

European Expert Meeting "The European Care Strategy"

25 October 2023 in Berlin

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Summary of key findings

Positive impetus for care policy across all phases of life

The Care Strategy provides positive impetus in the member states to develop a more cross-career perspective on care work. Combining childcare and caring for relatives is necessary in order to relieve the burden on women and protect them from poverty in old age, as they bear the main burden of care work in both areas.

Broad approach to improving long-term care

The experts welcomed the broad approach of the European Care Strategy with the pillars of improving the quality of care services, improving working conditions in the care sector, improving the reconciliation of paid work and care responsibilities, increasing investment in the care sector and improving the evidence base for care.

Further strengthening of care for relatives in national implementation processes necessary

In the member states, there are only a few benefits and rights to which family carers are directly entitled. Member states have a duty to improve the compatibility of care and work, facilitate cooperation between professional carers and family carers, expand access to counselling and psychological support as well as respite services and provide appropriate financial support for family carers.

Combating the shortage of skilled labour and promoting mixed care arrangements

The shortage of skilled carers across Europe must be addressed at national level by increasing the attractiveness of the caring profession through higher pay and better working conditions, among other things. At the same time, from the point of view of families, the "viability" of mixed care arrangements consisting of professional, family and other informal carers must be made easier.

Create quality standards and apply them to all long-term care providers

Member States should set binding quality standards for all forms of long-term care. These should apply to all providers of long-term care, regardless of their legal form and organisation.

Strengthen prevention of care risks and health risks from caring activities

General health promotion across the entire lifespan must be expanded in order to reduce the risk of long-term care and increase the proportion of disability-free life expectancy. In addition, prevention programmes for family carers must be expanded in order to compensate for the physical and psychological strain of caring for relatives.

Develop time policies for a fairer distribution of care work

Time policy measures such as paid leave from gainful employment for childcare or caring are important measures to relieve the burden on families. They must be designed in such a way that the unequal distribution of care work and poverty risks due to care work between the sexes is alleviated in the medium term.

Provide care coordinators with sufficient resources and involve civil society.

In order for the national coordinators to successfully drive forward the implementation of the EU care strategy, they need appropriate competences and resources. This is the only way they can organise solutions across departmental boundaries and federal responsibilities with the involvement of civil society.

Background

On 7 September 2022, the European Commission adopted its European Strategy for Care and Support. Its aim is to "ensure high-quality, affordable and easily accessible care and support services across the European Union and improve the situation of both those in need of care and support and those who care for them professionally or informally".

The European Strategy for Care and Support includes both recommendations for early childhood care, education and upbringing, which envisage higher care rates in the so-called Barcelona targets, and recommendations for improving long-term care.

The AGF's European Expert Meeting 2023 focussed on the second aspect of the Care Strategy, which concerns access to affordable and high-quality long-term care. The need to develop both care for older people and care for people with disabilities was discussed. In addition, time policy aspects of ensuring care and care work for family members in need of help and care were considered.

The AGF has thus taken up two lines of its work from previous years. Firstly, it continues to accompany the discussion and national implementation of family and social policy projects of the European Union, as it has already done with the EU Compatibility Directive¹ and the European Child Guarantee². Secondly, it continues the discussion of care-related issues from the perspective of families and carers. In recent years, the AGF has already organised this debate with the European expert discussion on "Ambivalences in the support of people in need of care by foreign care workers"³ and expert discussions on "Transnational family relationships: Supporting parents and grandparents in need of help and care"⁴ and the proposals of the independent advisory board on reconciling care and work.⁵

Experts from Belgium, Germany, France, Italy, Portugal, Spain and Hungary took part in the European Expert Meeting 2023. It was held in hybrid form.

¹ https://www.ag-familie.de/media/docs18/AGF_europ_expert_meeting_WLB_0718_en_de_web.pdf

² https://www.ag-familie.de/media/docs22/DE_COFACE_AGF_Doku_ChildGuarantee_Meeting_Sept2022.pdf

³ https://www.ag-familie.de/media/docs22/Doku_DE_Europ_FG_Pflege_Sept21_WEB_Print.pdf

⁴ <https://ag-familie.de/de/bericht-zum-fachgesprach-transnationale-familienbeziehungen-unterstuetzung-hilfe-und-pflegebeduerftiger-eltern-und-grosseltern/>

⁵ https://ag-familie.de/files/AGF-Stellungnahme-Pflegebeirat_Endbericht_Juli_2023.pdf

Overview of the state of long-term care in the EU and the objectives and measures of the European Strategy for Care and Support

Georgia Casanova, INRCA Centre for Socio-Economic Research on Ageing:
The socio-economic impact of long-term care on families in Europe"



In her presentation, Georgia Casanova highlighted empirical studies on the burdens of older people and their families due to the need for care. She set the findings on the financial and social burdens against the background of care policy structures in selected European countries, their family-supporting effects and challenges for further development for the respective care systems.

She mainly referred to the results of her SEREDIPE project. The project analysed the correlations between the need for long-term care and socio-economic burdens in Italy, Spain, Germany, Austria, Romania, Poland, the Netherlands and Finland.

Georgia Casanova explained how restrictions in daily live activities in old age, disability and the need for care on the one hand and socio-economic burdens and poverty risks on the other are inter-linked. She stated that the national health and social systems which include financial benefits and care and assistance play an important role for both preventive and as ad hoc support. It is their design and accessibility that determine the poverty risk and the social inclusion potential for both carers and those in need of care.

Georgia Casanova identified three strategies for

meeting the need for care:

- a public strategy with public service support (national and local health and social systems, municipalities, etc.),
- a private strategy, which relies on the private care market, including migrant care workers,
- the family-based strategy, which is based on (in-formal) family care.

These three strategies can be found in different intensities and mixes in the countries that had been analysed. Those result in specific national care regimes. The analysis of the respective care policy shows that states mostly use cash benefits to support family carers. The beneficiaries in most countries are those in need of care (instead of the family carer). Caring relatives and other caring persons like household members or neighbours and friends usually only benefit indirectly. The amount of the cash benefit is often differentiated according to three or more levels of care needs. However, in either case this amount does not compensate for the caring time and the loss of income as a result of taking on caring responsibilities.

Georgia Casanova explained that some countries have strengthened the rights of family carers and the financial compensation for family care. These include Spain, where a support for social security costs has been introduced. Additionally there is Austria, which has adopted a so-called family carer bonus. Still there are hardly any initiatives to promote the reconciliation of family and work life.

For families in all countries quantitative studies show a close link between the need for long-term care and the risk of poverty. She highlighted, that this correlation exists across the welfare state regimes and across the respective care systems. For families that already find themselves in precarious financial situations, the case of long-term care means a serious risk of a significant financial collapse. Yet the most important factor that reduces

the risk of poverty is the availability and accessibility of public nursing and care services. However, it still needs more research on how exactly the correlations of enlarged public care system and family poverty risks works.

The expert interviews conducted as part of the SEREDIPE study confirmed that the above-mentioned "public strategy" with a broad range of care and support services is the most effective way of reducing the poverty risks of households with members in need of care. Overall, an inadequate expansion of care services and accompanying cash benefits not only entails an acute risk of poverty. It also has long-term consequences, as family carers at a later stage of life often have to deal with an insufficient pension due to the time they have been out of paid work. She stated that experts favour a welfare and care mix that combines various resources, such as relatives, neighbours, NGOs, private and public care, household and nursing services.

In conclusion, Georgia Casanova emphasised that the European long-term care strategy was addressing the right issues. The risk of poverty and lack of social inclusion due to the need for long-term care was an increasing problem today. She pointed to the trends in various countries to reduce investment in healthcare and long-term care. In addition, demographic change, with the reduction in household

sizes and the decreasing availability of informal carers, exacerbates the care problems. What would be needed instead was a significant strengthening of care services and, in particular, public respite services. At the same time, the strong gender-specific inequalities in the share of care work and the resulting poverty risks must be reduced by political measures. The expansion of social security systems for family carers could also help to reduce gender-specific differences.

Discussion

In the ensuing discussion, as one major topic was raised in regards to whether there are different effects of care on households in which persons in need of care and the carer live together opposed to multi-local families and extended support networks. It was assumed that an analysis focusing solely on care households was more likely to underestimate the poverty risk of families than an analysis focusing on the entire support network.

It was also expressed that both research on the burdens of family caring relationships and political measures should place gender inequalities at the centre of their activities. Time policy measures, such as paid care leaves, also played an important role. It was stated that this was the only way to in the medium term mitigate the unequal gender distribution of poverty risks that are driven by care work.

Dana Bachmann. European Commission: The European Care Strategy: Objectives and status of national implementation



To underline the importance of the European Care Strategy, Dana Bachmann presented some data on the need of care and the amount of care support in Europe. She pointed out that the number of people requiring long-term care would increase by 23% to 38.1 million by 2050. She also highlighted that the care needs of almost 50 % of the 65+ years persons were unmet.

On the other hand, 52 million people, most of them women, do informal care work. One of the consequences is that 7.7 million women are unable to participate in the labour market.

She highlighted that there was a major shortage of skilled labour in the professional care sector across Europe. One of six job advertisements in Europe concerned in long-term care sector. And there is enormous job growth potential as estimations show that more than 1.6 million long-term carers will be needed by 2050, only to maintain the current ratio of people in need of care to professional carers.

Under the European Care Strategy, the Commission also proposed a Council recommendation on access to affordable and high-quality long-term care (adopted by the Council in December 2022). The recommendation has a broad scope as it includes

recommendations concerning adequacy, availability and quality of care, as well as for addressing staff and skills shortages and supporting informal carers. The European Care strategy takes a lifespan perspective to care. It also stresses the need to have synergies with other policy areas and corresponding EU initiatives, for example on skills, employment, disability and healthcare, as well as gender equality.

Specific objectives for the EU member states include improving the quality of care services, improving working conditions in the care sector and supporting a better balance between work and care responsibilities. Investment in the care sector are encouraged, too.

The Council Recommendation places the dimensions of adequacy, accessibility, availability and quality at its centre. Adequacy in this context means that Member States ensure that care services are provided to the ones in need as soon as the need for care arises and that this support is provided for as long as necessary. The care and support needs must be covered, regardless of whether the needs are due to mental and/or physical frailty. Additionally, an appropriate standard of living shall be guaranteed and people shall be protected from poverty due to their long-term care needs.

Availability should be improved by increasing the quantity and quality of long-term care services. A good mix of high quality care services options enables freedom of choice for people in need of care. It is important to expand home care and community-based care and improve services in rural areas. Additionally, the use of innovative technologies and digital solutions can support enhancing the offer of care services and the independent living.

In order to improve quality, the Council Recommendation invites Member States to have in place a quality framework underpinned by quality standards fined for all forms of long-term care. These should apply to all care providers, regardless of their legal form and organisation. To achieve the desired quality of services, sufficient resources should be made

available at national, regional and local level. Quality requirements for long-term care should be taken into account in public procurement procedures, where relevant. Enabling independent living and social inclusion despite the need for care should be at the centre of quality efforts. The Council Recommendation defines a list of quality principles that should be part of the quality framework together with quality assurance arrangements.

Member states are invited to appoint a national coordinator for the implementation of the Care Strategy or have in place a national coordination mechanism. The Recommendation also invites Member States to involve relevant stakeholders. The implementation process should be supported by a framework of monitoring indicators at European Level and at national level Member States are recommended to collect relevant long-term care data, including on gaps and inequalities in long-term care provision.

A number of measures are being rolled out at EU level to support the member states in the implementation process. Those include the initiation of European sectoral social dialogue for social services, and mutual learning processes as well as international cooperation with external partners such as the WHO and the OECD. The EU will also provide funding to improve long-term care, including ESF+ and other sources. In the area of monitoring, a task force has been set up by ESTAT to improve the LTC data availability.

The EU is also supporting a stakeholder driven large scale partnerships under the Pact for Skills with a focus on the long-term care sector. This brings together providers of long-term care services, social partners and providers of education and training to form a large-scale skills partnership for the long-term care sector with strong commitments for the training of the LTC workforce with a focus on digital skills and person centered care.

Discussion

During the discussion, questions were raised about the funds made available by the EU for the implementation of the Care Strategy. In addition to the aforementioned ESF+ funding for the 2021 to 2027 programming period, the technical support instrument can mobilise expertise for helping Member States design reforms in the field of long-term care, including for set up of integrated person centered care systems. This could include strategic or technical advice, studies to assess the feasibility of reforms.

Furthermore, the indicator-based monitoring of the implementation process is of great importance. To this end, the Commission is working together with Member States (in the Indicators Sub-Group of the Social protection Committee) to define a framework of indicators addressing the different dimensions of the Council Recommendation. There is a challenge to establish at European level outcome-oriented indicators on the situation of people in need of care and their carers.

Comments from European civil society organisations - Care across the lifespan - Does the care strategy approach make sense?

Camille Roux, COFACE Families Europe



Camille Roux began by explaining the work of COFACE Families Europe. COFACE is committed to the well-being, health and safety of all families and all family members. Its topics include gender equality, social rights, employment, work-life balance and energy poverty. COFACE works on many issues that are affected by the care strategy, but in her comments, she would mainly take the perspective of gender and disability as this was her main field of responsibility at COFACE.

COFACE and its Disability Platform immediately welcomed the adoption of the European Care Strategy, in particular because of important points:

- The definition of people with care needs includes disabled people, and the definition of informal carers also mentions children in need of care.
- The commitment to transition to community-based and home-based care promotes integration and respect for human rights.
- The strategy focuses strongly on gender equality and its mainstreaming, given that around 80% of informal carers are women.

- The strategy sees care as a task for society as a whole and not just as a task for family solidarity. It recognises and supports family carers as it has the awareness that the current system is not sustainable.

To COFACE the Care Strategy recommendation is central that the Member States introduce clear procedures to identify informal carers and support them by:

(a) facilitating their co-operation with long-term care professionals

(b) supporting them in accessing the necessary training. This includes the areas of health and safety at work, counselling, healthcare, psychological support and respite care, and reconciling job and caring responsibilities

(c) providing them with access to social protection and/or adequate financial support while taking care that such support measures do not discourage participation in the labour market.

The care strategy defines informal care as long-term care that is provided either by a relative or by an informal carer from the social environment. However, COFACE favours the term "family carers", as it is estimated that 92% of informal carers are family members.

When organising support for family carers, the effects over the entire lifespan of those in need of care and informal carers must be taken into account.

It is important to understand what needs to be considered when identifying family carers in order to build up support:

- age - at what point in life does the person enter a long-term care relationship?
- gender

- the relationship between the family carer and the receiving person, and
- the origin of the need for care.

It is important to see all of these factors in context, as they influence each other. Additionally, they may have different effect. For instance, the needs of a working carer are not the same as those of a retired carer or a young carer.

The lack of data is currently a major problem when it comes to identifying family carers. It is positive that the care strategy provides for concrete measures to solve this problem.

The available data showed a gender imbalance: For instance in the case of care by spouses in old age,

the distribution between men and women was almost equal. However, the proportion of women caring for a child was three times as high.

Conclusion: When it comes to informal carers, the lifespan approach of the care strategy makes sense and should be incorporated into the development of implementation measures to identify and support informal carers.

The overall picture should take into account additional factors, such as the type of relationship, the type of care needs and gender, in order to offer targeted measures. In addition, new data on the situation in informal family caring relationships should be collected as soon as possible.

Phillippe Seidel, AGE Platform Europe



Phillippe Seidel represented AGE Platform Europe, the largest European network of organisations by and for older people. The aim of AGE is to give a voice to the experiences and wishes of older people in the European Union and to raise awareness of ageing issues.

AGE's vision for care provision is based on core human rights principles and envisages ambitious changes in policy, services and social attitudes. The high quality organisation of care services is central when ensuring that older people can participate in society despite health and functional limitations.

AGE's vision for change is based on the results of "Rethinking Care", a process conducted with AGE members in 2021. AGE is committed to care systems that enable people at all stages of life to participate in society and support their autonomy: Care systems must ensure that elderly people can be part of society as equal and fully-fledged citizens.

However, he identified current deficits in access, affordability and, above all, the quality of long-term care in Europe:

- Ageism is widespread in our society and this is reflected in the nature of care and support services. According to the World Health Organisation (WHO), ageism refers to stereotypes (how we think), prejudices (how we feel) and discrimination (how we act) that are directed against people because of their age.
- Long-term care services are too often of poor quality and older people too often see their dignity jeopardised.
- Long-term care for older people is often treated as a secondary issue in public debates and political measures.

- A paternalistic culture in care services leads to older people being patronised. The care preferences and decisions of older people are not always respected.

These deficits have various causes:

Segregation: In care policy and care services, older people tend to be treated as a segregated group that does not have the same right to equality and inclusion as everyone else.

Organisational issues: Poor care is often characterised by a lack of coordination between services. Older people who require care often receive inadequate or inappropriate care.

Difficult working conditions: Nursing staff face difficult working conditions, including low wages, a lack of training and high workloads.

Incorrect treatment: Care services could worsen the health of the people who use them. Prevention and rehabilitation are weak or non-existent. There are situations that have to be categorised as abusive.

The existing problems of long-term care had become more apparent during the COVID pandemic, when preventable deaths, infections, lack of medical assistance, lack of protective equipment, forced isolation, etc. occurred.

The focus of the EU care strategy on the aspects of affordability, accessibility, quality and the situation of the labour force are positive. The Council's recommendation contain helpful quality principles. However, those still need to be put into practice: respect, prevention, person-centredness, continuity, orientation on results and transparency are important principles for the implementation process.

The instruments provided in the EU care strategy for funding (e.g. ESF+, Cohesion Fund), mutual learning and monitoring should now be taken up by the member states. The national care coordinators have a key role to play in the national implementation processes and need to be equipped with the necessary competences and resources.

Implications of the European Strategy for Care and Support for German care policy

Dr Nils Dahl, German Federal Ministry of Health



In his presentation, Nils Dahl showed the latest data on the age structure of the German population and illustrated the expected increase in the number of people in need of care of potential carers. He referred to long-term care insurance being the “fifth pillar” of social insurance in Germany and being an established collective cover for the risk of long-term care. In Germany, long-term care insurance is compulsory (73.5 million statutory insured persons and 9.2 million privately insured persons). The central benefits of long-term care insurance are designed as partial benefits, so that not all costs are covered. The remaining costs are covered by the person in need of care. However, the tax-financed social assistance system helps people with low incomes (315,000 people in Dec. 2021).

He explained that the German law on long-term care insurance defines the general provision of nursing care as a task for society as a whole: The federal states, the municipalities, the care facilities and the long-term care insurance funds work closely together with the involvement of the Medical Service to ensure efficient, regionally organised, local and coordinated outpatient and inpatient care for the population. He continued, that it was the Insurance funds obligation to guarantee needs-based and uniform nursing care in accordance with the current

state of medical and nursing knowledge. The federal states are responsible for the nursing care structure. The law also stipulates that long-term care insurance should primarily support home care and the willingness of relatives and neighbours to provide care. By this it should be supported that those in need of care can remain in their home environment for as long as possible. Against this backdrop, the people in need of care and their families take an important responsibility for the functioning of the overall care provision.

At the end of 2021, there were 4.9 million persons receiving benefits by the German long-term care insurance, of whom 4.0 million (82%) were cared for in home environment. 2.8 million received informal care only and 1.2 million received professional care to at least some extent. There were 15,376 outpatient care services with 442,860 employees. In inpatient care, there were 16,115 facilities with 814,042 employees (BMG 2023, Destatis 2021).

The German government has welcomed the European Commission's initiative for a European Care Strategy and has actively participated in the development of the Council Recommendation on access to affordable and high-quality long-term care. Dahl pointed out that in order to continue to keep long-term care appropriate, affordable and accessible despite the existing challenges, the current federal government has introduced a number of improvements. From 1 January 2024, the monetary care allowance and benefits in kind for outpatient care services will increase by 5%. In 2025, there will be a 4.5% increase in all care benefits. On 1 July 2025, the “joint annual amount for respite care and short-term care” will be introduced, which can be used for both monetary and benefits in kind flexibly according to individual needs. The next increase in care benefits has been set for 2028.

In addition, the government started implementing measures for improving working conditions in the care sector, for example by better pay, more staff and the recruitment of carers from third countries.

There would also be measures to improve training and further education as well as funding programs to relieve the burden on nursing staff through more digitalisation and an improved work-life balance. Since 2022, all care facilities must pay their employees wages at the level of a (regional) collective agreement. Since 1 July 2023, full inpatient care facilities have also been able to agree significantly higher staffing levels for nursing and care staff than before on the basis of standardised national staffing levels. As a result of legal changes, so-called standby pools (also across organisations) and other company contingency plans in long-term care could now also be financed on a regular basis to help out in cases of staff shortages.

Dahl stated that the German government has set guidelines for the recruitment of nursing staff from third countries to ensure high ethical standards. The procedures for the recognition of education are to be further standardised and simplified.

He stated that the financial sustainability of long-term care insurance was another important aspect. Long-term care insurance expenditure has risen due to high COVID-related costs and to the increase in the number of long-term care insurance beneficiaries (demographic change). Since 1 July 2023, the contribution rate of the care insurance was increased by 0.35 percentage points, which means an additional revenue of around 6.6 billion euros per year. Taxed based Federal funds are used to deal with current crises (COVID, energy costs). The Ministry of Health will draw up recommendations for the sustainable financing of long-term care insurance by the end of May 2024.

Discussion of specific aspects of the Care Strategy and assessment of the current status

In the afternoon, specific topics of the Care Strategy and specific country perspectives were discussed.

Country-specific notes

Georgia Casanova from the INRCA Centre for Socio-Economic Research on Ageing reported on the current Italian care reform, which is due to be passed in 2024 after 25 years of debate. The main focus of the reform is the introduction of a new cash benefit, the so-called "prestazione universale" (PU).

It is a benefit for people older than 80 years who need financial support due to a need for care while having low income. The aim is to ensure that these people can continue to receive home care. The new measure provides for financial subsidies and is differentiated in different degrees of care need.

People in need of care could choose between cash benefits and/or payment for care or home services. The new PU incentivises greater use of services, as those allowances will be higher than the amounts of cash benefits.

The approach of the Italian reform would therefore correspond in many respects to the cornerstones of the EU Care Strategy.

However, the reform lacks concrete approaches to increase the situation of family carers. The reform does not envisage any direct measures for informal carers. Positive effects are mainly to be expected by indirect support. Neither there are any contributions to the social insurance systems for family carers, which would help reducing the risk of poverty later on.

Georgia Casanova informed that the requirements of the EU Care Strategy to introduce clear procedures for identifying informal carers and supporting them have not been sufficient in the Italian case to ensure a significant direct improvement in the situation of family carers in the current political reform process.

She added that in addition to improving working conditions in the long-term care sector, it is also necessary to support family carers. This requires improved coordination between professional carers and informal carers. In addition, training, counselling, healthcare and psychological support for family

carers need to be expanded. For Italy she stated a lack in services such as respite care as well as in adequate financial support.

In her contribution, **Lía Barrese from the Barcelona Time Use Initiative (TUI)** pointed out the time policy aspects of the discussion on the EU Care Strategy and in regards to the support of family carers. At present, caring for relatives leads to great time pressure for carers (of which most are women) who have to reconcile the conflicting demands of work and family. Growing time conflicts, demographic change and the shortage of skilled labour in the care professions are some of the drivers of the current care crisis, which will in future times exacerbate the care gaps in families in general and in the elderly care specifically.

This is where the proposals of the Time Use Initiative come in. They see time policy as an instrument for changing the social organisation of time. The focus is on aligning social time patterns and the care infrastructure more closely with people's needs. The aim is to promote the health of family carers and a more gender-equitable distribution of care work through a better time policy.

She explained that based on the "Barcelona Declaration On Time Policies", specific recommendations for time policy measures have been formulated for Spain. They aim at actors on local level, the Spanish autonomous regions and at the Spanish national level. However, these do not only aim on the organisation of care, but also include a broad spectrum of the social organisation of time. Parts of the recommendations have already been taken up in the latest Spanish legislation and implemented at various federal levels.

In addition to the implementation of specific time policy measures, she highlighted the need to re-balance the assessment of paid work and care work and to achieve a comprehensive social appreciation of family and professional care work.

Care Strategy and families with disabled members

One in-depth topic was the consideration of the perspective of people with disabilities who are dependent on long-term care and support within the Care Strategy. **Jorge Falcato**, President of the Independent Living Centre, Lisbon, and **Elisabeth Lammers**, Vice President of the French parents, specialist and sponsoring association Unapei, provided input on this topic.

The Independent Living Centre in Lisbon, Portugal, is a non-profit organisation supporting people with disabilities to lead self-determined and independent lives. The centre offers a variety of services and resources, including information, training, support and technical aids to improve the independence and quality of life of people with disabilities. The French network Unapei is a national advocate for the rights and well-being of people with intellectual disabilities and their families. The organisation also provides support, education, employment opportunities and social integration for people with intellectual disabilities.

Elisabeth Lammers emphasised that the Care Strategy offers starting points to enable people with disabilities to live more independently and have a fulfilling life. This includes freedom of choice, financial resource allocation and participatory research. Families need support to ensure equal opportunities.

Professionals should receive higher salaries and an authentic training system should be developed. Investment in training programmes is also necessary to meet needs.

With regard to care and support services, bureaucratic hurdles should be removed to enable individual decisions. Additionally, families should be involved in decision-making processes. She added, that the Care Strategy not only takes into account the care of older people, but also starts at the birth of children with disabilities and thus addresses the specific long-life care tasks that have to be carried out in some families over two generations or more

Jorge Falcato focussed on the weaknesses of the Care Strategy for people with disabilities. He argued that the Care Strategy and its national implementation must do better in placing the rights and social participation of people with disabilities at the centre. In its current form, the people are addressed too much as objects to be cared for and not as subjects.

However, the starting point must be the right to self-determination of people with disabilities. The Care Strategy must help to develop a range of care and support options that enable to make free decisions about the own living and support arrangements. The focus should be on individual support rather than paternalistic care. While the Care Strategy offers some starting points for improving care systems, he sees a need to broaden the perspective on



people in need of care, who need to be seen more as the subjects of their lives and supported in this role.

Different positions were highlighted in the discussion about the importance of inpatient facilities. Jorge Falcato criticised care homes due to their institutionalisation, lack of self-determination, stigmatisation and impeded social participation, among other things. He called for alternative models that enable more autonomy and social integration. Elisabeth Lammers saw inpatient nursing and care facilities as a suitable form of living for certain groups. She referred to the ongoing development of facilities to become smaller and clearer and increasingly take into account the right to self-determination of their residents.

Mixed care arrangements

The participants recognized that many member states are currently focusing on the promotion/enabling of mixed care arrangements consisting of formal, family and informal care. This was a social care policy trend to be found regardless of the type of welfare state. The reasons for this were primarily seen in the Europe-wide shortage of skilled labour in the care sector. However, it was stated that the initial situations with regard to the burdens of female family members were different. The participants noted that there was a need for high quality cooperation and flexibility within formal care and respite services when being part of a mixed care arrangements. In addition, to be successful those care arrangements require well-developed counselling services. Those were needed to create non-discriminatory access to formal care services and also to support coordination between formal and family carers. In some countries this was not sufficiently provided. In addition, there often was a lack of short-term care and day and night care services. Worries were expressed that in some countries this could lead to a refamiliarisation of care and a permanent overburdening of families.

Prevention of the need for care

The participants agreed that prevention must be strengthened throughout Europe. This includes a general health approach across the entire lifespan,

which aims ensuring that disability-free life expectancy largely increases. Second, specific prevention programmes for family carers also need to be expanded in order to compensate for the physical and psychological stresses. This would have the additional impact to mitigate the risk of care need of the family carers themselves, which originates of the informal care work. I was additionally mentioned that the Care Strategy and in the national implementation processes should address this topic better.

The potential of digitalisation

When assessing the potential of digitalisation in care, there was no uniform picture. For family carers, digital communication plays an important role in providing long distance care in order to maintain contact between family members and those in need of care. Additionally, digital communication channels plays an important role in the organisation of distance care, especially in regards to coordinate various stakeholders in the care arrangement. Also, greater efficiency gains in formal care and support services were seen due to digital planning and deployment tools. However, scepticism was expressed as to whether digitalisation can compensate for the increasing problems of the shortage of skilled workers and the decline in informal care potential.

Live-in care

Many families face large problems in meeting the care and support needs of their relatives by the existing formal services and family care. Therefore Families increasingly make use of “live-ins” or “24-hour care arrangements” in some countries. However, the situation of care workers in those arrangements often is precarious. Even when there is a legal basis, the employment relationships often remain problematic in practice and below the usual labour law standards in the country. Some countries have a high proportion of informal care workers. The European Care Strategy was seen as a possible framework for putting the topic of live-in care on the agenda of the member states and strengthening the social discussion on a fair organisation of professional care migration. It was highlighted that this discussion must take equal account of the perspectives and interests of those in need of care and care workers and their respective families.

Migration and care

It was pointed out that the topic of transnational care, i.e. the care of relatives across national borders, is becoming increasingly important due to the growing migration. Here, too, the activities surrounding the EU Care Strategy could provide a platform to shed more light on this phenomenon, which has been little researched to date.

Evaluation of the Care Strategy

The positive impetus of the care strategy to develop a life span perspective on care was emphasised. The combination of childcare and caring for relatives corresponds to the realities in families, in which it is predominantly women who take on the main burden of care in both areas. However, the social policies of the EU member states have so far included only a few life span approaches to care. Neither the social policy structures are organised accordingly, nor are there comprehensive overall time policy strategies. The care strategy is therefore an important document, not only with regard to the improvements in the areas of childcare and long-term care, but also because of the life span and cross-family suggestions.

There was no uniform picture among the participants on a general assessment of the political impact of the European Care Strategy on national long-term care policies. It was generally acknowledged that the Care Strategy addresses the right factors for improving the quality of long-term care. The overarching consideration of the situation of those in need of care, the care system, professional carers, family carers and the extended support network is a good approach. However, it is already apparent that the member states attach very different levels of importance to the long-term care strategy for the further development of their own long-term care policies. It is important to create transparency about the care situation in the countries through well-functioning transnational monitoring. Ultimately, however, it is the responsibility of the member states to prioritise the issue of long-term care.

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