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Naše obavy z nesúladu medzi Dohovorom OSN o právach osôb so zdravotným postihnutím a Európskou stratégiou starostlivosti

Milá pani Komisárka pre osoby so zdravotným postihnutím, Zuzana Stavrovská,

Európska komisia 7. septembra 2022 zverejnila Európsku stratégiu starostlivosti, v ktorej navrhla odporúčanie Rady o dlhodobej starostlivosti a o Revízii Barcelonských cieľov v oblasti vzdelávania a starostlivosti v ranom detstve.

Spolu s členom Európskej siete pre nezávislý život v Slovenskej republike, Petrou Halmešovou, sme preskúmali návrhy Komisie a zistili sme, že sú zamerané na osoby so zdravotným postihnutím bez zohľadnenia Dohovoru OSN o právach osôb so zdravotným postihnutím.

Keďže EÚ je zmluvnou stranou Dohovoru OSN o právach osôb so zdravotným postihnutím, musí dodržiavať svoje záväzky vyplývajúce z Dohovoru. Na tento účel potrebujeme Európsku stratégiu starostlivosti s jednoznačným záväzkom deinštitucionalizácie, podporných služieb v komunite a najmä osobnej asistencie.

Pomôžte nám, prosím, vniesť tento pohľad do navrhovaných odporúčaní Rady. Na podporu vašej práce v Rade EÚ sme vypracovali komplexný súbor pozmeňujúcich a doplňujúcich návrhov, v ktorých sme načrtli návrh zmien, aby bola Európska stratégia starostlivosti plne v súlade s Dohovorom OSN o právach osôb so zdravotným postihnutím. Zatiaľ čo odporúčanie Rady o vzdelávaní v ranom detstve z nášho pohľadu vyžaduje len mierne úpravy, odporúčanie o dlhodobej starostlivosti vyžaduje zásadnejšie úpravy. Sme pripravení stretnúť sa s vami alebo s členom vášho tímu, aby sme podrobnejšie prejednali potrebné zmeny Európskej stratégie starostlivosti.

S pozdravom,

Ines Bulic Cojocariu

Riaditeľ Európskej siete pre nezávislý život

Petra Halmešová

Individuálny člen ENIL v Slovenskej republike

Európska sieť pre nezávislý život - ENIL je celoeurópska sieť ľudí so zdravotným postihnutím, ktorá má členov v celej Európe. ENIL je fórum pre všetkých ľudí so zdravotným postihnutím, organizácie nezávislého života a ich spojencov, ktorí nie sú zdravotne postihnutí, v otázkach nezávislého života. ENIL zastupuje hnutie zdravotne postihnutých za ľudské práva a sociálne začlenenie založené na solidarite, vzájomnej podpore, deinštitucionalizácii, demokracii, sebaprezentácii, krížovom postihnutí a sebaurčení. Viac informácií je k dispozícii na: www.enil.eu

Úplné vyhlásenie o európskej stratégii starostlivosti bolo uverejnené na našej webovej stránke v angličtine.

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**Amendments of the European Network on Independent Living**

to the Proposal for a COUNCIL RECOMMENDATION on access to affordable high-quality long-term care

**COM(2022) 441 final**
2022/0264 (NLE)

**When the European Union became state party to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in December 2010 this was a historic moment. Due to this commitment, all EU policies and initiatives on disability must be aligned with the UNCRPD. In September 2022, the European Commission proposed a European Care Strategy. In the context of this strategy, the Commission proposed a Council recommendation on long-term care, including disability. Our analysis showed that the proposed Council recommendation is not aligned with the UNCRPD. Since the adoption of the UNCRPD by the UN General Assembly, the official monitoring body for the Convention, the Committee on the Rights of Persons with Disabilities (CRPD), has published authoritative sources on the interpretation of the UNCRPD. Recital 6 of the proposed Council recommendation states that the present document shall be fully in line with the UNCRPD. In order to bring the Commission proposal in line with the UNCRPD, the sources by the CRPD need to be fully incorporated. These sources involve the General Comments, especially General Comment no 5 and the Guidelines on Deinstitutionalisation, including in emergencies. Through the amendments suggested in this document, the European Network on Independent Living makes concrete proposals on how to incorporate the mentioned sources and achieve UNCRPD alignment.**

| **Amendment 1** | |
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| **Title** | |
| *Text proposed by the Commission* | *Amendments* |
| Proposal for a | Proposal for a |
| COUNCIL RECOMMENDATION | COUNCIL RECOMMENDATION |
| on access to affordable high-quality long-term care | on access to affordable high-quality long-term care ***and disability support services*** |
| **Explanation:** The Commission draft mixes together various groups in need of support such as older people and disabled people. In the context of disability the term “care” represents the medical model of disability, turning disabled people into passive recipients of care, subject to professional authority. Art. 19 of the UNCPRD, CRPD General Comment no 5 and the CRPD Guidelines on Deinstitutionalisation as well as principle 17 of the European Pillar of Social Rights codify the right to support services to enable full participation in all areas of life, such as living in an own apartment, going to work, having a family, enjoying leisure activities anytime this is desired. | |
| **Amendment 2** | |

| Recital 1 | |
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| ***Text proposed by the Commission*** | ***Amendments*** |
| (1) Accessible, affordable and high-quality long-term care allows people in need of care to maintain autonomy for as long as possible and live in dignity. It helps to protect human rights, promote social progress and solidarity between generations, combat social exclusion and discrimination and can contribute to the creation of jobs. | (1) Accessible, affordable and high-quality long-term care ***and disability support services*** allow people in need of care ***and support*** to enjoy full participation in all areas of life ~~maintain autonomy for as long as possible~~ and to live in dignity. It helps to protect human rights, promote social progress and solidarity between generations, combat social exclusion and discrimination and can contribute to the creation of jobs. |
| **Explanation:** See explanation to amendment 1. | |
| **Amendment 3** | |
| **Recital 3** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (3) Long-term care services organised by public authorities, at national, regional or local levels, are primarily considered as social services of general interest as they have a clear social function. They facilitate social inclusion and safeguard fundamental rights of older people, complement and support the role of families in caring for the oldest members of society, and provide, among others, assistance for people in permanent or temporary need for care. | (3) Long-term care ***and disability support services*** organised by public authorities, at national, regional or local levels, are primarily considered as social services of general interest as they have a clear social function. They facilitate social inclusion and safeguard fundamental rights of older people ***and disabled people***, ~~complement and support the role of families in caring for the oldest members of society,~~ and provide, among others, assistance for people in permanent or temporary need for care ***or support***. |
| **Explanation:** Disabled people might have needs for support to fully participate in all areas of life (see explanation to amendment 1). Care keeps disabled people with support needs in a position of passivity. The task of supporting disabled people should not exclusively be assigned to family members, but Personal Assistants, paid for by the state, and other community support services as listed in the Guidelines on Deinstitutionalisation. | |
| **Amendment 4** | |
| **Recital 6 (new)** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| | ***(6) In 2023 the European Commission will issue guidance to member states on Independent Living*** |

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| | ***of disabled people and inclusion in the community. This initiative is developed under the framework of the European Strategy on the Rights of Persons with Disability (ESRPD). Any initiative developed under the ESRPD, which is the Union´s main framework on disability rights policy, has to take precedence over the principles laid out in the present recommendation on longterm care and disability support services.*** |
| **Explanation:** The ESRPD is the European Union´s main framework on all matters concerning disability policy. To avoid legal confusion it must be clearly stated that all materials, guidance, definitions and rules developed under der ESRPD take precedence. Otherwise the Union risks having conflicting policies in place. | |
| **Amendment 5** | |
| **Recital 6** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (6) This Recommendation respects the United Nations Convention on the Rights of Persons with Disabilities , which recognises the equal right of all persons with disabilities to live independently in the community, with choices equal to others. | (6) This Recommendation respects the United Nations Convention on the Rights of Persons with Disabilities, which recognises the equal right of all persons with disabilities to live independently in the community, with choices equal to others. ***This recommendation accepts the CRPD Committee's General Comments and Guidelines, as well as reports published by the UN Special Rapporteur on the rights of persons with disabilities as authoritative sources on the interpretation of the UNCRPD. The content of this recommendation needs to be fully aligned with these sources.*** |
| **Explanation:** The publications of the CRPD such as the General Comments and the guidelines on DI are authoritative sources on the interpretation of the UNCRPD. Following the UNCRPD is inseparably linked to following the General Comments and the DI guidelines. The EU is state party to the UNRPD and as such obliged to apply the rules following from these sources. | |
| **Amendment 6** | |
| **Recital 12** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (12) Relying heavily on informal care will not be sustainable and formal care needs and pressure on public budgets are expected to increase. | (12) Relying heavily on informal care ***and support*** will not be sustainable and formal care needs and pressure on public budgets are expected to increase. |
| See explanation to amendment 1. | |
| **Amendment 7** | |

| Recital 13 | |
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| ***Text proposed by the Commission*** | ***Amendment*** |
| (13) Social protection coverage for long-term care is limited and costs often represent a serious barrier to accessing long-term care. For many households, financial reasons are at the top for not using (more) professional home-care services. Without adequate social protection, the estimated total costs of long-term care can often exceed a person's income. While arrangements of social protection vary across Member States, in some, public support is available only to a small proportion of people with longterm care needs. Even when available, social protection is often insufficient, as even after receiving support, on average, nearly half of older people with long-term care needs are estimated to be below the poverty threshold after meeting the out-of-pocket costs of home care. | (13) Social protection coverage for long-term care ***and disability support services such as Personal Assistance*** is limited and costs often represent a serious barrier to accessing long-term care ***and disability support services***. For many households, financial reasons are at the top for not using (more) professional home-care services. Without adequate social protection, the estimated total costs of long-term care ***and disability support services*** can often exceed a person's income. While arrangements of social protection vary across Member States, in some, public support is available only to a small proportion of people *in need of longterm care and/or disability support services.* ~~with longterm care needs~~. Even when available, social protection is often insufficient, as even after receiving support, on average, nearly half of older people with long-term care needs are estimated to be below the poverty threshold after meeting the out-of-pocket costs of home care. |
| See explanation to amendment 1. | |
| **Amendment 8** | |
| **Recital 14** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (14) Many people cannot access the long-term care they need due to an overall low offer of services and, among other reasons, to the limited range of long-term care options and territorial gaps. In many Member States, the choice of long-term care is limited. Where there is a choice, it is mainly between informal care and residential care. The supply of home and community-based long-term care is still low. In addition, territorial disparities in long-term care provision makes equal access to long-term care difficult, especially in rural and depopulating areas. The choice is even more limited for persons with disabilities due to uneven accessibility of care services. | (14) Many people cannot access the long-term care ***and disability support services*** they need due to an overall low offer of services and, among other reasons, to the limited range of long-term care ***and disability support*** options and territorial gaps. In many Member States, the choice of long-term care ***and disability support*** is limited. Where there is a choice, it is mainly between informal care and residential care. ***Residential care settings for persons with disabilities and older people are not compliant with the UNCRPD, and must not receive public or private funding. State parties are obliged to implement the process of deinstitutionalisation, that is the closure of all residential settings, such as nursing homes, long-term psychiatric hospitals, orphanages or social care institutions within*** |

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| | ***short time frames.*** The supply of home and community-based ***support services*** ~~long-term care~~ is still low. ***Community-based support services involve Personal Assistance, peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, provision of assistive technology, support in securing housing and household help, access to mainstream services such as education, employment, justice systems and health care.*** In addition, territorial disparities in long-term care provision makes equal access to long-term care difficult, especially in rural and depopulating areas. The choice is even more limited for persons with disabilities due to uneven accessibility of care services. |
| **Explanation:** The UNCRPD, General Comment no 5 and the Guidelines on Deinstitutionalisation oblige state parties to deinstitutionalize disability care facilities and provide support services. To be aligned with the UNCRPD this recommendation must commit to deinstitutionalization. The CRPD Guidelines on Deinstitutionalisation list the most important Community based support services. To be aligned with the UNCRPD this recommendation must commitment to the provision of these services. | |
| **Amendment 9** | |
| **Recital 15** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (15) In long-term care, quality depends on an effective quality assurance mechanism, which in many Member States is lacking or is under-resourced. Quality assurance is often insufficient in home and community-based care. While quality of residential care is more regulated, quality standards often focus on clinical outcomes and do not address sufficiently the quality of life of people receiving care and their ability to live independently. Even when quality standards are in place, their enforcement is not always effective, often due to inadequate administrative set-up or lack of resources. Lack of high quality standards applied strictly to both public and private care providers leads to situations of neglect and abuse of care recipients and poor working conditions for carers. | (15) In long-term care ***and disability support***, quality depends on an effective quality assurance mechanism, which in many Member States is lacking or is under-resourced. Quality assurance is often insufficient in home and community-based support ~~***care***~~. ***Under the UNCRPD, State parties are obliged to adopt strategies or plans of actions on deinstitutionalisation, involving clear commitment to the closure of all residential facilities as a matter of priority. Deinstitutionalisation strategies have to involve independent monitoring mechanism with adequate political and administrative authority to ensure deinstitutionalisation is implemented across all governmental departments and public authorities.*** ~~While quality of residential care is more regulated, quality standards often focus on clinical outcomes and do not address sufficiently the quality of life of people receiving care and their ability to live independently.~~ Even when quality standards are in place, their enforcement is not always effective, |

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| | often due to inadequate administrative set-up or lack of resources. Lack of high quality standards applied strictly to both public and private care providers leads to situations of neglect and abuse of care recipients ***or people with disability under the assistance of this care providers*** and poor working conditions for carers. |
| Explanation: General Comment no 5 and the Guidelines on Deinstitutionalisation state the obligation to adopt strategies or plans of action on deinstitutionalization and contain clear definitions and descriptions on what those strategies entail. Neither the EU nor the member states currently have adequate deinstitutionalization strategies in place. To live-up to the obligations stemming from the UNCRPD as promised in recital 6, the Council recommendation on long-term care and disability support should contain a clear commitment to adopting such documents. | |
| **Amendment 10** | |
| **Recital 17** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (17) The skills required in the care sector are increasingly complex. In addition to traditional skills and competences, carers often need to have technological expertise related to using new technologies, digital skills and communication skills, often in a foreign language, and skills to handle complex needs and work in multidisciplinary teams. Without appropriate education and training policies, including on-the-job, the skills requirements can act for many as a barrier to enter or progress further in the sector. | (17) The skills required in the care ***and disability support*** sector are increasingly complex. In addition to traditional skills and competences, carers ***and supporters*** often need to have technological expertise related to using new technologies, digital skills and communication skills, often in a foreign language, and skills to handle complex needs and work in multidisciplinary teams. Without appropriate education and training policies, including on-the-job, the skills requirements can act for many as a barrier to enter or progress further in the sector. ***The precondition for living independently and being included in the community is access to Personal Assistance. Personal Assistants provide needs based support to persons with disabilites in all areas of life. Personal Assistance involves a one to one relationship between the person with disabilities and the assistant, in which the person with disabilities recruits, trains and supervises the assistant. The right to train the assistant oneself with the skills desired is an imperative feature of Personal Assistance.*** |
| **Explanation:** General Comment no 5 and the Guidelines on Deinstitutionalisation clearly outline the right of disabled people to train their Personal Assistants as they wish. | |
| **Amendment 11** | |
| **Article 8** | |

| *Text proposed by the Commission* | *Amendment* |
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| (18) Long-term care workers often experience non-standard work arrangements, irregular working hours, shift work, physical or mental strains and low wages. Low coverage of long-term care workers by collective agreements and limited public expenditure in long-term care contribute to low wages in the sector. | (18) Long-term care ***and disability support*** workers often experience non-standard work arrangements, irregular working hours, shift work, physical or mental strains and low wages. Low coverage of long-term care workers by collective agreements and limited public expenditure in long-term care contribute to low wages in the sector. |
| Explanation: From the information outlined earlier it follows that care and disability support workers are not the same thing. There a separate mentioning is required. | |
| **Amendment 12** | |
| **Recital 19** | |
| *Text proposed by the Commission* | *Amendment* |
| (19) Certain groups of workers, including live-in carers or domestic workers providing long-term care, face particularly difficult working conditions, including low wages, unfavourable working-time arrangements, undeclared work, and non-compliance with essential labour protection rules and irregular forms of employment. The 2011 Domestic Workers Convention (No. 189) of the International Labour Organization lays down basic rights and principles, and requires country competent authorities to take a series of measures with a view to ensure decent working conditions for domestic workers. | (19) Certain groups of workers, including live-in carers***, Personal Assistants*** or domestic workers providing long-term care ***or disability support services***, face particularly difficult working conditions, including low wages, unfavourable working-time arrangements, undeclared work, and non-compliance with essential labour protection rules and irregular forms of employment. The 2011 Domestic Workers Convention (No. 189) of the International Labour Organization lays down basic rights and principles, and requires country competent authorities to take a series of measures with a view to ensure decent working conditions for domestic workers. |
| **Explanation:** Providing disability support services is distinct from care work. Problems like labour shortages or unsatisfactory working conditions apply to both sectors. | |
| **Amendment 13** | |
| **Recital 20** | |
| *Text proposed by the Commission* | *Amendment* |
| (20) Informal care has been essential in long-term care provision, as informal carers, mostly women, traditionally carry out the bulk of caregiving, often due to a lack of accessible and affordable formal long-term care. Providing informal care can negatively affect carers' physical and mental health and well-being and | (20) Informal care has been essential in long-term care and ***disability support services*** provision, as informal carers, mostly women, traditionally carry out the bulk of caregiving, often due to a lack of accessible and affordable formal long-term care ***and*** |

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| is a significant obstacle to employment, particularly for women. That has an immediate effect on their current income, and affects their old-age income due to a reduced accrual of pension rights, which can be even more significant for carers with additional childcare responsibilities. Children and young people with a chronically ill family member tend to have more mental health problems and more adverse outcomes with long term effect on their income and inclusion in society. | ***especially disability support services***. Providing informal care can negatively affect carers' physical and mental health and well-being and is a significant obstacle to employment, particularly for women. That has an immediate effect on their current income, and affects their old-age income due to a reduced accrual of pension rights, which can be even more significant for carers with additional childcare responsibilities. Children and young people with a chronically ill family member tend to have more mental health problems and more adverse outcomes with long term effect on their income and inclusion in society. |
| **Explanation:** See amendment 1and 11. | |
| **Amendment 14** | |
| **Recital 21** | |
| ***Text proposed by the Commission*** | ***Amendments*** |
| (21) The organisation of long-term care differs across the Union. Long-term care is organised in an often complex system of services across health and social care and sometimes other types of support, such as housing and local activities. There are also differences in terms of the roles played by the national, regional and local levels of administration. Indicators used for monitoring long-term care also vary and administrative data are often not available or comparable at Union level. | (21) The organisation of long-term care **and *disability support services*** differs across the Union. Long-term care **and *disability support services are*** ~~is~~ organised in an often complex system of services across health and social care and sometimes other types of support, such as housing and local activities. There are also differences in terms of the roles played by the national, regional and local levels of administration. Indicators used for monitoring long-term care **and *disability support*** also vary and administrative data are often not available or comparable at Union level. |
| **Explanation:** See amendment 1. | |
| **Amendment 15** | |
| **Recital 22** | |
| ***Text proposed by the Commission*** | ***Amendments*** |
| (22) Long-term care stakeholders include those in need of long-term care, their family members and organisations representing them, relevant authorities at national, regional, and local level, social partners, civil society organisations, long-term care providers, and bodies responsible for promoting social inclusion and integration and protection of fundamental rights, including national | (22) Long-term care ***and disability support*** stakeholders include those in need of long-term care ***and disability support***, their family members and organisations representing them, including ***organisations of persons with disabilities who need to exercise co-decision functions***, relevant authorities at national, regional, and local level, social partners, civil society organisations, long-term care providers, and bodies responsible for promoting social inclusion and |

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| equality bodies. Social economy bodies, including cooperatives, mutual benefits societies, associations and foundations, and social enterprises, are important partners for public authorities in the provision of long-term care. | integration and protection of fundamental rights, including national equality bodies. Social economy bodies, including cooperatives, mutual benefits societies, associations and foundations, and social enter-prises, are important partners for public authorities in the provision of long-term care. |
| **Explanation:** Shaping support services for disabled people is primarily an issue of democratic self-determination, not of seemingly objective expertise. General Comment no 5 and the Guidelines on Deinstitutionalisation state clearly that the power to decide over matters of disability rests with disabled people, represented through disabled peoples organisations (DPOs). Actors who are not part of this group like service providers, doctors, parents, researchers or others have no right to decide "what is best" for disabled people. The way a societal group wants to live can not be determined through any means of abstract expertise but is a matter of preference of the societal group in question. Foreign determination is not accepted for religious groups, ethnicity and gender and must not be accepted for disability. | |
| **Amendment 16** | |
| **Recital 23** | |
| *Text proposed by the Commission* | ***Amendment*** |
| (23) The European Semester process, supported by the Social Scoreboard, has highlighted the challenges in long-term care, resulting in some Member States receiving country-specific recommendations in that area. The Employment Guidelines underline the importance of ensuring availability of affordable, accessible and quality long-term care. The Open Method of Coordination for Social Protection and Social Inclusion aims to promote accessible, high-quality and sustainable long-term care and supports that objective through monitoring, multilateral surveillance of reforms, thematic work, and mutual learning. The Social Protection Committee developed a European quality framework for social services , including long-term care. However, there is still no Union comprehensive framework to guide national reforms in long-term care. | (23) The European Semester process, supported by the Social Scoreboard, has highlighted the challenges in long-term care ***and disability support***, resulting in some Member States receiving country-specific recommendations in that area. The Employment Guidelines underline the importance of ensuring availability of affordable, accessible and quality long-term care ***and disability support***. The Open Method of Coordination for Social Protection and Social Inclusion aims to promote accessible, high-quality and sustainable long-term care ***and disability support*** and supports that objective through monitoring, multilateral surveillance of reforms, thematic work, and mutual learning. The Social Protection Committee developed a European quality framework for social services , including long-term care. However, there is still no Union comprehensive framework to guide national reforms in long-term care ***and disability support***. |
| **Explanation:** See explanation to amendment 1**.** | |
| **Amendment 17** | |
| **Recital 24** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (24) The Union provides many funding opportunities for long-term care, targeting different investment priorities in accordance with the specific regulations of | (24) The Union provides many funding opportunities for long-term care ***and disability support***, targeting different investment priorities in accordance with |

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| the various funding programmes, which include the European Regional Development Fund (with priority focus on non-residential family- and community-based services), the European Social Fund plus, and its Employment and Social Innovation strand, the Just Transition Fund, Horizon Europe, the Digital Europe Programme, support to design and implement reforms through the Technical Support Instrument, and the Recovery and Resilience<br>Facility for eligible reforms and investments in the context of the recovery from the COVID-19 pandemic. | the specific regulations of the various funding programmes, which include the European Regional Development Fund (with ***an exclusive*** ~~priority~~ focus on non-residential family- and community-based services ***such as Personal Assistance and peer support***), the European Social Fund plus, and its Employment and Social Innovation strand, the Just Transition Fund, Horizon Europe, the Digital Europe Programme, support to design and implement reforms through the Technical Support Instrument, and the Recovery and Resilience Facility for eligible reforms and investments in the context of the recovery from the COVID-19 pandemic. ***Any spending on any type of residential setting such as nursing homes, long-term psychiatric facilities, orphanages, social care institutions or group homes is not permitted.*** |
| **Explanation:** General Comment no 5 and the Guidelines on Deinstitutionalisation categorically exclude funding for insitutitons and obliged to redirect all available financial resources to community based support services such as Personal Assistance and Peer Support. | |
| **Amendment 18** | |
| **Article 1** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| 1. This Recommendation aims to improve access to affordable, high-quality long-term care to all people who need it. | 1. This Recommendation aims to improve access to affordable, high-quality long-term care ***and disability support services*** to all people who need it. |
| **Explanation:** See amendment 1 | |
| **Amendment 19** | |
| **Article 2** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| 2. This Recommendation concerns all people in need of long-term care, and formal and informal carers. It applies to long-term care provided across all care settings. | 2. This Recommendation concerns all people in need of long-term care ***and/or disability support***, and formal and informal carers. It applies to long-term care ***and disability support services*** provided across all care settings. |
| **Explanation:** See amendment 1 | |
| **Amendment 20** | |
| **Article 3 (a)** | |
| ***Text proposed by the Commission*** | ***Amendment*** |

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| (a) 'long-term care' means a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care. The daily living activities for which help is needed may be the self-care activities that a person must perform every day (Activities of Daily Living, such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions) or may be related to independent living (Instrumental Activities of Daily Living, such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone); | (a) 'long-term care ***and disability support services***' refer to ~~means~~ a range of services and assistance for people who, as a result of mental and/or physical frailty ~~and/or disability~~ over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care***, and to people with disabilities, defined as long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on equal basis with others, and who might be in need of support services***. The daily living activities for which help is needed may be the self-care activities that a person must perform every day (Activities of Daily Living, such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions) or may be related to independent living (Instrumental Activities of Daily Living, such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, ~~and~~ using a telephone, ensuring ***access to transport, information, communication, daily routine, habits, employment, personal relationships, religious activities, cultural activities and sexual and reproductive rights).*** |
| **Explanation:** Art. 1 of the UNCRPD provides an authoritative definition of disability. Since this Council recommendation is required to be in line with the UNCRPD, this definition has to be applied. General Comment no 5, chapter II, section 16, paragraph (a) provides a list of activities related to Independent Living. | |
| **Amendment 21** | |
| **Article 3 (c)** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (c) 'home care' means formal long-term care provided in the recipient's private home, by one or more professional long-term care worker or workers; | (c) 'home care' means formal long-term care provided in the recipient's private home, by one or more professional long-term care worker or workers. ***Home care services should follow a direct employer model where the person in need of support chooses and/or employs their care workers. Home care can not be delivered in residential care settings.*** |
| **Explanation:** To avoid the development of services that curtail, rather than promote, Independent Living, it is key to place all decision making power in the hands of the disabled person. | |

| Amendment 22 | |
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| **Article 3 (d)** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (d) 'community-based care' means formal long-term care provided and organised at community level, for example, in the form of adult day services or respite care; | (d) 'community-based ***support services refer to a range of quality, individualized support and inclusive mainstream services in the community. Support services include personal assistance, peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, provision of assistive technology, support in securing housing and household help, and other community-based services.*** ~~care' means formal long-term care provided and organised at community level, for example, in the form of adult day services or respite care;~~ |
| **Explanation:** The CRPD Guidelines on Deinstitutionalisation provide a definition and a comprehensive list of community based services. | |
| **Amendment 23** | |
| **Article 3 (e) new** | |
| **Text proposed by the Commission** | ***Amendment*** |
| | ***(e) Personal assistance. Personal assistance refers to person-directed/"user"-led human support available to a person with disability and is a tool for independent living.***<br>***(i) Funding for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. Individualized services must not result in a reduced budget and/or higher personal payment;***<br>***(ii) The service must be controlled by the person with disability, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom design their own service, i.e., design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service*** |

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| | ***providers;***<br>***(iii) Personal assistance is a one-to-one relationship. Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be "shared" without the full and free consent of the person granted personal assistance.***<br>***(iv) Self-management of service delivery. Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the responsibilities of "the employer" are contracted out, the person with disability always remains at the centre of the decisions concerning the assistance, the one to whom any inquiries must be directed and whose individual preferences must be respected. The control of personal assistance can be exercised through supported decision-making.*** |
| **Explanation: A**ccording to art. 19 UNCRPD, General Comment no 5 and the Guidelines on Deinstitutionalisation, every disabled person in need has a right to Personal Assistance. The Guidelines on Deinstitutionalisation list Personal Assistance as the first community-based disability support service. To avoid the development of services that curtail, rather than promote, Independent Living, clear definitions are required. | |
| **Amendment 24** | |
| **Article 3 ~~(e)~~ (f)** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (e) 'residential care' means formal long-term care provided to people staying in a residential long-term care setting; | ***~~(e)~~ (f)*** 'residential care' means formal long-term care provided to people staying in a residential long-term care setting. ***In the context of disability all forms of residential care are forms of institutionalization. Institutionalization of persons with disabilities refers to any detention based on disability alone or in conjunction with other grounds such as "care" or "treatment". Disability-specific detention typically occurs in institutions that include, but are not limited to social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels, leprosy colonies and*** |

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| | ***other congregate settings.*** |
| **Explanation: The Guidelines on Deinstitutionalisation provide a comprehensive definition of residential settings for disabled people. To align with the UNCRPD this definition has to be applied.** | |
| **Amendment 25** | |
| **Article 3 (g) new** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| | ***(g) Deinstitutionalisation: Institutionalization is a discriminatory practice against persons with disabilities, contrary to article 5 of the Convention. It involves de facto denial of the legal capacity of persons with disabilities, in breach of article 12. It constitutes detention and deprivation of liberty based on impairment, contrary to article 14. States parties should recognise institutionalization as a form of violence against persons with disabilities. Institutionalization contradicts the right of persons with disabilities to live independently and be included in the community. States parties should abolish all forms of institutionalization, end new placements in institutions and refrain from investing in institutions. Institutionalization must never be considered a form of protection of persons with disabilities, or a "choice". The exercise of the rights under article 19 of the Convention cannot be suspended in situations of emergency, including in public health emergencies.*** |
| **Explanation:** This addition is essential to produce alignment with the UNCRPD. | |
| **Amendment 26** | |
| **Article 3 ~~(g)~~ (h)** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (g) 'independent living' means that all people in need of long-term care can live in the community with choices equal to others, have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others, and are not obliged to live in a particular living arrangement; | ***(g) (h) 'independent living' means that persons with disabilities and other people in need of support are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and*** |

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| | ***health care, religious activities, cultural activities and sexual and reproductive rights. Independent living does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself. Rather, it should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy as enshrined in article 3 (a) of the Convention;*** ~~**that all people in need of long-term care can live in the community with choices equal to others, have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others, and are not obliged to live in a particular living arrangement;**~~ |
| **Explanation:** General Comment no 5 provides a clear definition on Independent Living. Independent Living is a key term, requiring a universally accepted definition. There must be no derogations from the definition provided in General Comment no 5. | |
| **Amendment 27** | |
| **Article 4** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| **4.** Member States should improve the adequacy of social protection for long-term care, in particular by ensuring that long-term care is:<br>(a) timely, allowing people in need of long-term care to receive the necessary care as soon as, and for as long as, needed;<br>(b) comprehensive, covering all long-term care needs, arising from mental and/or physical decline in functional ability, assessed on the basis of clear and objective eligibility criteria;<br>(c) affordable, enabling people in need of long-term care to maintain a decent standard of living and protecting them from poverty due to their long-term care needs. | 4. Member States should improve the adequacy of social protection for long-term care ***and disability support services***, in particular by ensuring that long-term care ***and disability support*** is:<br>(a) timely, allowing people in need of long-term care ***and disability support services***, to receive the necessary care as soon as, and for as long as, needed;<br>(b) comprehensive, covering all long-term care ***and disability support services*** needs, arising from mental, ~~and/or~~ physical ***or sensory*** decline in functional ability, assessed on the basis of clear and objective eligibility criteria;<br>(c) affordable, ***providing full coverage of all costs and avoiding out of pocket payments,*** enabling people in need of long-term care ***or disability support services*** to maintain a decent standard of living and protecting them from poverty due to their long-term care needs. |
| **Explanation:** Full coverage of all expenses is required under General Comment no 5. | |
| **Amendment 28** | |
| **Article 5** | |
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| *Text proposed by the Commission* | *Amendment* |
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| 5. Member States should increase the offer of long-term care services, while providing a balanced mix of long-term care options and in all care settings to cater for different long-term care needs and supporting the freedom of choice of people in need of care, including by:<br>(a) developing and/or improving home care and community-based care;<br>(b) closing territorial gaps in availability of and access to long-term care, in particular in rural and depopulating areas;<br>(c) rolling-out accessible innovative technology and digital solutions in the provision of care services, including to support independent living;<br>(d) ensuring that long-term care services and facilities are accessible to persons with specific needs and disabilities, respecting the equal right of all persons with disabilities to live independently in the community, with choices equal to others. | 5. Member States should increase the offer of long-term care ***and disability support*** services, while providing a balanced mix of long-term care ***and disability support*** options and in all care settings to cater for different long-term care ***and disability support*** needs and supporting the freedom of choice of people in need of care, including by:<br>(a) developing and/or improving home care and community-based ***support services ~~care~~***;<br>(b) closing territorial gaps in availability of and access to long-term care and ***and disability support services***, in particular in rural and depopulating areas;<br>(c) rolling-out accessible innovative technology and digital solutions in the provision of care services, including to support independent living;<br>(d) ensuring that long-term care ***and disability support*** services and facilities are accessible to persons with specific needs and disabilities, respecting the equal right of all persons with disabilities to live independently in the community, with choices equal to others. |
| **Explanation:** See explanation to amendment 1. | |
| **Amendment 29** | |
| **Article 6** | |
| *Text proposed by the Commission* | *Amendment* |
| 6. Member States should ensure that high-quality criteria and standards are established for all long-term care settings, tailored to their characteristics, and strictly applied to all long-term care providers irrespective of their legal status. To this effect, Member States should ensure a quality framework for long-term care which is guided by the quality principles set out in the Annex and includes an appropriate quality assurance mechanism, that:<br>(a) enforces compliance with quality criteria and standards across all long-term care settings and providers in collaboration with long-term care providers and people receiving long-term care,<br>(b) provides incentives to and enhances the capacity of long-term care providers to go beyond the | 6. Member States should ensure that high-quality criteria and standards are established for all long-term care ***and disability support*** settings, tailored to their characteristics, and strictly applied to all long-term care ***and disability support*** providers irrespective of their legal status. To this effect, Member States should ensure a quality framework for long-term care ***and disability support*** which is guided by the quality principles set out in the Annex and includes an appropriate quality assurance mechanism, that:<br>(a) enforces compliance with quality criteria and standards across all long-term care ***and disability support*** settings and providers in ***co-decision*** ~~collaboration~~ with long-term care ***and disability support*** providers and people receiving long-term care ***and*** |

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| minimum quality standards and to improve quality continuously,<br>(c) secures sufficient resources for quality assurance at national, regional and local levels and encourages long-term care providers to have budgets for quality management,<br>(d) ensures, where relevant, that requirements regarding the quality of long-term care are integrated in public procurement,<br>(e) promotes independent living and inclusion in the community in all long-term care settings. | ***disability support***,<br>(b) provides incentives to and enhances the capacity of long-term care ***and disability support*** providers to go beyond the minimum quality standards and to improve quality continuously,<br>(c) secures sufficient resources for quality assurance at national, regional and local levels and encourages long-term care ***and disability support*** providers to have budgets for quality management,<br>(d) ensures, where relevant, that requirements regarding the quality of long-term care ***and disability support*** are integrated in public procurement,<br>(e) promotes independent living and inclusion in the community in all long-term care ***and disability support*** settings. |
| Explanation: See explanation to amendment 1. | |
| **Amendment 30** | |
| **Article 7** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| 7. Member States should ensure fair working conditions in long-term care, in particular by:<br>(a) promoting national social dialogue and collective bargaining in long-term care, including supporting the development of attractive wages in the sector, while respecting the autonomy of social partners;<br>(b) without prejudice to Union law on occupational health and safety and while ensuring its effective application, promoting the highest standards in occupational health and safety for all long-term care workers;<br>(c) addressing the challenges of vulnerable groups of workers, such as domestic long-term care workers, live-in carers and migrant care workers, including by providing for effective regulation and professionalisation of such care work. | 7. Member States should ensure fair working conditions in long-term care ***and disability support services***, in particular by:<br>(a) promoting national social dialogue and collective bargaining in long-term care ***and disability support services***, including supporting the development of attractive wages in the sector, while respecting the autonomy of social partners;<br>(b) without prejudice to Union law on occupational health and safety and while ensuring its effective application, promoting the highest standards in occupational health and safety for all long-term care ***and disability support services*** workers;<br>(c) addressing the challenges of vulnerable groups of workers, such as domestic long-term care ***and disability support services*** workers, live-in carers and migrant care workers, including by providing for effective regulation and professionalisation of such care work. |
| **Explanation:** See explanation to amendment 1. | |
| **Amendment 31** | |
| **Article 8** | |
| ***Text proposed by the Commission*** | ***Amendment*** |

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| 8. Member States, in collaboration, where relevant, with social partners, long-term care providers and other stakeholders, should address skills needs and worker shortages in long-term care, in particular by:<br>(a) designing and improving the initial and continuous education and training to equip current and future long-term care workers with the necessary skills and competences, including digital;<br>(b) building career pathways in the long-term care sector, including through upskilling, reskilling, skills validation, and information and guidance services;<br>(c) establishing pathways to a regular employment status for undeclared long-term care workers;<br>(d) exploring legal migration pathways for long-term care workers;<br>(e) strengthening professional standards, offering attractive professional status and career prospects to long-term carers, including to those with low or no qualifications;<br><br>*Text proposed by the Commission*<br><br>(f) implementing measures to tackle gender stereotypes and gender segregation and to make the long-term care profession attractive to both men and women. | 8. Member States, in collaboration, where relevant, with social partners, long-term care ***and disability support services*** providers and other stakeholders, should address skills needs and worker shortages in long-term care ***and disability support services***, in particular by:<br>(a) designing and improving the initial and continuous education and training to equip current and future long-term care ***and disability support services*** workers with the necessary skills and competences, including digital;<br>(b) building career pathways in the long-term care ***and disability support services*** sector, including through upskilling, reskilling, skills validation, and information and guidance services;<br>(c) establishing pathways to a regular employment status for undeclared long-term care ***and disability support services*** workers;<br>(d) exploring legal migration pathways for long-term care ***and disability support services*** workers;<br>(e) strengthening professional standards, offering attractive professional status and career prospects to long-term carers ***and disability support services workers***, including to those with low or no qualifications;<br>(f) implementing measures to tackle gender stereotypes and gender segregation and to make the long-term care ***and disability support services*** profession attractive to both men and women.<br>***(g) Personal Assistance is a one-to-one relationship. Personal Assistants must be recruited, trained and supervices by the person granted Personal Assistance.*** |
| **Explanation:** The training of Personal Assistants by their disabled users is a key feature of Personal Assistance according to CRPD documents. | |
| **Amendment 32** | |
| **Article 9** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| 9. Member States should establish clear procedures to identify informal carers and support them in their caregiving activities by:<br>(a) facilitating their cooperation with long-term care workers;<br>(b) helping them to access the necessary training, | 9. Member States should establish clear procedures to identify informal carers and support them in their caregiving activities by:<br>(a) facilitating their cooperation with long-term care ***and disability support*** workers;<br>(b) helping them to access the necessary train- |

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| counselling, healthcare, psychological support and respite care;<br>(c) providing them with adequate financial support, while making sure that such support measures do not deter labour market participation. | ing, counselling, healthcare, psychological support and respite care;<br>(c) providing them with adequate financial support, while making sure that such support measures do not deter labour market participation. |
| **Explanation:** See explanation to amendment 11 | |
| **Amendment 33** | |
| **Article 10** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| 10. Member States should ensure sound policy governance in long-term care and ensure a coordination mechanism to design and deploy actions and investments in that area, in particular by:<br>(a) appointing a national long-term care coordinator, supplied with adequate resources and a mandate enabling the effective coordination and monitoring of the implementation of this Recommendation at national level and acting as a contact point at Union level;<br>(b) involving all relevant stakeholders at national, regional and local levels in the preparation, implementation, monitoring and evaluation of long-term care policies and improving the consistency of long-term care policies with other relevant policies, including healthcare, employment, education and training, broader social protection and social inclusion, gender equality, and disability rights;<br>(c) developing a national framework for data collection and evaluation, underpinned by relevant indicators, collection of evidence, including on gaps and inequalities in long-term care provision, lessons learned and successful practices, and feedback from people receiving care and other stakeholders;<br>(d) developing a mechanism for forecasting long-term care needs at national, regional and local levels and integrating it into the planning of long-term care provision;<br>(e) strengthening contingency planning and capacity to ensure continuity of longterm care provision when confronted with unforeseen circumstances and emergencies;<br>(f) taking measures to raise awareness, encourage and facilitate the take-up of the available long-term care services and support by people in need of | 10. Member States should ensure sound policy governance in long-term care ***and disability support services*** and ensure a coordination mechanism to design and deploy actions and investments in that area, in particular by:<br>(a) appointing a national long-term care coordinator ***and a separate coordinator for disability support services***, supplied with adequate resources and a mandate enabling the effective coordination and monitoring of the implementation of this Recommendation at national level and acting as a contact point at Union level;<br>(b) involving all relevant stakeholders at national, regional and local levels in the preparation, implementation, monitoring and evaluation of long-term care ***and disability support policies*** and improving the consistency of long-term care policies with other relevant policies, including healthcare, employment, education and training, broader social protection and social inclusion, gender equality, and disability rights;<br>***(c) States parties should closely involve persons with disabilities, and their representative organizations – and give priority to the views of persons leaving institutions, survivors of institutionalization, and their representative organizations – in all stages of deinstitutionalization processes, in accordance with articles 4 (3) and 33 of the Convention. Service providers, charities, professional and religious groups, trade unions and those with financial or other interests in keeping institutions open should be prevented from influencing decision-making processes related to deinstitutionalization. Persons with disabilities living in institutions, survivors of institutionalization and those at a higher risk of institutionalization should be*** |

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| long-term care, their families, long-term care workers and informal carers, including at regional and local levels;<br>(g) mobilising and making cost-effective use of adequate and sustainable funding for long-term care, including by making use of Union funds and instruments and by pursuing policies conducive to the sustainable funding of care services that are coherent with the overall sustainability of public finances. | ***provided with support and information in accessible formats to facilitate their full participation in deinstitutionalization processes.***<br><br>~~(c)~~***(d)*** developing a national framework for data collection and evaluation, underpinned by relevant indicators, collection of evidence, including on gaps and inequalities in long-term care ***and disability support services*** provision, lessons learned and successful practices, and feedback from people receiving care ***and/or disability support*** and other stakeholders;<br>~~(d)~~***(e)*** developing a mechanism for forecasting long-term care ***and disability support*** needs at national, regional and local levels and integrating it into the planning of long-term care ***and disability support services*** provision;<br>~~(e)~~***(f)*** strengthening contingency planning and capacity to ensure continuity of longterm care ***and disability support services*** provision when confronted with unforeseen circumstances and emergencies;<br>~~(f)~~***(g)*** taking measures to raise awareness, encourage and facilitate the take-up of the available long-term care ***and disability support*** services and support by people in need of long-term care ***and/or need towards disability support,*** their families, long-term care ***and disability support services*** workers and informal carers, including at regional and local levels;<br>~~(g)~~***(h)*** mobilising and making cost-effective use of adequate and sustainable funding for long-term care ***and disability support services***, including by making use of Union funds and instruments and by pursuing policies conducive to the sustainable funding of care services that are coherent with the overall sustainability of public finances |
| **Explanation:** The co-decision making of disabled people´s organisations is in all matters concerning disability is required under the UNCRPD. | |
| **Amendment 34** | |
| **Article 12** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| 12. The Council welcomes the Commission's intention to:<br>(a) mobilise Union funding and technical support to promote national reforms and social innovation in long-term care; | 12. The Council welcomes the Commission's intention to:<br>(a) mobilise Union funding and technical support to promote national reforms and social innovation in long-term care ***and disability support services***; |

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| (b) monitor progress in implementing this Recommendation in the context of the European Semester, taking stock of progress regularly with the Social Protection Committee and, whenever relevant, the Employment Committee, based on national action plans and progress reports from Member States and on the framework of indicators referred to in point €, and report to the Council within 5 years of the adoption of this Recommendation; | (b) monitor progress in implementing this Recommendation in the context of the European Semester, taking stock of progress regularly with the Social Protection Committee, ***disabled peoples organisations*** and, whenever relevant, the Employment Committee, based on national action plans and progress reports from Member States and on the framework of indicators referred to in point €, and report to the Council within 5 years of the adoption of this Recommendation; |
| € work jointly with Member States, through the national long-term care coordinators, the Social Protection Committee, and the Employment Committee, with social partners, civil society organisations, social economy actors, and other stakeholders to facilitate mutual learning, share experiences, and follow up on actions taken in response to this Recommendation as set out in the relevant national action plans referred to in point 11; | € work jointly with Member States, through the national long-term care ***and disability support services*** coordinators, the Social Protection Committee, and the Employment Committee, with social partners, civil society organisations ***including disabled peoples organisations***, social economy actors, and other stakeholders to facilitate mutual learning, share experiences, and follow up on actions taken in response to this Recommendation as set out in the relevant national action plans referred to in point 11. ***Disabled people´s organisations shall have co-decision powers on all matters concerning disability;*** |
| (d) work with Member States to enhance the availability, scope and relevance of comparable data on long-term care at Union level, building on the forthcoming results of the Commission task force on long-term care statistics; | (d) work with Member States to enhance the availability, scope and relevance of comparable data on long-term care ***and disability support services*** at Union level, building on the forthcoming results of the Commission task force on long-term care statistics; |
| € work with the Social Protection Committee to establish a framework of indicators for monitoring the implementation of this Recommendation, building on the joint work on common indicators on long-term care and other monitoring frameworks to avoid duplication of work and limit administrative burden; | € work with the Social Protection Committee ***and disabled people´s organisations*** to establish a framework of indicators for monitoring the implementation of this Recommendation, building on the joint work on common indicators on long-term care ***and disability support services*** and other monitoring frameworks to avoid duplication of work and limit administrative burden; |
| (f) draw up joint reports with the Social Protection Committee on long-term care which analyse common long-term care challenges and the measures adopted by Member States to address them; | (f) ***work with Eurostat, national statistics institutes and competent member state authorities to produce aggregate data on the number of persons with disabilities and older people living in institutions within the EU, produce aggregate data on the number of Personal Assistance users within the EU***<br>~~(f)~~ ***(g)*** draw up joint reports with the Social Protection Committee ***and disabled people´s organisations*** on long-term care ***and disability support services*** which analyse common long-term care challenges |

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| | and the measures adopted by Member States to address them; |
| **Explanation:** Despite the provision of aggregate data being required by General Comment no 5 and the Guidelines on Deinstitutionalisation including in emergencies, the EU and member states have not yet produced such information. Having this data is essential to produce strategies on deinstitutionalization. | |

**Amendments of European Network on Independent Living**

to the Proposal for a COUNCIL RECOMMENDATION on the Revision of the Barcelona Targets on early childhood education and care

**COM(2022) 442 final**
**2022/0263 (NLE)**

**When the European Union became state party to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in December 2010 this was a historic moment. Due to this commitment all EU policies and initiatives on disability must be aligned to the UNCRPD. In September 2022 the European Commission proposed a European Care Strategy. In the context of this strategy the Commission proposed a Council recommendation on the Revision of the Barcelona Targets on early childhood education and care.**

**The proposed Council recommendation rightfully calls for the full inclusion of disabled children in mainstream early childhood education and care settings. Art. 24 of the UNCRPD codifies the right to full participation in education for all disabled children. Documents adopted by the Committee on the Rights of Persons with Disabilities (CRPD), such as General Comment no 5 and the Guidelines on Deinstitutionalisation, including in emergencies, provide additional guidance on how to set-up care for disabled children and which care forms are to be avoided.**

**To improve the UNCRPD alignment of the Council recommendation, we have prepared the following amendments.**

| **Amendment 1** | |
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| **Recital 2** | |
| *Text proposed by the Commission* | *Amendments* |
| (2) The objective of this Recommendation is to encourage Member States to increase participation in ECEC in order to facilitate women's labour-market | (2) The objective of this Recommendation is to encourage Member States to increase participation in ECEC in order to facilitate women's labour-market |

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| participation and enhance the social and cognitive development of all children, and in particular for children in vulnerable situations or from disadvantaged backgrounds. | participation and enhance the social and cognitive development of all children, and in particular for children in vulnerable situations or from disadvantaged backgrounds. ***Being state party to the UN Convention on the Rights of Persons with Disabilities (UNCRPD), the European Union commits to the full inclusion of disabled children in all areas of life. Under the UNCRPD disabled children must have full access to mainstream education, including early childhood education, on the same level as non-disabled children. Childhood education and care must never take place in institutional settings. The UNCRPD commites state parties to ensure access to support services in the community, including personal assistance and peer support for children and adolescents with disabilities. The UNCPRD commits the European Union and its member states to the deinstitutionalisation of care for disabled children and their inalienable right to family life.*** |
| **Explanation:** The UNCRPD codifies the right of disabled children to full inclusion in all branches of mainstream education, including early childhood education. The UNCRPD obliges the EU and the member states to organize childhood care for disabled children outside institutional settings, by providing community-based support to the children and parents. The Council recommendation needs to reflect this. | |
| **Amendment 2** | |
| **Recital 11** | |
| ***Text proposed by the Commission*** | ***Amendments*** |
| (11) Furthermore, women with low professional skills and women from low-income households with children face more barriers in training and to finding a job and more disincentives to (re)enter employment because of financial and non-financial constraints to their children's participation in ECEC. Encouraging higher participation of children in vulnerable situation and from disadvantaged backgrounds in inclusive ECEC would have a beneficial impact on their mothers' return to work. The situation of women with disabilities or women with children with disabilities is especially difficult. | (11) Furthermore, women with low professional skills and women from low-income households with children face more barriers in training and to finding a job and more disincentives to (re)enter employment because of financial and non-financial constraints to their children's participation in ECEC. Encouraging higher participation of children in vulnerable situation and from disadvantaged backgrounds in inclusive ECEC would have a beneficial impact on their mothers' return to work. The situation of women with disabilities or women with children with disabilities is especially difficult. ***Disabled women and girls are subjected to multiple discrimination on the grounds of gender and disability. In*** |

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| | ***the EU only 48,3% of disabled women are in employment, compared to 53,3% of disabled men. Only 20,7% of disabled women are in full-time employment, compared to 28,6% of disabled men. Art. 23 of the UNCRPD gives all disabled people the right to family and parenthood. Disabled women are at heightened risk to have this right violated due to continued practices of forced contraception, forced abortion and sterilization. Within the EU disabled women are still at risk to be separated from their disabled or non-disabled children on the grounds of their disability. Article 23 (4) of the Convention protects against the separation of children from their parents based on disability of either the child or of one or both parents.*** |
| **Explanation:** See explanation to amendment 1. | |
| **Amendment 3** | |
| **Recital 14** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (14) Similarly, children with disabilities have the right to participate in mainstream ECEC on an equal basis with others. Half of children with disabilities are cared for only by their parents. It is therefore important to ensure that ECEC is accessible, inclusive and combined with targeted measures that help address specific needs, including through measures tackling barriers and segregation, equipping staff with the necessary competencies or hiring dedicated staff to address individual needs and individualised curricula where needed. | (14) Similarly, children with disabilities have the right to participate in mainstream ECEC on an equal basis with others. ***Placements in segregated education have to be prevented.*** Half of children with disabilities are cared for only by their parents. It is therefore important to ensure that ECEC is accessible, inclusive and combined with targeted measures that help address specific needs, including through measures tackling barriers and segregation, equipping staff with the necessary competencies or hiring dedicated staff to address individual needs and individualised curricula where needed. |
| **Explanation:** The Commission proposal rightsfully states that disabled children have the same right to participated in mainstream ECEC as non-disabled children. The proposed addition on segregated education will bring addition clarification. | |
| **Amendment 4** | |
| **Recital 17** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (17) Accessibility is another important dimension of | (17) Accessibility is another important dimension of |

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| ECEC provision. It includes adequate infrastructure and available reception capacities and opening hours. It further covers adaptation to special needs of parents, and assistance in overcoming complex administrative procedures. Support in navigating administrative procedures should be provided in various forms, including linguistic and digital support, especially for groups in a vulnerable situation or from disadvantaged backgrounds who, for example, are not able to use or do have access to digital tools. It also includes accessibility for persons with disabilities, including children, parents and professionals, in accordance with accessibility requirements set out in Annexes I and III of Directive (EU)2019/882. | ECEC provision. It includes adequate infrastructure and available reception capacities and opening hours. It further covers adaptation to special needs of parents, and assistance in overcoming complex administrative procedures. Support in navigating administrative procedures should be provided in various forms, including linguistic and digital support, especially for groups in a vulnerable situation or from disadvantaged backgrounds who, for example, are not able to use or do not have access to digital tools. It also includes accessibility for persons with disabilities, including children, parents and professionals, in accordance with accessibility requirements set out in Annexes I and III of Directive (EU)2019/882. ***General Comment no 2 on Accessibility, as published by the Committee on the Rights of Persons with Disabilities (CRPD) on 22 May 2015 should be taken in account on an equal level.*** |
| **Explanation:** The CRPD General Comments provide comprehensive guidance on many aspects of the inclusion of people with disabilities. | |
| **Amendment 5** | |
| **Recital 21** | |
| ***Text proposed by the Commission*** | ***Amendment*** |
| (21) One way to ensure adequate provision of accessible and affordable high-quality ECEC is by establishing a legal entitlement to ECEC, by which public authorities guarantee a place for all children whose parents demand it, regardless of their employment, socio-economic or family status. In most Member States, such legal entitlement already exists but the starting age for the entitlement varies significantly. Ideally, there should not be a gap between the end of adequately paid family leave and a legal entitlement to a place in ECEC. | (21) One way to ensure adequate provision of accessible and affordable high-quality ECEC is by establishing a legal entitlement to ECEC, by which public authorities guarantee a place for all children whose parents demand it, regardless of their employment, socio-economic***,*** or family status. ***Disabled parents and disabled children must received the same legal entitlements to placements in mainstream ECEC as non-disabled people***. In most Member States, such legal entitlement already exists but the starting age for the entitlement varies significantly. Ideally, there should not be a gap between the end of adequately paid family leave and a legal entitlement to a place in ECEC. |
| **Explanation:** We welcome legal entitlements to ECEC. The Council recommendation needs to ensure that disabled parents and disabled children receive these entitelements on an equal basis as others. | |
| **Amendment 6** | |
| **Recital 22** | |

| *Text proposed by the Commission* | *Amendment* |
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| (25) ECEC suffers from staff shortages in many countries. This can be addressed through multiple strategies, such as improving working conditions, career prospects and adequate remuneration, regular up- and reskilling possibilities, developing creative recruitment strategies, and calling on different under-represented groups to join the ECEC workforce, such as men or people with various cultural backgrounds, e.g. migrants and refugees. A simple and rapid qualifications recognition mechanism could help address shortages. For instance, the Commission Recommendation (EU) 2022/554 addresses the access of those fleeing the war in Ukraine to regulated professions. | (25) ECEC suffers from staff shortages in many countries. This can be addressed through multiple strategies, such as improving working conditions, career prospects and adequate remuneration, regular up- and reskilling possibilities, developing creative recruitment strategies, and calling on different under-represented groups to join the ECEC workforce, such as men or people with various cultural backgrounds, e.g. migrants and refugees ***and disabled people***. ***Disabled people need to have access to careers in ECEC on a basis equal to non-disabled people.*** A simple and rapid qualifications recognition mechanism could help address shortages. For instance, the Commission Recommendation (EU) 2022/554 addresses the access of those fleeing the war in Ukraine to regulated professions.<br>. |
| **Explanation:** Art. 27 of the UNCRPD codifies the right of disabled people to employment on an equal basis with others. Mainstream educational settings must not only include disabled children but also disabled carers and teachers. | |
| **Amendment 7** | |
| **Recital 30** | |
| *Text proposed by the Commission* | *Amendment* |
| (30) In order to better understand care needs and constraints, Member States should ensure the availability of adequate data with a sufficient degree of granularity, reliability and comparability. Given that Directive (EU) 2019/1158 does not contain specific provisions on data collection, this data should include the take-up of family leaves, taking into account the methodological manual for the work-life balance indicator framework developed by the Employment Committee and the Social Protection Committee to support the proper monitoring and evaluation of the Directive. | (30) In order to better understand care needs and constraints, Member States should ensure the availability of adequate data with a sufficient degree of granularity, reliability and comparability. ***These data need to include information on the access of disabled children to ECEC, the childcare support needs of disabled parents, especially women, and the access of disabled parents to legal entitlements concerning ECEC.***<br><br>Given that Directive (EU) 2019/1158 does not contain specific provisions on data collection, this data should include the take-up of family leaves, taking into account the methodological manual for the work-life balance indicator framework developed by the Employment Committee and the Social Protection Committee to support the proper monitoring and evaluation of the Directive. |
| **Explanation:** At the moment there are substantial gaps in the provision of data on the access of disabled people to various areas of life, especially ECEC and the support needs of disabled children and parents, | |

including disabled women.