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Eldercare services in Sweden and the United States – comparative perspective and examples of best practice[1]

Abstract: The aim of this paper is to discuss the characteristics of the eldercare sector in two considerably different welfare state regimes – Sweden and the United States. In the face of dynamic demographic changes and the ageing of the populations, sectors of care undergo transformation and face new challenges. This article compares and contrasts the American and Swedish eldercare sector, but also brings two examples of best practice selected from the experience of each country. The Programme of All-Inclusive Care for the Elderly is a successful exception in a fragmented and disintegrated landscape of long-term care in the United States. Extended state support for informal carers manifests a new Swedish approach to family care. The paper leads to a conclusion that most of the developed countries need to undertake different actions to prevent a long-term care crisis and prepare the societies for an unprecedented growth of the "oldest old" population.
Keywords: eldercare, long-term care, welfare state, ageing populations, best practice.
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Introduction

The provision of high quality eldercare is one of the most crucial challenges for the contemporary welfare state. Dynamic demographic changes and ageing populations result in a growing number of elderly people in general

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and "the oldest old" (85+) in particular. These processes influence the level of public expenditure on healthcare, long-term care and eldercare services. Simultaneously the structure of the family and patterns of care undergo transformation in most of the developed countries. The value of informal care is underestimated, the principle of "free choice" and privatisation are more frequently applied in practice. Economic crises and the current political composition of national governments are also meaningful in shaping the priorities in the field of eldercare.

The aim of this paper is to review the sector of the care of the elderly in the United States and Sweden. Apart from comparing and contrasting the sector of long-term care (LTC) in these two different welfare regimes the article also discusses two examples of best practice selected from the experience of each country: The Programme of All-Inclusive Care for the Elderly from the United States and the expanded state support for informal carers from Sweden. Results presented in this paper are part of a more comprehensive, earlier research on the policies of ageing in an international perspective. This paper represents a descriptive, theoretical study based on the analysis of national legislation, government reports, statistics and other secondary sources.

According to Gøsta Esping-Andersen [1990] the most evident contradistinction may be observed between the liberal and social democratic model of welfare regime. Although Esping-Andersen's classical typology has been criticised for being too simplistic, more recent classifications of welfare regimes [Liebfried 1992; Castles & Mitchell 1993; Siaroff 1994] always position Sweden and the United States at opposite poles, as belonging to liberal/ anglosaxon/protestant-liberal model (USA) or social democratic/scandinavian/ protestant-scandinavian/nordic model (Sweden). As there is no common agreement on which model of social policy is "the best" for the elderly the aim of my earlier research was to compare and contrast the two notably different models: the policy of the ageing of the United States (liberal model) and Sweden (social democratic model). This article focuses solely on elderly care services that have emerged and developed in both countries.

The paper is divided into five sections. The first section discusses the origins and current condition of the elderly care sector in the United States. The second part characterises the Programme of All-Inclusive Care for the Elderly as an example of best practice distinguished from the American reality. The third and the fourth sections focus on Swedish eldercare with a special emphasis on public support for informal carers, which is a symptom of a new interrelation between the state and the family in the Scandinavian welfare

model. The last section is a comparison of trends observed in both countries in the field of long-term care and closes with final conclusions.

1. Elderly care in the United States

The first piece of legislation referring to elderly care in the U.S. can be traced back to the beginning of the 17th century. The *Elisabethan Poor Law*, enacted in 1601, imposed on families an obligation to take care of their elderly relatives. The act of 1601 is considered a symbolic border which ends the era of church responsibility for elderly people and transfers responsibility to the state and families. Philanthropists and charity organisations were the main providers of care throughout the 17th century. Almshouses, financed by public resources, emerged in the 18th century. They gave shelter to diverse social groups: orphans, people with chronic illnesses, the poor and the old. In the 19th century, eighteen states introduced filial obligation and a system of financial fines for those families, which did not provide care for their elderly members. The 19th century was a period of a gradual development of financial benefits for Civil War veterans and their families [Achenbaum 2005].

Similarly to the European experience, deterioration of the quality of life of elderly people in the United States was simultaneous, and proportional, to the process of industrialization and urbanization. The labour market created the concept of "usefulness" of an individual which was co-related with personal production capabilities. Elderly people, who grew up in early, rural America had difficulties in adapting to the new industrial reality and were often left alone, hopeless, with no financial resources. Franklin D. Roosevelt, as a Governor of New York, before becoming the President of the United States, said that the poverty of elderly people is not a matter of dishonour, but simply a side effect of modern, industrialised life [Rimlinger 1971, p. 212].

Compared to European countries the United States developed institutionalised forms of elderly care relatively late. Stimulated by the Townsend movement,[2] Roosevelt introduced the Social Security programme in 1935 – four

[2] Francis E. Townsend was an American physician who lost his job during the Great Depression. Never engaged in politics before, in early 1930s he became a well-known old-age activist in favour of pensions for the aged. His plan, known as "the Townsend Plan", proposed to award 200 dollars to each unemployed person over 60, on condition that benefit is spent within 30 days on the territory of the United States. The plan never came into force, however

decades later than Otto von Bismarck in Germany and two decades later than Sweden, the first country in the world to establish a universal pension system.

One of the most fundamental differences between the United States and Europe in terms of elderly care is in the organisation and functioning of the healthcare system. The American system is privatised and costly. It is criticised for being fragmented and inefficient. Most of the European healthcare systems are publicly funded through taxation. Elderly people in the United States (those who are 65 and over) are the only social group covered by *Medicare* – the public, federal, social insurance programme. Created in 1965 by Lyndon Johnson's administration, *Medicare* gives access to healthcare insurance. Its twin brother – *Medicaid* – is a health insurance programme for the most needy people. Taking into account access to healthcare, seniors constitute a privileged social group.

The American system of long-term care is one of the most expensive in the world. The average cost of stay in a nursing home is approximately 80 000 dollars per year, the cost of an assisted living facility varies at around 37 000 dollars per year [Prohaska, Anderson & Binstock 2012]. *Medicaid* spends approximately 119 billion dollars per year on long-term care services for the elderly [Houser et al. 2012]. This is an impressive amount but seems small compared to recent calculations of AARP (*American Association of Retired Persons*), which estimated the economic value of informal care in America at 450 billion dollars per year [Feinberg et al. 2011]. This means that (unpaid) family support is one of the most popular forms of eldercare in the United States.

America's recent programme of healthcare reforms (*Patient Protection and Affordable Care Act*) included the concept of affordable, long-term care insurance, administered by the federal programme CLASS (*Community Living Assistance Services and Supports*). However due to a voluntary character of the programme, there was a risk of adverse selection and the future financial instability of the programme. The concept was rejected by the Congress in January 2013. A similar project, but based on a compulsory participation, is currently being worked on in Poland. In the face of the dynamic ageing of the population, long-term care insurance seems to be a rational solution, which in future could minimize the risk of bankruptcy or lack of assistance.

One of the characteristics of the American welfare state is a high number of means-tested social services. To apply for *Medicaid* coverage, individual in-

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it had strong impact on the enactment of Social Security. At its peak, the Townsend movement had almost 2 million supporters. It is considered a milestone in the development of the senior rights' movement in the United States.

come must be lower than, or equal to, 674 dollars per month [Kassner 2011]. As the limit is low, the majority of people have to cover the costs on their own. High cost, however, is not the only weak point of the elderly care system. In words of Andrew E. Scharlach and Amanda J. Lehning [2012, p. 229]:

> lacking any overall nationwide approach, the United States has a fragmented patchwork of isolated community-based programs which, while sometimes innovative, serve relatively small numbers of disabled seniors. The consequences for those in need of LTC include inadequate care and substantial vulnerability to impoverishment in later life, especially for the most disadvantaged Americans.

Lack of integration, fragmentation, diversity, a complex system of financing make elderly care not easily accessible, especially for immigrants and minorities. There is, however, an example of a comprehensive, integrated programme of care, which emerged in the 1970's and today, in the face of ageing populations, is becoming more and more popular. Based on a review of literature and field research in California, the Programme of All-Inclusive Care for the Elderly (see Section 2) may be classified as an example of best practice in the field of eldercare in the United States.

2. The Programme of All-Inclusive Care for the Elderly

The Programme of All-Inclusive Care for the Elderly (*PACE*®) is innovative and comprehensive because it integrates medical and social care services, which are provided by one, interdisciplinary team of employees in an adult day care facility. The programme offers a complete range of care, beginning with transportation and nutrition, ending with medical treatment and social care, without the need to live in a nursing home. What also makes it unique is that the PACE model underlies an integrated and simplified way of financing, thanks to which out-of-pocket spending per service is significantly reduced.

The first PACE site (*On Lok*) was established in 1973 in San Francisco [Eng et al. 1997]. Local authorities came to the conclusion that providing integrated medical and social care by one institution may lead to a lower number of nursing home patients. Current eligibility criteria for the PACE model of care include: a) age 55 and over, b) living within the programme's defined catchment area, c) condition of health qualifying for a nursing home [Eng et

al. 1997]. PACE centres are co-financed by federal programmes *Medicare* and *Medicaid*. Each site receives monthly "capitation payments" (fixed amount per person) according to the state rates. Those patients who are not eligible for *Medicaid* financial support cover part of the monthly costs on their own [Eng et al. 1997]. These costs are much lower than any other long-term care options, especially in case of seniors 65+, who are covered by the *Medicare* health insurance programme.

The Programme of All-Inclusive Care for the Elderly is particularly recommended for elderly people with a diagnosed frailty syndrome. It offers a complex and holistic approach to the health and well-being of an individual. An interdisciplinary team of carers consists of physicians, nurses, social workers, physiotherapists, dietitians, recreational therapists, transportation workers and other members. To ensure an individual approach to each client there are approximately 60–80 staff members per 120–150 patients [Eng et al. 1997]. In practice each morning participants are visited at home by a driver who takes them to a day care centre. They spend most of the day in a centre where they undergo therapy, rehabilitation, recreation and medical consultations. In the afternoon they are transported back home, where a social worker helps them prepare for bed and communicates with other members of their family. Such coordination of services:

a) is cost-effective,
b) prevents drug abuse and side effects, especially in case of comorbidity,
c) enhances the individual and holistic approach to a client,
d) gives a sense of belonging to a community,
e) prevents loneliness and social exclusion,
f) offers a unique combination of security and dignity with the opportunity to stay in their own household as long as possible.

Evaluation of the PACE model gives a number of positive outcomes such as increased consumer satisfaction and reduced utilisation of institutional (residential) care. The programme is gradually gaining in popularity: according to *The National PACE Association*, 88 centres operated in 29 states in 2012. The most dynamic proliferation of the programme is observed throughout the last couple of years: between 2007 and 2012 the number of centres rose by 100 percent. However geographical location is uneven. The vast majority of centres were established along the East Coast. The state with a record number of 18 sites is Pennsylvania [The National PACE Association].

Although the Programme of All-Inclusive Care for the Elderly might be classified as an example of best practice – especially in the American context, bearing in mind the fragmented character of its long-term care sector – there

are still some disadvantages and barriers which should become the subject of further analysis. An insufficient number of specialised geriatricians and highly qualified social workers poses a barrier to the further proliferation of the programme. One of the reasons for lack of interest in working at PACE might be the salary which is usually lower than in case of a private practice. Additionally excessive bureaucratic procedures make the very process of establishing a PACE site take up to as long as 5 years [Eng et al. 1997]. The programme might also be exclusive for some groups of patients. It is not financially attractive for people younger than 65 years old, who are not yet covered by *Medicare* and not eligible for means-tested *Medicaid*. This group of patients has to cover the full cost of participation independently which might become a burden for the household budget.

The relatively small number of publicly funded, long-term care options in the United States leads to a growth of local, grass roots initiatives based on the principle of reciprocal help. Also the American care sector can be distinguished in international comparisons by the high share of private providers, charity organisations and volunteerism.

3. Elderly care in Sweden

Sweden belongs to the Nordic model of the welfare state and is considered a role model, a benchmark in international comparisons – "a bumble bee which still flies" [Kautto et al. 2001]. It is perceived as one of the most generous systems in the world, a state which takes care of its citizens "from the cradle to the grave". The Swedish welfare state in the second half of the 20th century could be characterised by three terms: institutionalisation, professionalisation and defamilisation of care.

The church and families were responsible for eldercare by the mid-18th century. The *Undantag* law of 1700 enabled farmers to bequeath their land to children (or other relatives) on the basis of a contract. In return they were provided shelter and care till the end of their days [Johansson & Sundström 2006]. Municipalities and local communities have become engaged in providing eldercare services since 1788. Contrary to most European countries tithes collected from people were not passed to the church hierarchies. Instead the money was spent on the most needy social groups, such as the poor, the sick or the elderly [Johansson & Sundström 2006]. Tradition of local decision

making and spending local taxes on local needs has led to the later administrative division of the country into 290 municipalities.

Between 1910 and 1920 two fundamental principles of the Swedish system were shaped. In 1913 Sweden established the first truly universal pension scheme in the world (the principle of universality). The Poor Relief Law of 1918 obliged municipalities to provide institutionalised eldercare services on a local level (the principle of decentralisation of care). The first half of the 20th century was a period of dynamic development of almshouses and old people's homes. The quality of care, however, was low – homes were overcrowded, various clients were mixed together, single rooms were not available. In 1947 the Swedish parliament adopted a bill prepared by the Social Care Committee, which aimed to "eliminate the poor relief character of old people's homes" [Edebalk 2009, p. 9]. Since then conditions of living and the quality of care have become much improved. Due to the small fees elderly people started to be perceived as "clients" or "guests" instead of "almshouse inhabitants" [Edebalk 2009].

The economic crisis of the early 1990s was a turning point in the history of eldercare in Sweden. The necessity of cuts in public social expenditures and the proliferation of neoliberal policies have led to adoptation of the concept of New Public Management. The concept seems contradictory to the assumptions of a social democratic welfare regime. It assumes the partial marketisation of services, more competition and consumer choice. According to the philosophy of New Public Management the state decides the range and forms of services and these are providers, (whether public or private), who are responsible for the provision, quality and cost of care. The Act of Free Choice System (*Lag om valfrihetssystem* – LOV), which came into force in 2009, is one of the most evident manifestations of the new Swedish approach to elderly care. The act obliges municipalities to introduce vouchers which give elderly people the opportunity to choose freely from public or private providers of care [Meagher & Szebehely 2013]. The deadline for implementing this new regulation is 2014.

In recent years Sweden has started to emphasise the role of the family in caregiving (see Section 4). This, again, seems contradictory to social democratic values which traditionally accent state responsibility and the public supply of care services. However, the growing number of elderly people forces the authorities to search for alternative forms of care. Recent trends show that seniors prefer to stay in their own households as long as possible. From this viewpoint, informal care might be a good, supplementary option. What is particularly valuable and worthy of adoption in other European countries,

including Poland, is the expanded network of state support for informal carers. Its emergence and development in Sweden is analysed in the next section of this paper.

4. State support for informal carers in Sweden

In the 20th century, intergenerational contract in Sweden has been replaced by a "social contract" – a contract between the state and its citizens [Johansson et al. 2011]. Throughout the last two decades, however, we may observe a gradual process of re-familisation of care, which is expressed by the increasing number of public initiatives targeted at families and other informal carers. An example of "best practice" in this field may be described in three steps: (1) The Swedish government has noticed and appreciated the crucial role of families in the care sector, (2) it has adjusted legislation accordingly to the changing landscape of the care sector, (3) it has allotted extra funds and undertaken several initiatives to give concrete support to informal carers. This process represents a responsible, wise and far-reaching approach that leads to the harmonious combination of the roles of the three main providers of care: the state, the market and the family.

In 1998 the Swedish Social Services Act was amended and a new paragraph was added: "Social services should support and provide relief for families who care for next of kin with chronic illnesses, elderly people, or people with disabilities" [Regeringens proposition 1996/97:124, translated by Johansson et al. 2011, p. 340–341]. Because of the use of the term "should" many municipalities interpreted the amendment as a recommendation (soft law) [Johansson et al. 2011]. By the year 2005, only 73 percent of municipalities – 212 out of 290 – had applied for extra funds targeted at informal carers' support [Swedish Association 2007]. For this reason, in 2008, the government decided to change the status of the amendment: from recommendation to obligation. The new paragraph is as follows: "The (municipal) social welfare committee is obliged to provide support to help the people who care for loved ones" [Socialdepartamentet 2008, quoted in: Johansson et al. 2011, p. 342]. The term "should" has been replaced by "is obliged to". Apart from this legislative adjustment, a special government programme *Anhörig 300* was established. In the years 1999–2001 the programme spent 300 million kronas on public support for informal carers [Swedish Association 2007].

There are three most popular methods of providing support for informal carers:

a) by providing vicarious, temporary care for an elderly person (in a residential care institution or at home), when the informal carer has to leave, take a few days off or has other short-term obligations;
b) by professional consultancy, education and psychological support, for example, in the form of regular meetings of support groups for family members of a senior with Alzheimer's disease;
c) by providing financial aid, such as a monthly allowance for informal carers who had to resign from their job in order to take care of a senior.

Sweden applied a wide definition of an "informal carer". Public support is not limited to spouses or family members – it may be also granted to a friend or a neighbour. Such an attitude reflects typical Scandinavian respect for cohabitation and other forms of informal relationships.

Unpaid, informal forms of care predominate in the United States. Sweden, however, is a country where numerous care options are available. State support for informal carers is good practice because it gives choice and offers an alternative to institutionalised care. It does not encourage people to provide care within the family structure but compensates and indemnifies those who decide to quit their professional activity and take care of a family member. State support helps to maintain dignity and a good mental state. It recognises informal carers as a group at risk of depression and poor well-being.

Conclusions

Influenced by ageing processes international sectors of care undergo dynamic transformations. Recent trends observed in the United States and Sweden are, to some extent, analogous. What is common for both countries is the attempt to withhold the growth of public expenditure on elderly care and at the same time increase the quality of care. Public provision of care has always been unsatisfactory in the liberal American welfare state. Today it is also becoming inadequate in Sweden, a country which has traditionally taken care of its citizens "from the cradle to the grave". Both countries undertake different actions to prevent a long-term care crisis: while Sweden "rediscovers" the institution of the family [Johansson et al. 2011] and invests in informal carers, the United States relies on charity, volunteer work and grassroots initiatives.

With the *Obamacare* programme, the current administration is attempting to make access to healthcare and long-term care more affordable and easy.

Although this paper discusses two examples of "best practice" in the field of eldercare, both countries have to contend with their own systemic weaknesses. The high costs of long-term care in the United States result in a low percentage of residential care recipients (around 5 percent of population 65+) [Gelfand 2006]. Municipal responsibility for providing eldercare in Sweden leads to fragmentation and a diversified supply and an unbalanced quality of services across the country. From the perspective of Poland, however, a country which has only initiated the debate on ageing policies, both countries may pose a rich source of practices and laws which could become an inspiration for further development.

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