



## What we talk about when we talk about long-term care

*A conversation with Barbara Da Roit, coordinator of the EU-funded LeTs-Care project*



[LeTs-Care project](#)

March 2026

Author: [REVES Aisbl](#)

"At the dawn of the new millennium, the European Commission tasked a well-known Danish sociologist with developing a strategy to revive European welfare, which had been in crisis after decades of neoliberal policies.

The scholar, Gøsta Esping-Andersen, came up with idea of social investment. The thinking behind it was that investing in childcare services would be the best way to ensure the future sustainability of the welfare state and break the intergenerational transmission of inequalities. High-quality early childhood education and care services would create skilled, well-paid female employment, while also offering children from disadvantaged backgrounds the same cognitive and social opportunities as their peers. This in turn would reduce future social costs linked to school dropout, marginalisation, and low productivity. The wide availability of nurseries would allow mothers to remain in the labour market, thereby increasing immediate household income and generating greater tax revenues for the future pension system."

"Brilliant, right? Great. But what happened?"

Barbara Da Roit is an Italian sociologist of international standing. For years she has studied care policies and practices, with a particular focus on long-term care for older adults with disabilities – one of the most pressing issues on the EU agenda in the face of profound ongoing demographic changes.

Since 2024 she has been coordinating LeTs-Care, a project funded by Horizon Europe and led by Ca' Foscari University of Venice together with partners from seven other EU countries. The goal: to build a shared framework capable of identifying locally meaningful solutions for long-term care.

We asked her to guide us through the rich and intricate landscape of a study that lives in the tension between the need to capture the complexity of each context and the urgency of finding answers to a challenge that affects millions of people across Europe.

### **So what happened to that brilliant idea you mentioned?**

"What happened is that in contexts where services and resources didn't exist and this strong idea that 'a mother is a mother and should stay at home' still holds out, it took us twenty years just to get this debate off the ground. In the meantime, the indicators set by the EU in 2002 – such as asking member states to guarantee a nursery place for 33% of children aged 0 to 3 – produced a paradox."

### **Which one?**

"These indicators come in, and what happens in countries with weak welfare systems trying to reach that 33% of children in nurseries? It's very hard to change course, and when you manage to do it, a lot of private services open up that are either very expensive for users, or reduce the quality of work in order to remain economically accessible. What's the result? You haven't reached the coverage target and at the same time you've weakened a sector by triggering a chain reaction. Then people get used to the idea that 'unfortunately, care work is just poorly paid work – what can you do?' It's easier to import the logic of the indicator than the logic of the thinking behind it, isn't it?"

### **How does the story you've described relate to long-term care, the subject of your study?**

"The topic of care in general, and care for older adults in particular, runs up against a series of difficulties that European policies have already encountered in other areas. The EU produces ideas, words, messages, and resources that it makes available. But at the same time, these ideas either don't exist at all in national contexts, or are marginal and take decades to become relevant, or they do exist but mean something entirely different due to the cultural and political heritage of each country. In long-term care there is a lot of emphasis on keywords like 'integrated practices' or 'personalised care practices.' All very interesting, but in reality we don't know exactly what they mean. When we say 'person-centred care,' it means thirty thousand different things depending on where you go. It doesn't really mean anything, in practice."

### **What is the landscape of long-term care within the European Union?**

"When the EU Care Strategy was issued, we found ourselves facing a vicious cycle. In many countries and territories we have too few services and a great deal of stress among care workers: there's little staff, high turnover, frequent burnout. Quality is low, services are poorly accessible, there are huge inequalities, and the stress also weighs on informal caregivers – that is, on families or those who care for elderly people with disabilities on a voluntary basis and through personal relationships. The

challenge was to transform the vicious cycle into a virtuous one: more investment to increase service availability, and higher quality so that not only does the service solve problems, but those who work in it can also work and feel well."

### **How did LeTs-Care come about, and what are its core ideas?**

"The project grew out of a critical analysis of the 'best practices' approach that is at the centre of European policies in various fields – the idea that you need to experiment with practices locally, identify the best ones, and then spread and scale them. What we know is that best practices are often 'best' without anyone knowing why they're best. They're best because whoever designed them is capable to present them as best. That's a problem. But even if they genuinely are best – meaning they work well in that particular context – there's no guarantee they'll work in another context, because the surrounding conditions are completely different."

### **What is the alternative you are exploring?**

"We told ourselves: let's forget abstract models. Let's go and look concretely at what is being done in seven countries – how policy makers and stakeholders are addressing a set of challenges that exist everywhere but have different meanings depending on context."

### **Can you give me some examples?**

"Staff shortages are a common theme – our research shows it affects all countries. But when we say staff shortages in Denmark, it's not the same as staff shortages in Spain or Italy. Denmark has an enormous care sector, and the shortage is largely due to the fact that there simply aren't enough people to do the work. In Italy the care sector is so small that the shortage isn't about a lack of potential workers, but about a hyper-fragmented system that is hard to access and has dreadful working conditions – nothing like those in Denmark. Spain is very similar to Italy in terms of fragmentation. But in Spain the debate on this topic started more than 20 years ago, and when the pandemic hit they seized the opportunity – using funds tied to the Recovery Plan – to put in place a whole series of ideas, thoughts, and initiatives gathered over those twenty years in order to drive change. In Italy, the debate has been confined to a small circle of experts and interested parties, but no one – especially at the national policy level – has taken ownership of the problem. And Italy's national recovery plan, from a long-term care standpoint, has produced zero results. So the problems differ depending on where you go. Another one: when we say 'care workers' in a context like the Netherlands or Denmark, we know what we're talking about. There's a clearly defined perimeter of long-term care, within which there are professional figures with specific training. There are systems for tracking how many of these workers there are, what kind of training they have gone through. If you go to Lithuania, no one knows how many long-term care workers there are. In Italy, long-term care workers don't exist because long-term care itself doesn't exist as a policy field.

So we have long-term care workers who we don't recognise as such – the 'badanti' (live-in carers, often migrant women). But no one would think of them as long-term care workers. Because when you

think about long-term care workers in the national debate, you think of those in care homes and, to a lesser extent, home care. Full stop."

### **What about family members?**

"That's another example. Support for informal care is all well and good, but an informal caregiver in the Netherlands or Denmark is not the same as an informal caregiver in Spain, Portugal, or Italy - because the absence of a structured formal care system means the informal caregiver becomes essentially a jack-of-all-trades, handling everything from medical and healthcare tasks to transportation, bureaucratic management, and more. So what are we actually talking about? It's not the same thing."

### **It sounds like a very tangled knot to unravel.**

"I think of it more as constellations in motion. Every long-term care system is a constellation of practices, policies, interventions, and ideas – a constellation in which there are specific distances and tensions between one element and another. Each one is different from the others; all of them are shifting. And you have to study the relationships between the stars, and between the constellations, and see how they move."

### **How are you moving forward?**

"When we submitted the project, what we intended to propose was a reflexive approach – one that asks questions. It's a project that pushes stakeholders to ask themselves questions. I think the innovative element of the approach lies in the fact that we connect local reflexivity with its relevance for national and European policies. The new idea is to move from best practices, which have dominated the debate, to what we call 'meaningful practices' – practices considered meaningful based on how they function within a specific context. In some countries this approach is entirely new. A great deal of qualitative research with stakeholders is done in other fields too, but the link to policy is what makes this approach novel."

### **What kind of response have you encountered from the settings you've studied regarding your approach?**

"Significantly, one thing emerging from the ethnographies and the workshops with stakeholders and policy makers is that there is a great hunger for thought, research, and collaborative work on these topics. An ethnography is intrusive: we're talking about researchers spending extended periods of time inside a facility or a service. There are privacy concerns; we had worried about having access problems. But apart from a few cases tied to specific circumstances, there was great openness and a great appreciation for the ethnographic approach – the idea of going to see how a practice actually works day-to-day, beyond what people tell you. What do people do together, what don't they do, what happens, what are the tensions? And this idea was very well received, because this is a sector that in many countries is essentially invisible. And so what mattered to those involved was that it be made

visible, that it become a recognised and recognisable field. And in this I found a tremendous resonance not only from those who manage services, but also from older adults in care, family members and workers involved in these practices. We gave voice both to those who are directly involved in the practices working with great enthusiasm and care, and to those who have a policy role but whose voices often go unheard. In many workshops we were told: 'We are talking about important things, and it's important to do it this way — we're sitting around a table that didn't exist before.' Then it's a matter of building bridges between the level of practice and the level of policy, and that's very hard, because you need to explain clearly to national and European policy makers that the grammar of policy is different from the grammar of practice."

### **In what sense?**

"Policy makers rarely see the things that matter to those who develop practices. But those who develop practices tend to do so within given resources – resources in a broad sense: financial, organisational, and so on. And it's very hard for them to demand from policy makers a change the broader context, which is what is needed in most cases."

### **Could you give me a practical example here as well?**

"Last year we held a workshop in Italy on staff shortages in care homes, with managers of residential facilities, trade unionists, and voluntary organisations. Three categories of problems emerged very clearly: one relating to the workers' poor employment conditions; a second linked to the fact that the funding quotas that regional governments pay to care homes are insufficient to cover the cost of the staff needed to provide the services that residents require while keeping fees accessible; a third related to internal organisational issues. Towards the end of the workshop we asked participants which of the three areas they would prioritise in order to bring about change. And what was the answer? 'Let's start with organisational issues.' I found this revealing, because it means that in a situation where what prevents you from doing things well is the context, the first thing you try to change is your own way of working. So the point is that policy makers need to realise that the context they establish through their decisions is a fundamental factor in how practices function — and if they don't address that, it's very hard. On the other hand, those engaged in practice, who should be aware of this and demand contextual changes, don't do so."

### **Which policy makers are you primarily addressing?**

"That's another problem. Policy domains vary greatly across countries – there are countries where these policies are extremely decentralised, others where they are more centralised, others still where there is a different balance. There are countries where the third sector plays a huge role, and others where everything is public. Countries with 2 trade unions dealing with these issues and others with 25. Since the contexts are so different, the choice of policy makers and stakeholders is also very different. The objectives and framework are the same, but within each country we operate differently – because the interests differ, the actors differ, the levels differ. In Italy, for example, the work unfortunately has to be done at the regional and local level. I say 'unfortunately' because there is no national coordination, and that is part of the problem."

### **How are you trying to bridge the two realities?**

"What we are trying to do is pose questions to policy makers and encourage them to ask themselves questions. The policy learning toolkit we are developing promotes reflection on reasonable objectives, resources, constraints, and possible or impossible changes. In other words, we are asking policy makers to do a work of self-analysis and context analysis."

### **The more we talk, the more I get the sense that this study isn't so much about providing answers as about building better questions.**

"It actually does provide answers too. We have produced an analysis of meanings; we have tried to explain why these meanings differ; and we have also explained what the consequences of these different meanings are. When I told you that in some countries people know how many care workers there are and in others they don't — we explain why that is and we explain what problems it causes. It's the case because there is no policy field, and this means that precisely where there is no policy field, there are even fewer tools to respond to serious problems. We will say the same about practices — we will produce an analysis of individual contextualised practices that will offer insights both scientific and policy-related. So there are answers, but certainly from the standpoint of broader policy implications, what we would like to do is ask policy makers and stakeholders to stop and think, and to ask themselves questions."

### **How does a project that emphasises differences and opens up all these questions end?**

"It doesn't end. In the sense that I hope this project is the first of many — not because I'm asking the European Union for more money, but because it's a project that tries to introduce an approach, and so it will need to be tried again in other contexts and in other ways. It's a seed that we hope will produce more flowers and fruit."

### **Where are you now, and what lies ahead?**

"We have completed the ethnographic work, and at our last meeting we had a first discussion of the data and observations from the ethnographies. We already have a short report for each ethnography and are working on putting them in dialogue and offering analytical insights. Between April, May, and June we will hold the second wave of workshops. We have produced policy briefs and more will follow on the second part of the project. We are also developing the policy learning toolkit. From the beginning of next year, it will be a matter of bringing all the pieces of the project together."

### **Since we're on the subject of reflections, I'd like to ask for one on the future of long-term care in a European landscape increasingly shaped by dramatic demographic changes.**

"I think there is something that needs to be addressed now, otherwise in 10 or 20 years it will be a disaster. And the heart of the question is: what do we mean by long-term care? As I was saying at the start, this is a field that doesn't exist. The very idea of long-term care is one that emerged in European policy — it doesn't exist in those terms in individual countries. We don't have a shared definition of

what long-term care needs means, and we don't have a shared definition of what long-term care itself means.

My view is that long-term care should start from birth, not from the age of 70. Because we have a productive, reproductive, and healthcare system that creates problems. We can't think we're healthy just because we don't have gastritis. Health also means not eating junk food, playing sports. But if schools don't have gyms, that's rather difficult. We are super stressed because we work too much, and that makes us ill. The healthcare system patches things up and gives us drugs. And when we are very old and very disabled, the way we are cared for is still very similar – especially in some countries – to the way we are cared for when we are adults: they give us drugs.

I believe this situation calls for a reflection by society as a whole on how we live, how we are cared for as children, as young people, as adults, and also when we're old. We need to rethink what things are truly important for protecting us and helping us live better.”

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Translated from the original in Italian

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