ETORKIZUNA
ERAIKIZ
think tank

NEW FUTURES OF THE WELFARE STATE
REPORT OF THE 5. MEETING

14/12/2020

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1. Programme

Theme	Presenter/Driver
Introduction and presentation of the workshop	Maite Peña
Presentation "There's no place…like home"	Alfonso Lara
Dynamics of reflection and debate	Javier Castro
Evaluation and end of session	Maite Peña

2. Participants.

- Maite Peña
- Patxi Leturia
- Joseba Zalakain
- Rakel San Sebastián
- Xanti Moriones
- Julián Florez
- Ander Arzelus
- Belén Larrión
- Koldo Aulestia
- Mikel Malkorra
- Sebas Zurutza
- Gari Agote
- Iñigo Kortabitarte
- Adriana Sanz
- Andoni Zulaika
- María Muñoz
- Javier Castro
- Miren Larrea
- Ainhoa Arrona

3. Introduction and presentation of the workshop

The Deputy for Social Policies welcomed everyone to the session and thanked them for taking part.

She reminded them that at the previous session they had agreed to change the dynamic to allow the debate begun on person-centred care to be continued in this session. Consequently, they are putting off the space originally earmarked for discussion of Covid-19 and instead today's session will focus on the topic they agreed on.

She reminded them that the areas of consensus reached at the last meeting are set out in Document No. 3, and she highlighted three of them:

(1) "Define a common conceptual framework of the PCC model for all areas of social policy. This model must include a system of internationally validated indicators".

(2) "Map good practices and existing experiences in Gipuzkoa and evaluate their degree of success, difficulty and innovations based on the PCC Model".

(3) "Define a working methodology to reach a consensus on the conceptual model based on territorial and international evidence (Gipuzkoa model)".

She said that they would also be changing the dynamic of today's session, based on suggestions submitted on the evaluation form from the last meeting. "On the evaluation sheets you quite prominently suggested that the expert who forms part of the debate and focuses the topic could also be involved in the debate and at the end, could give feedback

in the form of conclusions". Therefore, she said, today's expert will participate in the discussion and debate groups and will give his opinion on these reflections at the end.

Before introducing the speaker, the Deputy told them that the Driver will later report on the input from last meeting's speaker, Teresa Martinez, to the document that the group is working on.

Finally she presented the deliberation agenda for the session, "From centre to home: how to deinstitutionalise care centres and how to provide sufficient support at home", and introduced the speaker, Alfonso Lara.

She said they were particularly grateful to Alfonso for taking part. He is the executive director of the ESN (European Social Network) and supervises the network's strategic management as well as running the policy programme (co-funded by the European Commission). He has more than 12 years' experience in public policy and has authored and co-authored a number of books academic publications in specialist journals. Finally, she said that he has a special relationship with Gipuzkoa: "He has always been particularly in touch with the work we do in Gipuzkoa, and he was our ally in the work we did to publicise the way we do things in Gipuzkoa".

Thanking him again for his participation, the Deputy handed over to Alfonso Lara.

4. Presentation: "There's no place…like home"

Alfonso Lara took the floor and thanked them for the invitation. He said he was also grateful for "this initiative to build the future (...), and this Think Tank, for placing such importance on care policies".

He began his talk by saying that "there is a lot of talk in Spain at present about the term 'care'" and he mentioned some of the questions and considerations about care that came up at a congress of associations of social services directors in Spain he had attended that same day: "They talked about care, and how it should be an integral part of the welfare state. What is care, though? Is it part of the social sphere? Is it part of health? Should it be a discipline on its own, or should it be bundled together with social services?". With these questions and saying that there was a lot more to discuss, he thanked them again for the invitation, and said that it was a pleasure to work with the Provincial Council of Gipuzkoa, which is also a member of ESN. And so he began his presentation.

Introduction and the ESN Network

Alfonso began by explaining the reason for the title "There's no place... like home". He said he felt that something along the lines of "from the centre to the home" would have seemed too technical, and he wanted to convey the idea, "Let's think about how we want to live, and how we want to care and be cared for", hence the title. "It's what Dorothy says in the Wizard of Oz; *'There's no place like home*'" he added.

Alfonso said that he was the director of the ESN, of which the Provincial Council and other Basque institutions, including the Basque Government and the SIIS (Social Services and Social Policy Documentation Service), are members. He gave them some more information on the network:

- It is an independent European network of public social services.
- "It is mainly made up of regional and local governments, but it also includes social service associations, applied research centres such as SIIS, and agencies that are in charge of monitoring the quality of social services".
- "We operate through working groups and congresses and we organise European awards..." In the last edition of the prizes, he said, the Gipuzkoan initiative, "OK at Home", was short-listed.
- "We promote investment in social services and recognition of services as a network, as social investment, and as an investment that will advance the local economy".
- "We cover all population groups". He said that ageing is something that affects us all from the moment we are born, and institutionalisation is an issue that affects all population groups (children, young people, people with mental health problems, disability, etc.).

Trends and situation in Europe

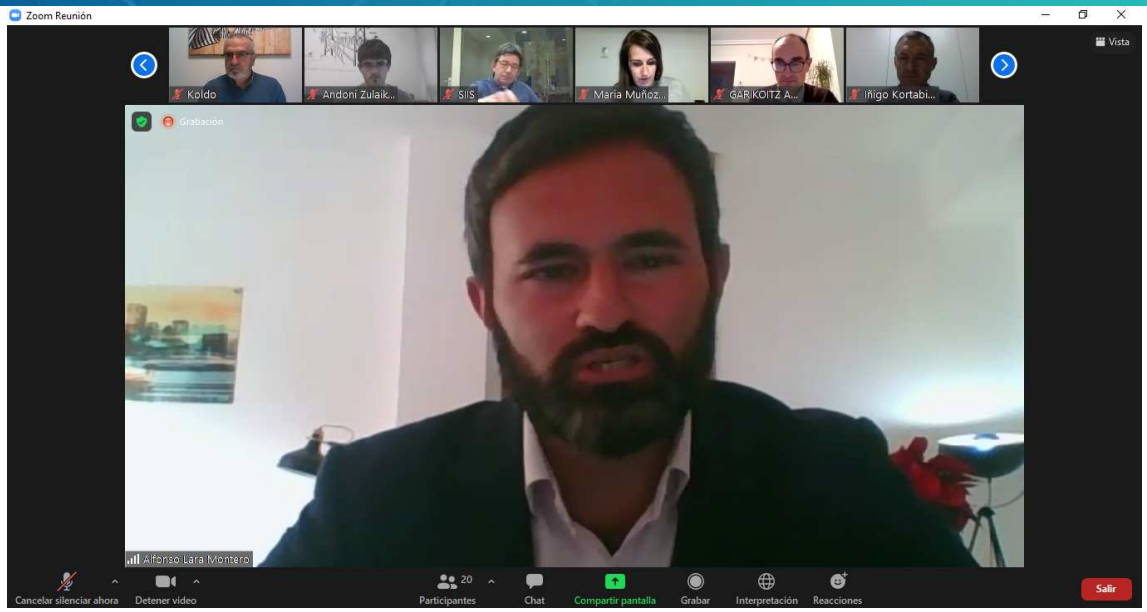
Alfonso went on to give examples of a number of trends that are currently being observed. (1) Population ageing; (2) Changes in family patterns; (3) Increased use of formal long-term care. He said that "increased use of formal care can take different forms. The most traditional form is residential solutions", but there are also packages combining different instruments, such as the (4) "combined care packages / personal budgets", where "the user becomes the employer". These are budgets that can be managed by the person

themselves, negotiating directly with the authority, or delegating the work of managing their personal budget to a provider". According to Alfonso, all these arrangements reflect another trend: (5) "greater expectation of service quality among people". In this regard, he noted that there has been a major growth in policy initiatives, reforms and programmes for people in need of long-term care, but this expansion has not been uniform across Europe (depending, *inter alia*, on economic pressure, political choices, etc.).

In addition, long-term care policies "are sometimes bundled with health, and sometimes with social services". In Spain, he said, this area is covered by the 2016 Dependency Act, in which the promotion of autonomy is given an important role. Alfonso then discussed the term "dependence". He said that this issue needs to be worked on, because "viewing people as dependents tends to hobble people, personnel and the system itself". Elsewhere in Europe, Alfonso noted, the term used is *long term care*. Various studies suggest that this is a policy area in itself, "erroneously associated with the elderly, or with disability". He gave the example of a person with mental health issues, who may have long-term care needs, but is able to contribute to society, and should not therefore be considered as dependent.

With regard to these trends, Alfonso highlighted two major challenges: (1) "Viewing care as a broad concept that should not be associated with age". According to Alfonso, this can otherwise lead to situations of discrimination, such as those experienced with Covid-19. It should therefore be seen as a "policy area that affects all population groups". And he added that these people can and should contribute to the system. (2) "This approach must be translated into public policies". Alfonso mentioned the European Pillar of Social Rights, adding that an action plan in this respect should be adopted at a national level. Principle 18, he said, "states that everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services".

Regarding the situation in Europe, he said that it varies from country to country. There is a bloc of Western European countries with a wide range of care policies, and another bloc of countries that have been taking the first steps in recent years (and some in which the topic is not even covered by the legislation). These differences can also be seen in indicators such as expenditure and staffing ratios, which Alfonso showed in two graphs on his slides.



The work of the European Union

Alfonso went on to speak about the work of the European Union (EU) in this area. Its work, he said, is mainly supportive, "because the powers lie with the member states. Moreover, they are sometimes regional, autonomous, or local"; the situation varies from country to country.

In this support work, there are a number of developments that he thinks merit particular attention. The 2014 report of the Social Protection Committee, which "concludes that there is a compelling case for countries to put in place an adequate system of protection for long-term care", and that they should go from a reactive to a proactive model with innovative solutions.

He also highlighted the work of developing indicators, "which is challenging", because "it is difficult to measure the effectiveness of care, to know what is being done, how it is being done, whether it is being done well, and whether it is having the intended effect". He said there was a working group within the Social Protection Committee whose purpose is to generate common indicators for all countries. It includes indicators in three dimensions: access, sustainability, and quality. He gave details on these. With regard to access, he said there were already 11 indicators in place. With regard to sustainability, he explained that there is already initial agreement to continue developing indicators to cover elements such as public spending, fiscal sustainability, the average amount people have to pay and difficulties in paying for formal care. Finally, in the area of quality, he said that discussions will begin in 2021, and that "we have asked that it should include work with

member states to re-analyse the voluntary framework of social services approved in 2010," among others, "because the concept of quality has changed".

The EU is also involved in funding. Alfonso stressed that "it is important to talk about funding, because it is the tool that helps to implement plans and principles". He described the Recovery and Resilience Fund and the ESF, which is intended to provide support for structural reforms in each country. He gave some details and figures about the fund, which Spain is entitled to access, and he mentioned that care for the elderly is one of its axes. In addition, the most relevant objectives of the European Social Fund, according to Alfonso, include promoting active aging, improving access to sustainable and affordable services of good quality, modernising social protection systems, and improving service efficiency. He listed some specific activities that can be funded, including: staff training, support for integrated care and independent living services, active and healthy ageing programmes, and expanding access to and coverage of long-term care.

Alfonso stressed that "it is a very important instrument for advancing in the development of care priorities, and for making structural reforms". In the Basque Country, it could be structured through the programme submitted by the Basque Government.

Quality and the need for a paradigm shift

Alfonso went on to address the issue of quality, "a fundamental challenge" in his words. "In Europe the emphasis is on access and coverage, but the fundamental challenge is to define what model of care we want to implement as a society: one that centres on the individual; is steered by their free choice; that recognises the person's needs but also their contributions and wishes; that encourages care in the home and community; and that defines the concept of quality in the extent to which people's quality of life is improved".

He added that "this model requires an analysis of the way in which quality is defined", and that this is where elements such as the welfare model, contracting specifications, etc. come in. Regarding the latter, he noted the problem of pre-established standard rates and said that to date, the emphasis has been on process indicators. In "a person-centred model it is important that quality is not only based on process criteria, but also on results". For this reason, he said that in some countries progress is being made in contracting services by results.

Alfonso went on to focus on the care model, which he stressed, can be justified not only on human-rights grounds, but also on economic grounds, since it is more profitable than institutional care. He noted that "the principles underpinning such care should be: people-centred, available, accessible, affordable, ongoing, results-oriented". Therefore, he added, "the contractor has to work with the funder and provider to make sure that it is based on those principles".

He also highlighted that a key factor for quality, and a key function of the public authorities, is to foster a strong care market. This can be achieved through different measures.

At the same time, he stressed, "quality is also about improving quality of life, not just quality of care". Therefore, he said, the results of the services also need to be analysed, not only based on technical criteria. "We need to examine whether the care has improved the quality of people's lives". "Objective criteria need to be included, such as the number of people supported, the length of time they remain at home...", but "any analysis should also include subjective, such as personal autonomy, social connections, sense of well-being, sense of purpose, etc.".

Alfonso again stressed the need for a paradigm shift in the field of care. Care, he said, "should not be associated with age; rather, we need to understand that aging is a process that begins at birth"; we need to "find a sustainable formula, which adheres to a series of principles", taking into account social as well as economic factors; "that promotes integrated care, taking in for example care that targets ageing amongst people with disabilities"; "that takes into account the fact that as soon as you go over to more person-centred models, the person or their family member becomes an evaluator of those services", and therefore, "the frameworks must be adapted to those beneficiaries or caregivers".

Summing up, he said, a "paradigm shift means going from a medicalised and paternalistic model to a model that focuses on people's quality of life".

5. Dynamics of reflection and debate

The Driver thanked Alfonso for his presentation and invited him to participate in the discussion groups, and then give feedback on what he has heard in the groups.

Feedback from Teresa Martínez on the working document

Before presenting the reflection dynamic, the Driver told the group that Teresa Martínez, the expert speaker at the session on 26 November 2020, had been asked to give feedback on the deliberation group's Document No. 5. He said he wanted to share some pf her ideas, "to throw into the mix of the discussions". He then discussed some of the remarks Teresa had sent in (see appendix):

First, he commented on the point she had made that "PCC-focused models should refer to more than just personalisation. It is therefore necessary to discuss personalization and the surroundings - the barriers and levers to personalization in the surroundings". This means that "we have to discuss the issue of context, rather than just focusing on the individual".

The second point relates to understanding that "individualised care services are not the same thing as personalised care". The difference lies in "the degree of self-determination of the person in care".

The third point the Driver mentioned was that "we need a system in which personalised care is related to interpersonal relationships". This is related to the context, to the community, and, therefore, to how organizations and professionals are structured.

The third remark he highlighted was "whether the PCC model or personalization (which are not the same thing) might be applied universally for all types of public policy and the populations they serve". Quoting verbatim from Teresa, he said:

> *In my opinion we should not be thinking in terms of a single PCC model for all services. Yes, it is possible to identify a common set of values, in terms of defining the approach, derived from the point of view of the people and groups receiving care/support, but in terms of defining models aimed at making PCC operational in services, I believe that it must be formulated taking into account the mission of those services*. (excerpt from text sent by Teresa Martínez, quoted by the Driver)

In the Driver's opinion, "this is an interesting point because we are debating whether or not the PCC model can be used for all services". He added that it is necessary to make a mix and contextualize.

The fifth point mentioned by the Driver was assessment, which Teresa thinks is relevant for monitoring change and for research-related objectives. The Driver again read from Teresa's text:

If the aim is to evaluate the quality of the services, the assessment must be more comprehensive; PCC is one axis of quality, but it is not the only one. Comprehensiveness and safe care environments are also important. It is important to include standards and indicators related both to the structure-process and also, above all, to the quality-of-life results (health, rights protection, wellbeing and self-determination) (extract from text sent by Teresa Martínez, quoted by the Driver)

The Driver noted that this is related to with quality of life and mentioned that Alfonso had highlighted the same idea in his presentation. This, therefore, is an important issue: "how to build indicators that analyse not only quality of service, but also quality of life".

The Driver said they would share the document with the group, together with a video Teresa had sent them.

Questions and conclusions of the group reflection

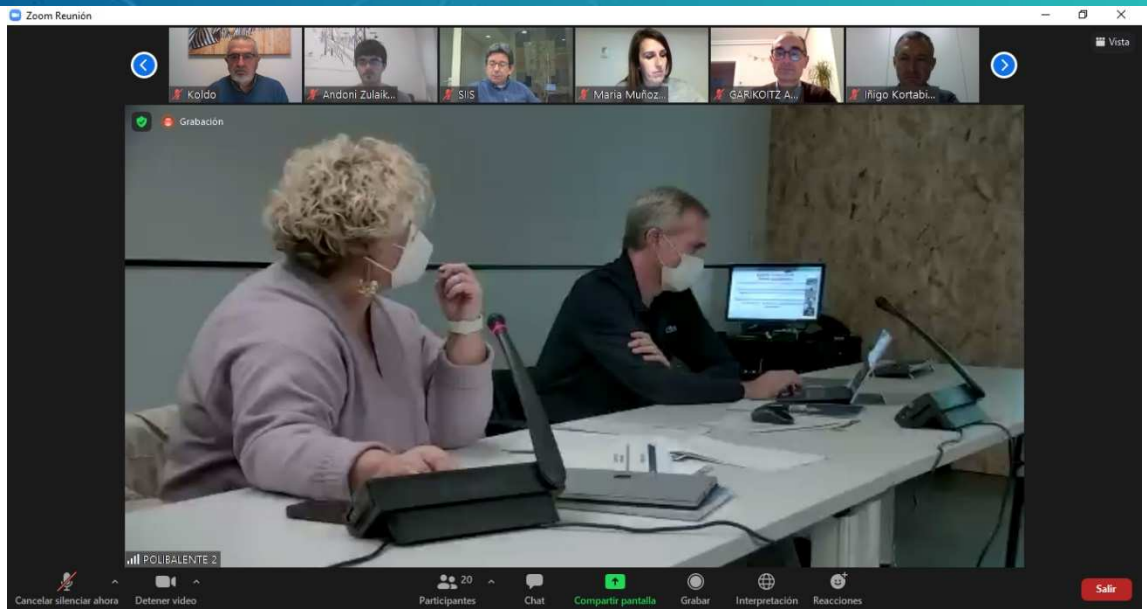
The Driver then presented the question that the participants will have to answer in the group reflection dynamic, in four pre-established groups. The question is as follows:

What three actions or types of policy could we implement for personalized care at home?

He explained that last time there was a lot of discussion about centres; now the debate and reflection should focus on the home, so that they could come up with a document that includes all the different dimensions.

Following the explanation, the participants began deliberating in groups.

The group reflection lasted approximately 45 minutes, after which the participants returned to the plenary group and the Driver handed over to the group spokespersons, who shared the conclusions of their respective groups.



ECO2, spokesperson for one of the groups, began by saying that there had been a lot to talk about, because the group included people from different situations.

He said there were three aspects they think need developing:

1. “Knowing the person's wishes. Taking into account not what we *think* the person wants, but what they *actually* want”. He added that there are groups in society that are not able to explicitly state their wishes. It is therefore also necessary to work on the issue of anticipated wishes.
2. “Adaptation of the whole ecosystem: housing, technological aspects, training, social issues, urban planning... everything involved in the ecosystem, and even people in the community (...) There is a very complex ecosystem involved. We are supposed to be living in an inclusive society, but sometimes society excludes people”. He said that this is a complex issue that requires study.
3. “Measurement. It needs to be evaluated; it has an important value”. He said that to date, all evaluation has been quantitative. However, as mentioned in the talk, the qualitative side is also very relevant for assessing quality. “How do we evaluate quality, which is not as easy as it might seem". We need to focus on qualitative aspects, "based on needs and initial desires; how do we evaluate them”.

He concluded by expressing his satisfaction with the exchange of knowledge and different situations between all the people in the group.

ECO14 then took the floor on behalf of another group. He explained the three actions defined in the group:

1. “The importance of getting the diagnosis right", and of it being "holistic, multidimensional and proactive" to take into account the person's abilities, hobbies and interests, etc. He said that what usually happens is that "the diagnosis is limited to the resources available; we need to go further”. He gave the example of an elderly person who might have digital problems, who might benefit from going to a KZGune (local IT education and services centre). This example shows, he said, that "the diagnosis is often limited to the work that can be done, and it is necessary to use a holistic view of the person”.
2. “We need to define the care package well and strengthen the role of the case manager, or package manager”. He added that the services and programmes that work with the community dimension need to be strengthened; there are difficulties there. It is often individualized, but it is necessary to look for a broader vision of these services. “It may be better to take two people for a walk at the same time than each one on their own”. Therefore, the aid package must be well-defined, and the figure of the manager needs to be strengthened.
3. “An operational system to overcome the lack of information transfer between the health and social services”. The case manager should have access to the person's life history, in order to be able to follow up and act as a link between different personnel. “Not to generate a new figure, or to work on that itinerary, but rather to act as an operative system that structures the role of the different personnel”.

DFG1 then took the floor, representing the third group. She said that there are aspects that they worked on in reference to the centres that can also be applied to home care, such as the issue of training, for example. And she said that they have focused on actions related to the home:

1. “Identifying the minimum elements and values that characterise PCC, and identifying indicators", referring to the user, environment, family, and service providers.
2. “Giving the person decision-making capacity, maximising self-determination", and broadening the range of services provided for this purpose, so that they can choose.

3. “Establishing a care pathway, with a broader care service and with alternatives" in a regulated fashion, complemented by private services. She said that there could be an agency for service assessment, working with the same indicators as elsewhere in Europe.

Lastly, she said that because it was a complex model involving the powers of several different institutions, it would be necessary to raise awareness of the PCC model in all institutions.

Finally, ECO1 took the floor to share the conclusions of the fourth group:

1. “Referentiality and case management. There should be a system in which people are helped to choose (giving them sufficient information about options and the aspects they can choose (providers, etc.)), based on a real knowledge of needs and expectations”. He added that "grassroots social services should do this work" but if that is not possible, there might be others, such as independent living offices, which could provide a similar service.
2. “Free choice", allowing people to choose "not only the services, but the bodies responsible for providing the service”. Because, he said, users have very little ability to choose which body provides the service. He added that this is where the debate and the accusations of liberalization, of making the service less public, come in. However, "in many countries, services are provided via financial benefits; people receive and contract the service from the provider they like the most”. “There are risks involved in this process," he added, but the "advantage is that the person has been given help in structuring their care package, and it is the person's choice”. It is therefore necessary to reflect "on whether it is the public authority that does the hiring, or the person themselves”.
3. Assessment. He mentioned that the public authorities can play two fundamental roles: as a service provider, albeit indirectly; and by providing quality assessment and quality assurance, researching indicators, etc. He said that the role of the service provider could also be performed by private bodies, but "what no one else can do is guarantee quality, and create a service, not of regulatory inspection, but of quality assessment, of care in terms of quality of life, user satisfaction, the impact of the service on the quality of life”. And this

should be done by the public sector, through assessment agencies, etc.. Nonetheless, he said, "that requires institutional territorial frameworks", at least at a regional (autonomous community) level.

As stated at the beginning of the session, Alfonso Lara gave feedback on what he had heard in his group and on all the issues raised by the other groups. “This was a very interesting session. I was sitting in on one of the groups, but listening to everyone, it becomes clear that there are a number of aspects that are common to all of them, that touch mostly on the question of provision. There are other strategic aspects, too, which are related to the construction of future policies”. He added that there is a message for the provincial government, within the wider framework of the Basque Autonomous Community and the Spanish state.

He said that he would try to construct a narrative and he shared his interpretation of the conclusions of the focus groups:

“One of the things that was emphasized is the importance of analysing people's needs. What I understood was that you have to go beyond the pre-established templates”. Because "we may discover that things as we thought they were. By asking, we can ensure that services are more in line with what the person needs”. And the analysis must take into account the whole ecosystem of the person, the home, the neighbourhood, the relatives…

“That makes it necessary to define indicators or principles”. Seeing what needs to be considered, questions focusing on the person, in order "by following up on this, to develop planning and assessment of home care” and "define packages and strengthen the figure of the case manager and the care package”. He said that the issue of the care package is important, because it involves integration: “We cannot gain a proper understanding of a person 'in fragments'"; we need to collate and assess the communication between all these agents. “The case manager can bring those services together and could do so through an operating system that allows them to manage data and providers”.

He also stressed that it is necessary to "give the individual decision-making capacity", but some work is required to ensure that they can "have information on available services, on the services and providers they can use to build their care package”.

Another of the aspects he stressed is that "quality should not be viewed merely from a quantitative perspective, but also, and above all, from a qualitative one". There are different instruments for this purpose, such as, for example, having the `public authorities provide financing based on results, or having it finance aspects that are more community- than residential-based. This leads to a strengthening of home and community care.

He went on to mention the importance given to monitoring, both of individual services and integrated care packages. And for this, it is important to have an agency, "that is independent; it should be publicly run, but independent".

He also said that it would be necessary to see "what the public authorities can do better, to determine who is best-placed to do what". He mentioned, for example, that there could be encouragement for the development of cooperatives and small businesses for community and home-based care. He added that "planning for the development of the market, in order to give decision-making capacity to the individual, is something that should be done only by the public authority" and, also, that it should be the public authority that conducts the assessment of these services and guarantees that they are being carried out properly.

Alfonso ended by saying that the group is "developing along very interesting lines".

6. Evaluation and end of session

The Deputy for Social Policies once again thanked the group and Alfonso for their participation. She said that "the dynamic proposed by the participants works well, with the expert enriching the debate with his contributions after listening to the groups". She added that "core issues have been discussed that we will report on" and that they will take it back to the group.

She reminded participants to fill in the evaluation questionnaire, which is "so important" and from which "interesting issues for improvement" arise.

She ended the session by convening the group for the next meeting, to be held on 28 January 2021, and set out the topic for the session: Territorial organisation, structure of powers and inter-institutional coordination.

7. Appendices

a. Working Document No. 5

DOCUMENT NO. 5

Etorkizuna Eraikiz Think Tank:

Workshop results

What is meant by personalisation in the PCC model?

(workshop held on 26 November 2020)

1. What is meant by personalisation?

1.1. Personalisation viewed as a **service offer** that caters to individuals' **preferences.**

In this perspective, the dynamic weight of *personalization* is placed on the individuals' **preference** as to the type and quality of services they wish to receive (health, accompaniment, support). The aim is to develop a broad and diverse portfolio of services that offers users different **options** and different means of **accessing** the services. This perspective emphasizes the autonomy and freedom of individuals to choose which services they want and how they access them. The direct consequences of this perspective are that people who can choose how and where they live and what life project they want, gain in self-determination, self-esteem and mental and physical health.

1.2. Personalisation viewed as **adapting** care to the individual's **needs.**

In this perspective the dynamic weight of *personalization* is placed on the individual's **needs** and the capacity of the services (health, accompaniment and support) to **adapt**. The aim is to develop flexible and adaptive **services**, but not necessarily diverse and multiple ones. In this perspective, needs are negotiated between the users (and their support groups) and the professionals who support the services. This approach emphasises the flexibility and adaptive capacity of the services over the autonomy and freedom of the users. To this end, the services must be structured on the basis of certain criteria such as promoting the life project, adapting spaces to create friendly environments (meaningful environments), facilitating as far as possible continuance of the users' lifestyle, respectful treatment and respect for personal identity. Case management could be one management model adapted to this perspective of service personalisation.

1.3. Personalisation viewed as **adapting** care to the **life histories** (clinical and social)

In this perspective, the dynamic weight of *personalization* is placed on adapting the services (health, accompaniment and support) to the users' own **trajectories**. In this approach, personalizing means adapting services to the **life histories** (clinical and social) of the users. This means developing **intelligent services** where technology plays an important role in service management. That does not necessarily mean greater diversification of the range of services on offer. It is a perspective that places greater focus on technologies and efficiency of care. This means developing intelligent

services and promoting development, integration and access to the users' life histories. Personalizing care based on life history assumes that care and attention are longitudinal processes that not only include the individuals' (past) trajectories but also roll out care and attention over time (future).

1.4. Personalization viewed as **integration** of the context (family, social) to **design** Individual Care Plans

In this perspective, the dynamic weight of *personalization* is placed on **integration** of the family and social context into the space of attention and care. Personalization is not viewed as an individual dimension (the user) but as a micro-social dimension (family-community). In this approach, the **Individual Care Plans** are micro-social and non-personal, addressing the care of both the end user and his or her immediate social context (support group). The user is seen as a relational and related subject and personalization as a collective process. This means developing **services that are contextualized** to the care environment and not focused solely on the end users and their needs. Contextualisation of services requires greater integration and networking between services as opposed to the current situation of segmentation.

1.5. Personalization viewed as a **normative instrument** to **design** Individual Care Plans

In this approach, the dynamic weight of *personalization* is placed on the development of **legal** and service-**management instruments** (health, accompaniment and support) to design **Individual Care Plans** focusing on users' needs in order to offer them a better quality of life. This is a perspective based on people's right to dignified care according to their different levels of vulnerability and capacities. Personalisation is linked to the dignity of people and this is consolidated in a legal framework that orients service management. On the management side, each user needs Individual Care Plans that are adapted to their care needs. Thus, this legal perspective **of personalization** requires development, updating and modernization of **regulations**, as well as development of the **instruments** that can make this regulation an operative and functional process.

2. What resources are needed to personalise care?

2.1. Institutional innovation: new social policy framework

Personalization requires promoting the generation of a new framework of social policies that include, among other dimensions, the following: a) Innovating the portfolio of services to promote more flexible care and attention models, oriented by PCC and tending to lead to the personalization of services, b) Reviewing the budgetary structure of the public authorities to invest and finance in other ways — in infrastructures for the adaptation of physical spaces to the new care model, and in social innovation to promote a change in the model and the generation of care ecosystems; c) Addressing a change in the regulatory model (regulatory decrees, etc.) to facilitate the transition towards a new model oriented towards PCC and service personalization; d) Promoting a cultural change at institutional level (internal to the public administration) especially in terms of planning and evaluation of services that need to be performed according to the PCC model and personalization; e) Promoting digitalization of organizations and service management systems in order to provide support for the management of personalization and to develop transfer networks (local good practice). All of these elements require a political and institutional commitment to foster a transition towards a new care model.

2.2. Organisational innovation: Personalization management

Management models for developing "personalisation strategies" are a key resource for promoting the PCC model and personalisation of care in organisations. Firstly, these management models must be made up of multidisciplinary teams that enable all dimensions of a person's care to be understood. Secondly, the management of personalization is more efficient if it is based on digital

technologies that facilitate the tasks of planning, information gathering, trajectory analysis, and recording of subjective lessons learnt. Thirdly, managing personalization also involves managing three 'times'. The time of care (time of direct support to the individuals receiving care), the time of evaluation (time of assessment with the support circle) and time of learning (time of considering the progress of the Individual Care Plan with the interdisciplinary team). Fourth, managing personalization requires redefining staff/caregiver ratios. Staffing ratios must be associated with care times (the three times) and user profiles (what type of care they need). Fifthly, management of personalisation is effective if it connects users to the local community or immediate environment through the performance of meaningful and socially-enhancing activities.

2.3. Physical infrastructures: new physical and urban spaces

Personalization requires reconfiguring physical spaces, organizing friendly, reduced, manageable, habitable spaces. In this new conception of the architectural space, a network is formed that extends from private homes, through residential centres to urban spaces. It is about conceiving space and its architectures as supports for a care ecosystem, and therefore encouraging and assisting in the architectural and ergonomic adaptation of homes to facilitate "living at home" with home-based support. Investing in residential facilities to adapt them to the personalized care model, with housing units, smaller facilities, and adaptable spaces. Finally, contributing to the urban development of friendly cities, safe spaces for meeting and socializing, within the framework of a sustainable urban development strategy.

2.4. Technologies: rights-based smart technologies

Personalization based on ecosystemic structuring and management models requires the dynamic and intelligent support that technologies can provide. However, it is important to note the mistrust generated by technologies with regard to the use of personal data. Technologies will have a greater capacity for integration into ecosystems and management models when there are legal and operational guarantees on data governance (institutional, legal and social control of the data).

2.5. Training and education: development of new skills

Training in new skills is key to promoting organizational and institutional changes in order to develop new models of care management. Service personalization requires new skills in a range of areas such as ethics, human rights, communication and empathy, case management, inclusive accompaniment, participatory design of Individual Care Plans, management of digital technologies, strategic planning, community management and quality-of-life assessment. There is consistent mention of the need to make a relevant change in the "way of doing", which implies a cultural change and a change in the training of professionals and policy managers, but also of users and their support environment.

2.6. Financing the transition: comparative analysis of real costs of the care model vs. the PCC model.

There is a lack of empirical knowledge about how much the new care model, based on personalization, actually costs. As a matter of urgency it is recommended that a comparative estimate of real costs be made between the two models. It is also pertinent to estimate the cost of the "transition" from one model to another, which in the short term may represent a greater economic outlay, but in the long term a much lower cost than the current model. In terms of financing, it is important to promote more efficient spending models, intelligent controls and rationalization of resources.

3. What impact does personalization have in different sectors?

3.1. Impact on people's quality of life and well-being

Personalization of attention and care improves people's quality of life. Firstly, it has a positive impact on end-users because personalization is dynamic and adjusts to users' needs as they evolve. The care is tailored to their needs and preferences. Secondly, it has a positive impact on the social care environment (family, friends, etc.). since it reduces and helps to organise care demands. The better the quality of life of the person being cared for, the better the quality of life of the caregivers. Thirdly —and this is linked to the second point— personalisation has a positive impact on the personnel providing care and attention, since the well-being of the people being cared for and their social environment offers professional satisfaction, which ties in better with the personnel's mission, since their work has meaning and contributes social value.

3.2. Organizational impact

Personalization of care and attention has an impact on the organizational and management models of organizations and institutions. Personalization orients the social-health space towards multidisciplinary care, based on new and adapted itineraries, structured in Individual Care Plans adapted to users' needs and preferences.

3.3. Technological impact

New technologies are an excellent support for developing and implementing the personalization of attention and care. Likewise, technologies such as Artificial Intelligence, Big Data, Machine Learning, the Internet of Things, etc. are all technical platforms facilitating the creation of ecosystems. However, social and organizational mistrust about the use of personal data and the use of these technologies for other purposes and unstated objectives puts a brake on the adoption of these technologies. This mistrust must be overcome by creating not only legal but also operational guarantees on the proper use of information and technologies applied to care.

3.4. Economic impact

The personalisation of care and attention is costly (new infrastructures, new technologies, new management models, new training systems, etc.) but it is considered to be more efficient. One relevant aspect of personalisation-oriented models is their preventive nature and capacity for early intervention. This has an impact not only on the well-being of people needing care but also on future costs. Moving towards models focused on personalization may have high upfront costs, but in the long-term it leads to cost reduction and a more efficient way of spending.

3.5. Impact on care and attention services

Promoting models oriented towards personalization would have a great impact on the whole portfolio of primary care services: assessment, diagnosis and orientation service, home help service, socio-educational and psycho-social intervention service, support service for carers, service for the promotion of participation and social inclusion, day and night care services and accommodation services, among others.

3.6. Legal/regulatory impact

The transition to a personalization-oriented model necessarily requires changes in standards, instruments of regulation and inspection of care services. Standards often lag behind actual care practices. Changing and updating the standards can be slow and laborious, so it is important to advance the transition at "grassroots" level". By changing the empirical state of affairs, it becomes much easier to change the regulations.

4. What actions can be implemented to promote service personalization?

4.1. Deliberation and consensus on the conceptual framework of the PCC model and personalisation to be used in the transition towards a new model of attention and care for Gipuzkoa.

The PCC model is widely felt to be heterogeneous and to orient diverse types of care practices and processes. One of the first steps that needs to be taken, therefore, is to develop a joint definition of PCC based on one of the existing international definitions and to explore its adaptability and usefulness for the care environment in Gipuzkoa.

In this regard, there are a number of concrete actions that could be proposed:

A. Set up a "PCC Working Group" to make a conceptual assessment of the PCC model and personalization strategies. The purpose would not be so much to validate theories and concepts, but to offer a unique model that could be taken on by provincial agents linked to care and attention within Gipuzkoa (action-oriented conceptualization). This model should be evaluable and comparable, offering a model of indicators and a monitoring strategy (evaluating outputs may be preferable to only evaluating inputs). It would be much better if these indicators were to be part of internationally proven standards.

B. Map best practice and experiences already existing in the province with regard to implementation of the PCC model and assess their degree of success, their difficulties and any innovations generated (for example, projects such as Etxean Bizi, Coexistence Units, Care Ecosystems, etc.). Compare these experiences with the conceptual model developed in order to improve operationalization of the model based on empirical evidence and territorial adaptation (learning from experimentation). Such mapping would also help in understanding how to apply the model to different areas of social policies (social exclusion, dependency, childhood, etc.) (ability to adapt/adopt the model).

C. Establish the methodology for building consensus and agreement on the PCC model and personalization strategies. The agreement should facilitate the transition towards the PCC model. Even it may not be possible to take up many dimensions of the model at present, it is necessary to agree an agenda for integrating these dimensions in the future (transition agenda for the long term).

D. Define a work agenda to address the task of conceptualizing and operationalizing the PCC model in the short term. The Think Tank can take on part of this task and ADINBERRI could be a driving force in the process (operational agenda for the short term).

b. Document sent by Teresa Martinez (return of results)

Feedback report of the results of the workshop 'What is meant by personalisation in the PCC model?'

Teresa Martínez Rodríguez 13/12/2020

1. Some remarks on Section 1. What does 'personalizing care' mean?

First of all, I had the impression (possibly incorrect) that in the conclusions document, **PERSONALIZATION is** sometimes **seen as being a synonym of PCC**. In the literature I have reviewed in recent years, at least as far as long-term care is concerned, **models that focus on PCC see it as being broader than just personalization.** Some models that develop the PCC approach in long-term care services tend to distinguish between two major and complementary dimensions: personalization of care and the environment (conditions of the environment that may be facilitators or barriers to implementation).

Personalization. This first dimension establishes the key components that define care, beginning with a vision of the individual as someone who is endowed with dignity and rights, including the right to lead a self-determined life. These components should be seen as a joint defining core. In turn, they can be formulated both as objectives of care and as defining criteria for the quality of services.

The key components most frequently mentioned in personalization are: knowledge and recognition of the person from a holistic and biographical view, promotion of their autonomy/self-determination, respectful and empowering communication, individualization and protection of their privacy. In each component, it is important to note different key actions for development, which may include attitudes, professional practices, methodologies or organizational elements which are key to its application.

Environment. This second dimension refers to the elements within the environment that facilitate personalised care. Here one might include environmental elements (physical, activity, social relations, community) and organizational elements.

Your thinking has focused on identifying the characteristics of services that would facilitate certain components of personalization. You have rightly pointed to important elements of services such as the diversity of services on offer (this would correspond to choice, a component of self-determination). You also mention service flexibility, to adapt to the needs of individuals (this would correspond to individualization). And you also refer to the adapting services to life histories (towards a biographical approach).

I think **it is important to broaden somewhat more the defining core of what care personalization means, bearing in mind that, these characteristics should also be viewed in the round, and not in isolation**. Let me give an example: if the individualisation

of care does not go hand in hand with self-determination, we end up back with classic individualised care, which is when services or care are determined for each person on an individualised basis (i.e. not uniformly for everyone), but often without the person themselves taking an active part. This is the main difference between individualized and personalized care.

If you are interested, I have sent Carlos Alfonso a number of articles that have been published on the PCC-gerontology model, which I have been working on for the last 10 years, where the aim is precisely to make PCC operational in the context of long-term care in gerontological services. This model is structured into 2 dimensions, 10 components and 50 key actions, which are in turn described from best practice, according to person-centred care. It is designed from the stance of services for the elderly but as an operative formula, it might be useful in your work. As you can see, this framework has been developed for designing services, evaluating them and also for guiding any training processes.

3) I also wanted to comment on the issue of incorporating the life history (biographical and life-continuity dimensions) into the clinical and social histories. The holistic and biographical approach is an integral part of person-centred care, but it is important to be careful when incorporating this information and perspective, and not only in terms of confidentiality and data protection issues. I think it is more helpful to highlight the importance of knowing and incorporating certain biographical elements in any comprehensive evaluations than to refer to the inclusion of life histories in computerized records. The biographical information to be disclosed and included should be commensurate with the service's mission. A life story is a constructive account made by the person of his or her own life. I believe that in the course of the intervention it should be considered as optional, to avoid the risk of the person's losing control over their own narrative, i.e. of the life story becoming just one more document.

2. Some remarks on Section 2. What resources are needed to personalise care?

You refer to a diverse range of resources that are required, especially in terms of innovation, for personalising care. I would have liked to see this section **beginning with the change in model and the need for a reflective/training/awareness-raising exercise** on two issues:

a) Looking to people receiving the care (their value, their needs viewed as capacities, their rights, etc.) is the starting point for advancing in thinking, feeling and relating within a PCC framework. If this is not done well, everything else — methodologies, supports, technologies, linked to innovation, the evaluation model, which are mere means, instruments— all collapse under their own weight.

b) Care from the position of interpersonal relationships of encounter and recognition of the other based on trust. Interventions that must be viewed from a perspective of accompanying organizations, professionals and teams, which are indispensable in this long journey.

3. Some remarks on Section 4. What actions can be implemented to promote service personalization?

Your reflection undoubtedly includes some actions of interest. I would like to refer to two issues:

a) In my opinion we should not be thinking in terms of a single PCC model for all services. Yes, it is possible to identify a common set of values, in terms of defining the approach, derived from the point of view of the people and groups receiving care/support, but in terms of defining models aimed at making PCC operational in services, I believe that it must be formulated taking into account the mission of those services. In this sense, some components and the elements of action may vary. For example, a residential centre is not the same as a temporary service with therapeutic objectives or a resource aimed at promoting social inclusion amongst younger people where access to employment may be a key element.

b) Specific evaluation of PCC is of interest for understanding and monitoring the change in model as well as for research purposes. If the aim is to evaluate the quality of the services, the assessment must be more comprehensive; PCC is one axis of quality, but it is not the only one. Comprehensiveness and safe care environments are also important. It is important to include standards and indicators that have to do both with the structure/process but (above all) with the results in terms of quality of life (health, protection of rights, wellbeing and self-determination).

4. Key elements in home care service

Finally, Javier Castro also asked me to give specific details on some key elements for personalization in home care services, since this is the topic of your next session.

The future model of long-term care suggests the need for a definitive commitment to deinstitutionalisation, to home-based support.

I think that creating a conceptual framework (PCC in dimensions and components) that makes it possible to go all the way down to operational levels (key actions) is also a valid approach for home care services. It may be useful both for identifying the components of personalised care and the enabling environment and the corresponding key actions at both a meso level

(design/organization of services) and at a more micro level, referring to accompaniment and care of people.

I would simply list some important ideas for personalization of care in home care services:

With regard to the conceptualization of home care services:

- The transition from offering standardized services to a configuration of personalized and coordinated supports for supporting the life project in the community. Diversity in services, increased eligibility and coordination (between institutional and community resources).
- A look at the family group: needs, expectations and supports.
- Connection with the local community environment.

With regard to training:

✓ Key competencies aligned to PCC (knowledge/recognition, self-determination, communication, individualization for well-being, privacy).

With regard to key methodologies:

- Case management/support coordination
- Life stories
- Preparation and development of personalised care plans based on co-participation.
- Processes of listening, support and supervision for personnel, families and people receiving care.

I hope you will find these comments useful for you as you continue this process of encounter, alignment and reflection.

c. Presentation used by the Deputy for Social Policy

PERSONALIZATION OF HOME CARE AND ATTENTION

14 December 2020

Results of the previous session

(26 November – Document No. 5)

A. Define a common **conceptual framework** of PCC model for all areas of social policy. The model must include a system of internationally validated indicators
B. Map **good practices** and existing experiences in Gipuzkoa and evaluate their degree of success, difficulty and innovations based on the PCC Model.
C. Define a working methodology **to reach consensus on the right conceptual model** based on territorial and international evidence (Gipuzkoa model).

Agenda for deliberation
(14 December)

From the centre to the home: how to de-institutionalise care centres and how to provide sufficient support at home

(CONTINUATION OF THE DISCUSSION AT THE PREVIOUS SESSION ON CUSTOMIZATION OF THE PCC MODEL)

ETORKIZUNA ERAIKIZ

International Expert
Alfonso Montero Lara
Executive Director of ESN (European Social Network)

Alfonso oversees strategic management of the European network and leads the policy programme (co-funded by the European Commission).

He has more than 12 years' experience in public policy and has authored and co-authored books and academic publications in specialist journals.

ETORKIZUNA ERAIKIZ

Next session

Territorial organisation, jurisdictional structure and inter-institutional coordination
(28 January 2021).

ETORKIZUNA ERAIKIZ

THANK YOU

d. Presentation used by Alfonso Lara

European Social Network

Social Services Network in Europe

There's no place... like home

Etorkizuna Eraikiz, Think Tank, 14 December 2020
Alfonso Lara Montero, CEO

The European Social Network is supported by the European Union

Our Network

- Independent European Network of Public Social Services
- Associations of social services directors, regional, provincial and local social services departments, inspection and investigation agencies
- Promotion of community-based and person-centred social services

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Trends

- Population aging
- Changes in family patterns
- Increased use of formal long-term care
- Combined care packages - personal budgets
- Greater user expectations

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Trends

- Very significant expansion in policy initiatives, reforms and programmes
- Not uniform across Europe
- Long-term care as a policy field in its own right

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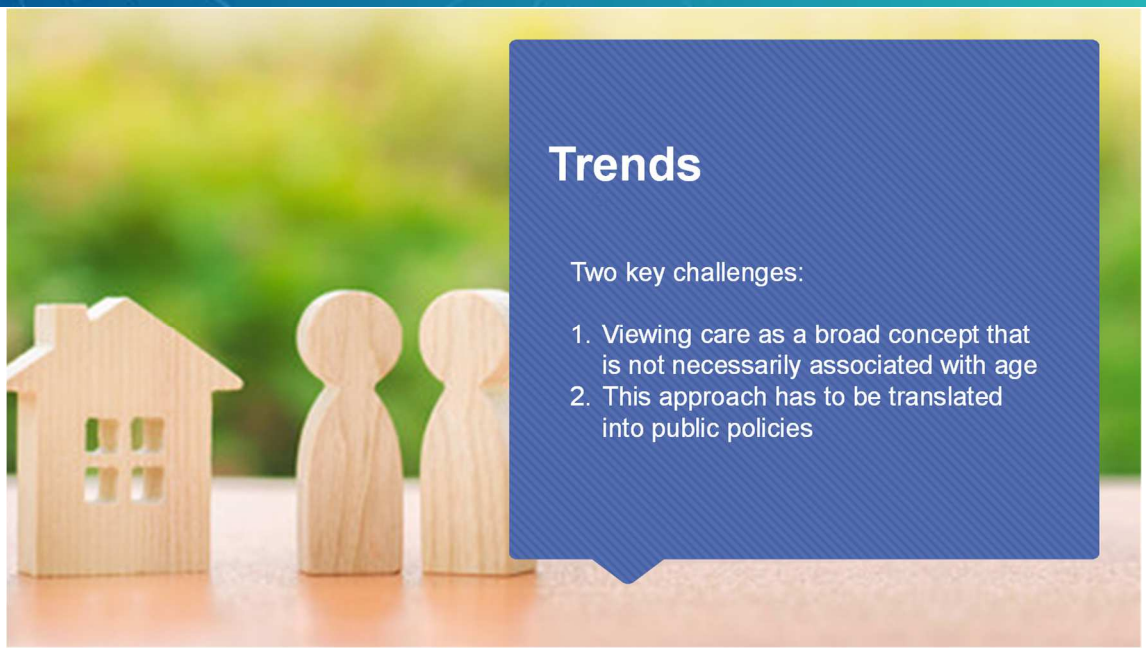
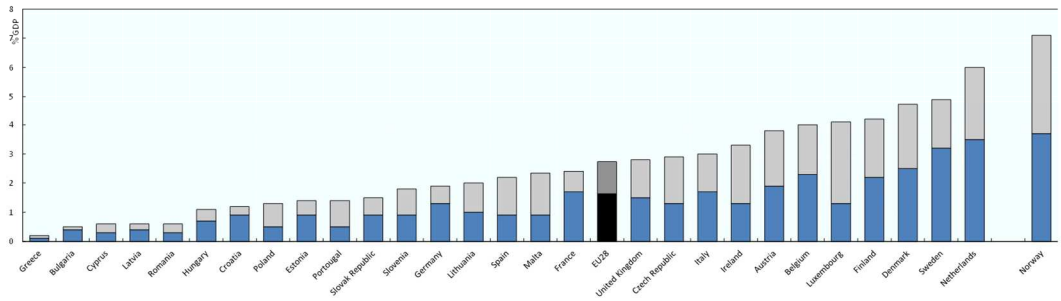


Trends

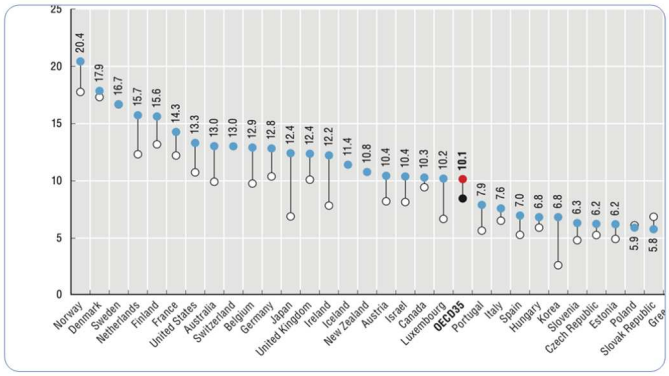
Two key challenges:

1. Viewing care as a broad concept that is not necessarily associated with age
2. This approach has to be translated into public policies

The situation in Europe



- **Public spending on long-term care as a percentage of GDP, 2016 to 2070, EC and EPC, 2018**



Share of social and health care professionals in the total labour force, 2000 to 2015, OECD 2017

The situation in Europe

The work of the European Union

- EU: Support work
- Different national powers
- Report of the Social Protection Committee

The work of the European Union

SPC Indicator Group

- Access
- Sustainability
- Quality

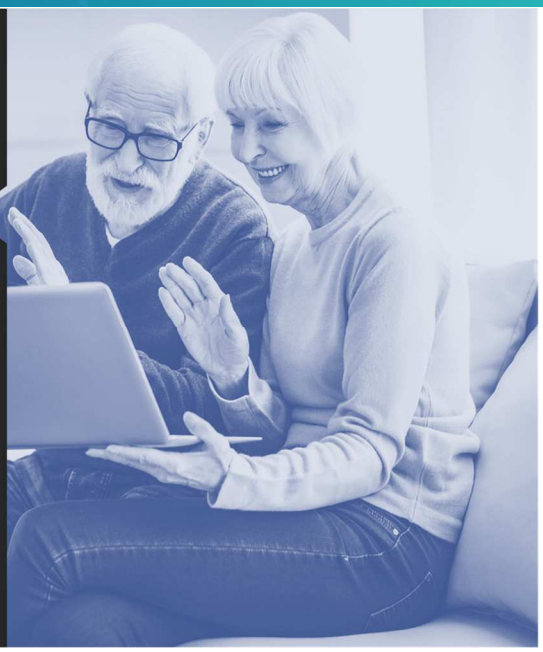
Financing

- The European Social Fund +
- Recovery & Resilience Fund and ESF+
- Specific targets and activities that can be funded
  - Staff training
  - Supporting integrated care and independent living services
  - Active and healthy ageing programmes
  - Expanding access to and coverage of long-term care

Fundamental challenge: Quality

Defining a new care model that

- is really person-centred
- is guided by the individual's free choice
- recognizes the individual's needs but also their contributions and wishes
- encourages care in the home and community
- defines the concept of quality as an improvement in people's quality of life



There's no place like home

- Reasoning: Human Rights, Economic
- Care
  - Person-centred
  - Available
  - Accessible
  - Affordable
  - Continuous
  - Results-oriented
- Care market
- New staff
- Quality criteria
  - Objective
  - Subjective

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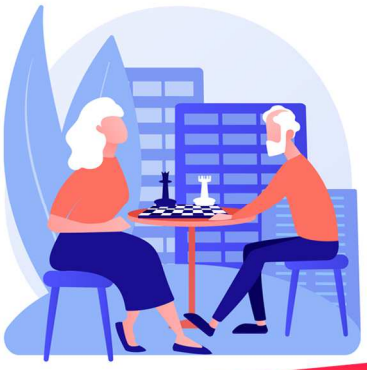
Paradigm shift

- Not associated with age
- Sustainable
- Not only social but also economic
- Takes into account the totality of life situations (ageing and disability)
- Quality framework adapted to personal and customised care
- Centred on people's quality of life



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Thank you very much

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