THE INTEGRATED SOCIAL DESIGN OF FUTURE LONG-TERM CARE

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Abstract

The future of long-term care can be sketched out or just passively expected. This article endeavours to answer the questions: Is it necessary to have an integrated system of services for the future of long-term care? What would be the features of an integrated design of services for the future of long-term care?

We are outlining, clarifying, arguing and making a connection between two phrases: "integrated social design" and "the future of long-term care". The framework that we propose in the relationship integrated social design – the future of long-term care involves subsuming the design process factors to that of social design, that is placing the economic, functional, technical, structural and aesthetic factors in the perspective of the social factors when outlining decisions. The form, aspect, location, infrastructure, and operation of long-term care services will depend on the human, social dominant component. The results of our analysis highlight the individual path of each person, determined by their way of life, their expectations and their personal and social resources, on the historical context, on the proposed solutions, but also by the commitment to obtain the final outcomes. We also draw a conclusion regarding the need to rethink services by involving the future clients in their design, through a participative, transformative approach. Future studies will test out this paradigm.

Keywords: social design, integrated service system, long-term care, dependence, transformative approach

Résumé

L'avenir des soins de longue durée peut être préfiguré ou simplement attendu. Dans cet article, nous répondons à la question: Ai-je besoin d'un des services intégrés de soins de longue durée à l'avenir? Quelles seraient les caractéristiques d'une conception sociale intégrée des services pour l'avenir des soins de longue durée? Forme, clair, et nous soutenons par rapport à deux phrases: « conception sociale intégrée » et « futur îngrijrii long terme. » Le cadre que nous proposons dans le cadre de la conception sociale intégrée – l'avenir des soins à long terme consiste à subsumer le processus de conception des facteurs sociaux ou les rapports des facteurs économiques, fonctionnels, techniques, structurelles, sociales esthétiques dans l'élaboration des décisions. Forme, l'apparence, l'emplacement, les infrastructures, l'exploitation des services de soins de longue durée se référera constamment à l'humanité sociale dominante. Notre analyse met en évidence parcours individuel de chaque personne, déterminée par les attentes de style de vie et les ressources personnelles et sociales, le contexte historique des solutions proposées, et la participation à l'élaboration des

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résultats finaux. Conclure également sur la nécessaire refonte des services par la formation des futurs bénéficiaires dans leur conception grâce à une approche participative, de transformation. Des études complémentaires permettront de tester ce paradigme.

Mots-clés: design sociale, système de services intégré, soins de longue durée, dépendance, approche transformatrice

Rezumat

Viitorul îngrijirii pe termen îndelungat poate fi prefigurat sau doar aşteptat. In articolul de faţă răspundem la întrebarea: Este necesar un sistem integrat de servicii pentru îngrijirea pe termen îndelungat în viitor? Care ar fi caracteristicile unui design social integrat al seviciilor pentru viitorul îngrijirii pe termen îndelungat? Conturăm, clarificăm, argumentăm şi punem în relaţie două sintagme: "design social integrat" şi "viitorul îngrijrii pe termen îndelungat". Cadrul pe care îl propunem în relaţia design social integrat – viitorul îngrijirii pe termen îndelungat presupune subsumarea factorilor procesului de design celui social, respectiv raportarea factorilor economici, funcţionali, tehnici, structurali, estetici la factorii sociali în conturarea deciziilor. Forma, aspectul, amplasarea, infrastructura, funcţionarea serviciilor de îngrijire pe termen îndelungat se vor raporta, în permanenţă la dominanta umană, socială. Rezultatele analizei noastre evidenţiază parcursul individual al fiecărei persoane, determinat de stilul de viaţă, de aşteptările şi resursele personale şi sociale, de contextul istoric, de soluțiile propuse, dar şi de implicarea în conturarea rezultatelor finale. Deasemenea, concluzionăm cu privire la necesara regândire a serviciilor prin antrenarea viitorilor beneficiari în designul acestora, printr-o abordare participativă, transformativă. Studii ulterioare vor testa această paradigmă.

Cuvinte cheie: design social, sistem integrat de servicii, îngrijire pe termen lung sau îndelungat, dependenţă, abordare transformativă

1. Introduction

Integrated social design must address not just social needs, but also physical, personal, psychological and spiritual, as well as economic needs, thus helping people continue and conclude their life with dignity.

The concern for dignified aging can be found in international documents (The Madrid International Plan of Action on Ageing, 2002), in continental documents (The European Charter of Rights and Responsibilities of Older People etc.), in national documents (the recognition of world plans regarding ageing, Strategies for Active Ageing), but also in unwritten form, in the sum of desires and aspirations of each individual who advances in age. Similar concerns and actions are also present in the area of protecting individuals with severe disabilities and of dependent persons.

Dignified ageing and ensuring a dignified life for dependent persons involve respect for human beings and providing quality, suitable, adapted and integrated care even when the individuals can no longer decide, when

they can no longer request or bear the burden of the costs of care adapted to their needs.

The research carried out in various countries on several continents have shown that most people prefer to die at home, but only a small number of these individuals will have this wish fulfilled. For instance, a study made in 2015 concludes that 70% of Australians wish to die at home, but only 14% of these have this wish fulfilled, the rest dying in hospitals or in care homes; in Europe, over 80% of people over the age of 80 wish to die at home, but only 20% manage to; the rest, as in Australia, die in hospitals, palliative care centres, residential centres etc. (Auditor General, Palliative Care, 2015).

Integrated social design must have a systemic scope: an integrated system provides support in the transition from pre-diagnosis to diagnosis, curative care, palliative care, death and mourning. Support for transition between the parts of the system is important in order to achieve the expected outcomes, both for the individuals going through the abovementioned stages and for their close ones.[1]

Europe has seen an increase in life expectancy, but not necessarily an increase in the expectancy of healthy life. The European Platform on Health and Social Equity / PHASE estimates that eight out of ten individuals having reached the age of 65 are chronically ill. Some of their illnesses cause disability in the long term.

The concern for a long-term care adapted to needs is also present in the ranks of European institutions. In 2014, a report regarding social protection adapted to the needs of long-term care, issued jointly by the EU Social Protection Committee and the European Commission highlighted the ageless anger of such services.

The European Network of National Human Rights Institutions, after analysing in 2016 the national reports on social protection sent by the EU states, found that 19 member states had mentioned challenges related to long-term care. (LTC). Eleven of the states focused on row supply and coverage, pointing to the low participation of women to the labour market and issues related to sustainability. Of the countries that reported challenges related to LTC, only two – Spain and Slovenia – also analysed long-term risks and possible solutions. The low number of recommendations may

[1] See: TACSI, Investing in Systemic Impacts to Improve End of Life Outcomes: Summary Report available at: https://www.tacsi.org.au/wp-content/uploads/2018/07/Systemic-Impact-in-End-of-Life_report-updated-02.07.2018.pdf

indicate a lack of attention given to this sector. Although a declared commitment for fundamental rights exists, it does not always translate into adequate attention granted to human rights. (ENNHRI – European Network of National Human Rights Institutions, 2016).[2] Although data availability has improved, and the life expectancy has grown throughout the EU, an analysis of the recent reforms of national policies indicates that many member states do not plan adequately for the future. We analyse the current and potential meanings of long-term care, the necessary relationship with an integrated service system, devised in order to respond to the person as a whole and to the parts of the system. An integrated design of long-term care services is difficult to analyse for the offer of today but starting from here we attempt to find a formula for the future.

2. Perspectives on long-term care

Carrying out basic day-to-day activities and living independently are every individual's goals. When they are impossible to reach, there is a need for "a number of services and assistance for individuals who, as a result of long-term disability or physical or mental frailty depend on help for their everyday activities and / or require permanent care" (SPC and EC, 2014).

Other authors in the domain (de la Maisonneuve and Oliveira Martins 2015) distance themselves from the age criterion and from the ageing phenomenon in assessing the need for long-term care, specifying instead the closeness of the moment of death.

In Romania, services and payments for long-term care are granted to people with disabilities and to people who have reached the standard retirement age[3], if they are in need of such care. The ways long-term care is provide include: home care with a personal carer (or an allowance provided as al alternative to providing an actual personal carer), care in day centres, care in residential centres or allowance for a carer. Dependent persons who

[2] See: http://ennhri.org/Long-term-Care-in-Europe

[3] People with disabilities are persons whose social environment which is not adapted to their physical, sensory, psychiatric, mental and/or associated needs, completely prevents or restricts their equal access to life in society, necessitating protection measures to support their social integration and inclusion.
Dependence means the situation of a person who, as a result of the loss of his or her independence due to physical, psychiatric or mental causes, requires significant assistance and/or care in order to carry out his or her basic day-to-day living activities.
See: http://ec.europa.eu/social/main.jsp?catId=1126&langId=en&intPageId=4757

have reached the standard retirement age are entitled to home care, care in day centres, care in residential centres depending on their degree of dependence, established based on a national chart for assessing the needs of the elderly (HG 886/2000).

The European Ageing Network[4], representing over 8,000 of long-term care centres across Europe, serving over 800,000 beneficiaries, is currently running projects and contributing to unified methodologies of training the staff that works with people who are old and/or dependent, in order to increase the quality of services.

There are also states that are looking for the best or the most suitable option for responding to the threat of population aging, of increased life expectancy in the absence of increase of healthy life expectancy, on the backdrop of a negative natural population growth. Romania is one such state in this situation, searching for solutions in order to fund a health system with over 17 million beneficiaries, but with little over five million contributors to the national health insurance fund.

3. From design to integrated social design

The known and accepted meaning of *design* (at least in the Romanian language) regards the "outwards appearance of an object developed in accordance with the laws of aesthetics" (according to the 2002 edition of the main dictionaries, NODEX). The French etymology of the word also includes the utilitarian aspect – "designing an object that combines aesthetics with utilitarian criteria", as well as "the social, economic functional, ergonomic, technical, aesthetic factors that determine the featured of the product" (NODEX 2002). Thus, the starting point for combining the aesthetic with the useful and the other context elements exists at lest in etymology; therefore, the phrases "social design" and "integrated social design" come to underline this connection, not to create it.

The novelty of this article resides in interpreting the characteristics of design in an integrated form of a social and socio-medical service, rather than in an object, in a finished material product. How can we design integrated social services for long-term care that is adapted to the future beneficiaries?

Social design has various meanings and scopes of application. the core of the phrase "social design" underlines the role and the responsibility of

[4] See: http://www.ede-eu.org/en

whoever develops products, services, constructions, in order to effect social change. It is a relatively new domain, for which few universities in the world provide training. It is also a relatively little accessed domain, bearing in mind the possible restrictions, that is: shifting the exclusive focus from the market, with its demand and supply, to the needs of the clients; turning conventional design into an innovative design, adapted to the users' needs, resources and desires. The users might include individuals who are sick, who have deficiencies, who are old, poor, who come from minority groups or from disadvantaged environments etc., and who require products that are useful and adapted, not just pleasant looking.

Social design is a challenge for a paradigm shift, for a re-conceptualisation of the values that underpin the design process. the challenges come from the residential social environment, but also from the various economic and demographic transformations and particularities.[5]

Social design will thus be understood as an invitation to responsibility, to transformation, but also to critical, strategic thinking, resulting in an increase of the users' quality of life. The object/service thus created will have to be not juts "pleasant looking" and "useful", but also good, appropriate to needs, desires and context.

The aim of this article is to carry out a prospective critical analysis of the starting points in integrated social design for the future of long-term care.

Integrated social design means designing services, products and infrastructure in order to respond to the needs, desires and particularities of people who require and/or will require long-term care.

The framework we propose for the relationship integrated social design – future of long-term care involves placing the design process factors in the perspective of the social process, that is placing the economic, functional, technical, structural and aesthetic factors in the perspective of the social factors when outlining decisions. The form, aspect, location, infrastructure,

[5] The "philosopher of design" – and of social design as well – is considered Victor Joseph Papanek (1923-1998). As a designer and educator, he supported a product and service design that is socially and environmentally responsible. Nowadays we believe that social design does not involve solely the reuse and the re-placement of products so that they can be reused, but also ensuring the quality of products, services, infrastructure, in order to provide a dignified life to the beneficiaries. One such example can be found in Papanek's works (1971, 1995), where he warns about the dangers to which design is exposed when looking solely for answers to the aesthetic desires of the users, to the detriment of their real, actual needs. Therefore, the challenges come not only from the designer, but also from the users, who must be taught to request products and services that are adequate for their real needs.

and operation of long-term care services will depend on the human, social dominant component.

4. What is being done at the moment for an integrated social design? A brief analysis of the situation in Romania

The starting points of integrated social design can be found in policies, practices and actions.

The Ministry of Labour and Social Justice is currently carrying out a study regarding the quality of life of dependent older individuals in Romania. Meanwhile, it has put out a call to research institutions and to universities to develop a *methodology for the continued monitoring of the quality of care in the institutions providing long-term care services.* Both studies are part of the Ministry of Labour and Social Justice for the interval 2018-2020.[6] In terms of policies, Romania has the general legislation (Law 292/2011) and the legislation regarding the protection of the elderly (Law 17 of 2000), of individuals with disabilities (Law 448 of 2006), laws regarding the quality standards of services provided in day or residential centres, as well as at home (Law 197 of 2012 and the attached standards). Such laws stipulate the minimum space for each client, the mandatory number of hours per day and week for interacting with the client, as well as the maximum time allowed for providing a certain socio-medical service.

Recent regulations introduced in Romania invites, through its new standards, public a private residential social service to develop means for continuing the provision of services and to relocate the clients into dignified and decent conditions, even in the situation in which such clients are no longer entitled to receiving the abovementioned services.

Only 30 years ago, Romania was part of the Mediterranean model of caring for dependent individuals, in the family environment. The demographic and economic changes of the past 20 years have effected great changes in the procedure of providing care for (semi)dependent family members.

Currently, Romania's population has already dropped below 20 million (19,500 thousand as of 1 January 2018, a decrease of 120,000 compared to 1 January 2017), with a negative natural population growth (the number of deaths being 71,125 higher than the number of births). The population is

[6] See: http://www.mmuncii.ro/j33/index.php/ro/transparenta/anunturi/5219-anunt-rezultat-selectie-proiecte-tor3-tor4-27082018

mostly female (51.1%), with a life expectancy at birth of 75.76 years, with gender differences (78.91 years for women and 72 years for men). The feminisation of ageing is a present and constant phenomenon.

The *healthy life expectancy* is, however, worrying: only 59 years. A quick calculation shows that this would mean almost 20 years of living with health problems for women and, respectively, 13 years for men.

The data needs to be correlated with the demographic peaks of the 1967-1977 decade and with those in the following decade. Unlike in other countries, where the baby boom phenomenon occurred immediately after WWII, in Romania the number of births almost doubled within one year (1966: 97,969 births, 1967 – 187,737 births) due to the legislation enacted by the government of the time (measures for encouraging childbearing and for outlawing pregnancy terminations).

The ageing of Romania's population is fed by another social phenomenon: the emigration of the young population, mainly of young people in the 20-40 age group: over 40,000 women and over 50,000 men were recorded on 1 January 2018 by the National Statistic Institute as having emigrated from Romania.

Whereas a significant proportion of young and adult women that emigrate temporarily for work in countries such as Italy, Spain, the UK, Germany, Austria provide care for semi-dependent and dependent persons, ensuring personal long-term care, in Romania the access to services that are adequate for the needs depends on the supply of the public and private providers, on the map of service availability. A significant imbalance occurs, in terms of supply, between residence environments, as the rural environment is at a disadvantage. One alternative exists: the "personal professional carer", paid and certified, as of 2018, by the relevant institutions in the domain. A new methodology for monitoring the quality of care provided by the personal professional carer (Order nr. 1690/2018 of the Ministry of Labour and Social Justice) comes to reset the balance in observing the standards of care both in centres and in families.

The General Directorates for Social Assistance in each county are currently developing strategies for developing medium and long-term social services – 5 and 10 years, respectively (according to Government Decree HG nr. 797/2017), in accordance with the needs identified among the potential clients.

It is necessary to have a log-term strategy as well, for the next 20, 30, 50 years. What factors need to be taken into account for such a strategy? OMS and OCDE documents launch and analyse hypotheses based on precisely such

intervals, considering not just demographic factors – such as natural population growth, population ageing, emigration –, but also economic factors, policy factors, and factors that pertain to the new technological developments and even to education.

Considering this multi-faceted integrated system – with actors, needs, resources, institutional and technical structure – it is by learning from the past and from the present that we can shape the future for the current generations of young people, adults and elderly.

The interpretation mistakes made in economic analyses and in forecasts come from taking into account only the "age" factor, or only the "health" factor, or, at best, "the health of the elderly". The challenge might come from the fact that long-term care has no age. For instance, we need to care for the over 4.2 million individuals with chronic diseases registered by GPs (2016). The (semi)dependent status of an individual may be present irrespective of age, and the society must be prepared to provide long-term care based on a systemic and integrative design.

5. Conclusions

The authors premise regards the sustainability of long-term care: looking today for solutions that will still be valid tomorrow, without additional costs, with resources that are still available. The undertaking is based on assuming responsibility for training the current generations of adults, as well as of future professionals and, why not, of future beneficiaries.

The numeric demographic arguments mentioned in the article would support an education of beneficiaries and of future users of long-term care.

As it has been shown, many states are preparing in order to face, in the future, a long-term care system that will be not only costly, but also very demanding. The article discusses the sustainability of economic systems, the adequacy of social and financial policies, quality assurance, the integrative perspective in developing and providing long-term care services. Romania is one of these states, looking for means to cope with current and future challenges. One such challenge is having a prospective integrative social design, in a manner that would integrate medical services with social, financial, technical and technological services, with infrastructure etc. Will this mean one institution, or several, as we have today, but working in a coordinated manner? These are questions that we still have to find the answer to.

It is the adequate research and interventions, the strategies of social planning adapted for individuals with severe or strong handicap, for the increasingly numerous generations of retirees appearing in Romania as of 2032 (for those born in 1967, average age 65), that will turn the answers given by the welfare system from a burden into an opportunity.

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