic data on the amount of care required in hospitals for this co-care?

There are only rough estimates. Relevant information can be obtained in discussions with rescue centres. However, this is difficult because it is always possible to find some kind of diagnosis with which such a case can be included as a separate case at the expense of the health insurance company. In any case, the paramedics on site cannot be blamed for this: They are confronted with precarious situations and have to find a solution quickly - and they get very creative in the process. This may be good and helpful in the current case, but it is certainly not a tried and tested solution in the long term. One option would be to further expand the care support centres that we have in Berlin in the direction of an emergency structure; another would be to provide outpatient care services for such emergencies - the discussions on this are wide-ranging and we should also allow ourselves the necessary space for these discussions in order to find decisive and sustainable solutions.

And to top it all off with a kind of case management in the sense of a social pilot.

We are already doing that, we just don't call it that yet. For cases that are brought to us, we look for the right contacts in the system after a declaration of consent has been given and then guide these people through the system. However, this is not one-sided: for example, we inform a nearby care support centre that there is a new client and ask them to contact us. Once the counselling has taken place, we ask the client to contact us again. We then move on to the next building block together. We accompany some clients for a few days, but sometimes for six or eight weeks, until a satisfactory solution is found.

How many clients contact your office?

Last year - from the start in September to December - we dealt with 88 cases and had 199 contact points in these cases. Sometimes there is only one point of contact, for example if the problem brought to us can be solved with one phone call, or two or three if we have to call the health or care insurance company to understand the situation and find possible solutions.

It seems to be structured like classic case management.

Absolutely, but only for the individual case that requires it. We see ourselves more as guides in the system and empowering the client is our top priority: teaching and building skills so that they can act competently in the system themselves is the goal.

Why are there so few cases?

We would have to extrapolate the data from September to December to a full year. But even then, it would still be too few given that there are around half a million potential target groups. However, this is only because, on the one hand, our team is not yet fully staffed and we still have to reduce our availability somewhat, for example through office hours, and on the other hand, my office is not yet well enough known. We are working on that. For example, we don't yet have any flyers or posters and need to do a lot more press work and also be able to use social media channels, even if the latter don't necessarily address our main target groups directly, but their children and grandchildren do.

What do you do with less educated subgroups who don't read daily newspapers or watch the rbb24 evening programme, but still live in certain care settings?

This is a major problem for which we have not yet found a patent solution. Perhaps we could install a kind of communication platform via the care services involved. But unfortunately we're still a long way off that, partly because there are so many providers with financial interests and partly because they have different IT control models that are usually incompatible with the telematics infrastructure. At the same time, the IT connection for care is to be implemented in the middle of the year, when it is known that this is only technically possible for 40 per cent of care facilities, and as far as I know, no one has an overview of outpatient care services.

In economic terms, we talk about the care market.

Although it is called a market, it is an absolute free space. Practically anyone can do what they want. How are you supposed to realise the obligation to connect to the telematics infrastructure? The companies operating here can take all the time in the world, which applies to the care facility itself, but also to the IT companies that programme the corresponding interfaces if they want to. On this basis, there will be no consistent care reports, because some of the participants in this documentation simply cannot document online.

This is probably simply because gematik has not taken this into account.

No wonder, if you think about everything from a doctor's perspective. After all, the medical profession has a much better lobby than the nursing profession. Unfortunately, this imbalance causes a lot of damage in the care sector because the doctor-centred approach only ever represents a small part of care. It is good that nursing is finally to be given a seat with voting rights in the G-BA, as envisaged in the coalition parties' position paper. This is then to be implemented with the 100-day programme and the Nursing Competence Act. That would be a decisive step forward.

Frau Professorin Meyer-Rötz, thank you for talking to us. <<

The interview was conducted by MVF publisher Prof Dr Reinhold Roski and MVF editor-in-chief Peter Stegmaier.

Link to the Care Monitor:
1: https://t1p.de/uzbuw

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