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Understanding the Concept of Life Quality within the Framework of Social Service Provision: Theoretical Analysis and a Case Study

Zuzana Palovičová

Additional information is available at the end of the chapter

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Abstract

The study discusses the quality of life concept and its relation to the right to lead an independent life as a social service recipient. The combination of these concepts can be found in various strategic documents at the national and international level. The study articulates the thesis that the concept of capabilities is the basic concept for both the definition of quality of life and the definition of the right to independent living, as the level of freedom and capability (capabilities) provides information on real opportunities and possibilities of individuals to make free decisions as well as allows to identify disparities caused by the social structure that disadvantages, marginalises or discriminates certain groups. The aims of the study are to provide a clear definition of the right to lead an independent life and to explicate the link between the concepts of quality of life, self-determination, autonomy, competence in the context of the rights of disabled people to the integration and social inclusion. Reflecting on the experience from the Slovak Republic, the study suggests that the social service transformation process does not always imply an improvement in the life quality of the disabled. Instead, an ill-prepared deinstitutionalisation of the social services might dissolve the available system without providing an adequate replacement.

Keywords: quality of life, capabilities, social functioning, human rights, social services

1. Introduction

The level of human welfare and well-being is considered an important indicator of social inequality and social justice. In classical economics, the welfare is usually interpreted to mean welfare benefits, which are normally one-dimensionally measured by indicators such as

income, expenses, gross domestic product, investment, etc. Recently, however, other criteria than purely monetary are beginning to be taken into account in economics. This stream was initiated by A. Sen, who proposed to focus on issues of human welfare and quality of life through the freedom of choices that an individual has. His idea accurately conceptualises in the concept of capability and social functioning that serve as indicators of the human welfare. From this perspective, the lack of basic capabilities can be interpreted as a lack of freedom, which implies that it becomes a human rights consideration.

The study deals with the clarification of the quality of life with regard to the right to live independently in the context of social services. It defends the thesis that the concept of capabilities is the basic concept for both the definition of quality of life and the definition of the right to independent living, as the level of freedom and capability provides information on real opportunities and choices of individuals to make free decisions and allows one to identify inequalities caused by social structure that disadvantages, marginalises or discriminates against certain groups. The study is divided into four parts. The first one focuses on Sen's analysis of the mutual relationship of the terms benefit, material resources, capability, freedom and social functioning, because through these terms, the human well-being and welfare are usually explained. We are observing, whether these indicators, which are of concern for human welfare and well-being, are equal or there is a reason to prioritise some of them. Having regard to the theoretical relevance of Sen's interpretation of human welfare in the next part of the study, we look at the possibilities for the practical implementation of this approach. We will show that the practical application of this methodology provides additional information to conventional methods based on revenues or gross domestic product. Another section is devoted to the analysis of the right to live independently with regard to the right of persons with disabilities to integration and social inclusion. Based on the conceptualisation of the right to independent living, we will attempt to articulate arguments and reasons against the segregation of people with disabilities and to identify the specific elements that are essential for the transformation of the social care system. In the fourth part, we will demonstrate the main arguments from part one to part three and exemplify them on the example of the Slovak Republic.

2. Sen's interpretation of the human well-being

The basic starting point of Sen's approach is the quality of human life in its plural forms. He conceptualises the human welfare through the terms *social functioning* and *capabilities*. Social functioning is defined as a condition that one has reached (e.g. they are educated) or an activity that one is able to do (e.g. travel) [1]. Functioning reflects different aspects of satisfaction of human needs, desires and preferences and concerns various dimensions of human welfare from survival to self-expression in art and culture. According to Sen, social functioning is subject to the available material resources and their characteristics and depends on so-called conversion factors that may be personal (age, gender, disability, etc.), social (legislation, population density, crime, etc.) and environmental (climate, environment, infrastructure). These factors, along with varying resources and their characteristics, determine the level of

functioning, which one is able to achieve, and thus their capabilities. The concept of *capabilities* then represents various combinations of functioning that a person has the potential to achieve. It defines them as 'a person's ability to do valuable acts or reach valuable state of being. The capabilities represent alternative combinations of things that a person can do or be' [2]. In fact they reflect the 'freedom to choose lives for which they have a reason to value' [3].

Sen questions the assumption that the individual's well-being is dependent only on the resources, whether in terms of revenue, gross domestic product, etc. It shows that one can, from the same resources, achieve various ways of functioning just because of the conversion factors that determine to what extent they are able to turn available resources to the real level of social functioning. He exemplifies the correlative relationship between the material resources, functioning, capabilities and benefit on the example of a bicycle. Bicycle is a product whose essential characteristic is transportation, so that it enables mobility. Whether these factors are converted into the capability to move, such conversion factors as optimal health and condition of the roads decide on these. For example, a bicycle for a person without disabilities can have mobility characteristics, while a one for a man in a wheelchair has at most characteristic of a decorative object. If we consider mobility as an important part of the human well-being, an individual without a disability can fulfil this function by buying relatively inexpensive bicycle, while a disabled person has to buy a considerably more expensive, specially adapted car to fulfil his need of own mobility. Owning a bicycle thus contributes to the greater benefit of the individual. However, this benefit may be distorted by several factors that have a direct impact on the capabilities. This implies that higher income does not necessarily mean better functioning. Even at the same income level, social functioning of individuals can vary greatly. Furthermore, A. Sen does not consider the measured level of social functioning to represent a sufficient indicator of the actual human well-being. One of the problems is the erroneous interpretation of the reasons and motives that determine the extent, in which an individual achieves the actual level of functioning. For instance, fasting is not only hunger, but it can be a form of ritual, protest and so on. It is a voluntary starvation, when a person does have a choice not to starve. It is this possibility of choice, which is implied in the description of the functioning, which allows fasting to be evaluated differently from other forms of starvation [4].

Sen's approach equally problematises the interpretations that reduce the human welfare on a subjective feeling of satisfying the needs or preferences of the individual. In this context, it highlights the problem of personalised preferences when a man customises to their possibilities, even if it not always in their best interests, and usually they are not even aware of it. For example, to a poor man, even a little financial boost adds to a greater degree of satisfaction than to the rich one. Moreover, one can achieve functionality in restrictions on freedom, too. An example can be publicised attempts of homeless in the freezing cold to get into the prison because they will be warm and have access to food. Consequently, material resources, functioning, capabilities, benefits and freedom are closely linked and cannot be separated. Measuring the human well-being only through means does not take into account other aspects that people can appreciate and which they consider to be part of the good life. A person can follow things that are unrelated or at least not only to their own interests and those they consider as valuable as own happiness, material welfare and so on. It is the capabilities that reflect the real opportunities available to humans in a given situation and at a

specific time. In other words, they represent the potential to choose and achieve various ways of functioning, which a man appreciates. Utilitarian understanding of welfare affects politics and economics, however, disregards the choice in its measurements.

Sen's way of thinking implies that freedom is a primary goal and the main mean for human development. In contrast to approaches where the main indicator of the development is GDP growth, income growth, industrialisation, technological progress and modernisation, Sen defends the idea that 'the development of society should be understood... in the first place as a real freedom (substantive freedom) that the members of society have achieved' [1]. The income is within the purview of Sen's thinking only instrumental freedom, not real (substantive freedom). From this perspective, poverty is not only low income, but it is mainly deprivation and the lack of basic capabilities [1]. The emphasis on capabilities enables Sen to interpret poverty as a lack of freedom to avoid deprivations and therefore on the level of human rights. Sen identifies five types of instrumental freedom, which he considers crucial for the achievement of individual freedom of action—political freedom, economic resources, social opportunities, transparency guarantees and protection of safety [1]. Sen's concept of capability does not refer only to the procedural aspect of freedom in terms of the range of things that one can do without somebody limiting or punishing them, but to the positive liberty within the meaning of freedom as an opportunity, which it is determined by personal and social circumstances. Stated differently, the relationship between freedom as an opportunity and procedural freedom can be interpreted as the relationship of certain possibilities and guarantees, where the possibilities withdraw from the potential of individuals to achieve certain goals (e.g. their individual abilities, material conditions, etc.) and guarantees rather from the quality of the overall environment (and legal guarantees). Freedom as opportunities and procedural aspect of freedom are, in a sense, the two sides of the same coin. Freedom rests on the right. The rights form the first and fundamental condition of liberty. But people need more than just law to freedom. They need not only the right of their choice but also the possibility of its application. The power to vote is based on the resources and options within the offer. A person who has the rights, resources for its implementation and their social environment offers them the appropriate choice and has the real power to make free elections. Procedural freedom along with freedom as an opportunity forms a 'real freedom', which is the basis of the human development. In other words, human development is a multidimensional process that involves changes both at the individual level and at the level of economic, social, political and institutional mechanisms. It cannot therefore be reduced to just economic development. The welfare is from this perspective a heterogeneous multidimensional, dynamic and socially conditioned fact that is to a substantial extent dependent on the amount of random circumstances both personal and social [1]. In this respect, the measurement of well-being must be done at different levels.

Given that the social and economic environment affects the scope of competences of individuals, which capabilities are attributed with a value, and given the highest priority by the people, which ones are relevant to the policies and institutions? The authors advocating the approach to capability offer different methodologies so as to arrive to the relevant list. Sen intentionally does not specify a list of core competencies, because he believes that each social group should be able to decide through social dialogue and participatory democracy, what exactly

is a social minimum that this particular group values. He does not describe certain factors that indicate quality of life even as these capabilities are combined in the overall indicator of well-being or the quality of life [1]. An example of this approach is the Human Development Index developed by the United Nations. Its authors set a very approximate index that exceeds the purely monetary definition of development. It is based on the data that can be obtained in most countries. They relate to poverty, literacy, education, life expectancy and other factors that provide a better indicator of welfare than income itself. The first Human Development Report from 1990 states that the human development is a process of the enlargement of human freedom and the most crucial indicators are a long and healthy life, the opportunity to get education and a decent standard of functioning. Other choices include political freedom, guaranteed human rights and self-respect [5]. In other words, the human development has two sides: the first side relates to human capabilities such as health, skills and abilities, and the second one relates to the freedom of leisure activities and opportunities to be active in cultural, social and political issues. In contrast, an American philosopher M. Nussbaum, who recently significantly developed Sen's approach further, found the basis for identifying the core capabilities in Aristotelian concept of the life flourishing, which is based 'on the list of the basic human entitlements that create the conditions for different ways of life; the claims contained in the idea of human dignity' [6]. The author suggests ten key human capabilities, which in her view provide the basis for 'the constitutional principles that should be respected and implemented by all governments of the world' [7]. Perhaps, the most famous list of ten of these capabilities is the Universal Declaration of Human Rights, which provides the legal framework for the indicators of well-being that people value.

3. The measurement of the welfare

While Sen's approach is relevant in the theory, the problem is how to implement it in practice and to measure the human well-being through capabilities. Again, the classical economists considered income a useful indicator of welfare because it allows individuals to compare themselves with one another. Sen questions the assumption that individuals differ only by income and identifies three basic problems measured by income: Firstly, measuring the income disregards the production in the home (e.g. you cook and clean up on your own), non-market products and services (e.g. help of the family when you are sick, someone will look after you) and payments and transfers within the family, family or friendly relations (i.e. in-kind transfers such as pocket money, paid lunch) that enhances individual well-being. Secondly, the classical economics ignores individual differences between people such as age, sex or disability that may affect the conversion of income on well-being and thanks to which people manage the same resources to achieve different types of operations. Thirdly, the measurement of well-being through income does not reflect the intrinsic value of choice, and choice increases the benefit of individuals [2]. The fact that the income or gross domestic product does not include these factors makes the comparisons of well-being among the individuals problematic. Measurement using living, which is based on the achieved results, takes into account the presence of non-market products.

The severity of variable factors in the conversion of resources to the real quality of life demonstrates pioneering work of a German economist W. Kuklys: Amartya Sen's capability approach. Theoretical insights and empirical applications (2005). The author identifies two problems of implementation of Sen's approach into practice. Firstly, the methods of measurement of capabilities are not developed to be comparable to conventional econometric techniques. Measurement of capability and of functioning is relatively new, so it is still a matter of debate, to actually implement Sen's approach. Secondly, there are only very few attempts to measure Sen's concept of capabilities. The measurement of well-being is focused mainly on the level of performance which, while taking into account the above criticism (distribution of the family, non-market products, etc.), does not solve the problem of capability. In other words, two people who observed to exhibit identical social functioning may actually realise different levels of functioning if they have different capabilities. When measuring the social functioning, a variety of problems occur. With respect to the welfare measurement, what defines the standard of functioning, what methodology and indicators should be utilised to measure it? Approaches aiming to measure the functioning initiated by Sen then usually use one of the following methodologies: Human Development Index, fuzzy set theory, ****principal component/factor analysis and time-series clustering theory. Associating a specific numeric value with a particular functioning and hence with the overall well-being of the individual also represents a difficulty. Yet another problem emerges, when one wants to compare the measurements of the social functioning with the classical welfare measurements (consider, e.g. how does the Human Development Index relate to the conventional one-dimensional factors such as income or gross domestic product). Furthermore, operationalisation of the capability concept and thus determining the level of capabilities based on the measurement of the functioning are also not straightforward [8].

W. Kuklys focused only on two indicators in her measurements of social functioning. These are good accommodation and health. She lists two reasons for this focus. First, it allows her to concentrate on the methodological issues associated with measurement of functioning. These indicators also represented the two key issues in the UK, where her approach was applied. W. Kuklys analyses statistical data from the UK from r. 1991–2000. Social functioning is interpreted as a latent factor which is a factor that cannot be measured directly, but which can be measured using other observable factors. She focuses on the relationship between the functioning, resources available to the individuals and their conversion factors such as gender and age. She tries to estimate numerical values for the functioning and uses them in the analysis of poverty to illustrate the differences in prosperity when measured by the social functioning and income. According to W. Kuklys, it is more difficult to measure capabilities than the functioning, where the capabilities then better reflect the actual well-being of the individuals. This is illustrated by the results of the poverty measurements among the people with disabilities. These people are disadvantaged in two ways compared to the healthy population. Firstly, they have less income because they have less chances of employment and work in professions with lower income, for example, sheltered workshops. Secondly, because of their special need, they have a higher cost of living. Standard monetary methods of welfare reflect only the first disadvantage (lower income) but disregarded the other type of disadvantages (higher cost of living). In the analysis of inequality, this neglect may lead to a seemingly better social

situation of disabled people than they actually have. Poverty indexes based on standard indicator underestimate the actual poverty among the disabled persons as these do not take into account these additional costs. Kuklys actually introduces a general methodology that takes into account the differences in the needs of individuals. Persons with disabilities are used in her work only as an example.

Kuklys presents a methodology based on Sen's approach, which allows adjusting the income of households with special needs. Herewith, the welfare implied by income becomes comparable to the well-being of households without specific needs. Kuklys presents several conditions, which need to be fulfilled when measuring the capabilities by income. First, variable factors are nonmonetary limits for decision-making. This means that a person with disabilities is not only limited by income but also by such variable factors such as health, wheelchair accessibility environment, current legislation and so on. In other words, variable factors have a direct impact on the set of capabilities of an individual. Second, the same source has the same characteristic for each individual (e.g. bike allows mobility). Third, all products are market base in their nature, and therefore there are no non-market products and services. In other words, it is assumed that the care and support from the family are the same regardless of whether it is a person with a disability or a healthy person. Fourth, a higher income leads to a greater scope of eligibility. In essence, this is a basic assumption of classical welfare economics. In a market economy with many consumers, all consumers face the same product prices, and there is a perfect information (i.e. people know the price and quality of all products, rate of return for the investments is known *ex ante*, etc.). Within this system, people are assumed to be identical, to maximise their benefits, i.e. to choose the products that are on the market. Their choices are limited only by their income [8].

Based on these assumptions, W. Kuklys can simplify Sen's theoretical model so that the capabilities of an individual are determined by their income and the variable factors. In practice, she operationalises it in such a way that, she examines the differences in the needs of households and compares the needs of households with a disabled member with the needs of households without such a member. According to Kuklys, the needs of the family cannot be measured directly, only through such indicators such as the number of adults, the number of children, age groups of children, the number of disabled members, etc. She points out, however, that in literature it is not yet fully established which indicators affect the family's needs. Comparing the needs of households with a disabled member with the household with healthy members, she gains a rate (coefficient), which she then uses to calculate the adjusted household income. In this way, she expresses the difference in the welfare of the households surveyed. She found that the scope of capabilities of a disabled person in the UK is reduced by approximately 40% compared to a non-disabled person [8].

***It should be noted that this 40% reduction appears independent of Kuklys already taking into account the compensatory allowances for people with disabilities in social policy, which should help them to cope with the increased cost of living. The poverty rate in households with disabled members has doubled when taking into account disability as a conversion factor compared to the measurement using the methodology of income. In this case, about half of the families with a disabled member lived below the poverty line. Kuklys shows that these

findings suggest two conclusions for social policy. First, the level of support for people with disabilities should be reconsidered, given that their level does not seem to be high enough to compensate for the additional costs incurred by the disabled people. Second, in addition to traditional methodologies for measuring poverty and the distribution of welfare, it would be desirable to present the indicators adapted to disability, to obtain a more credible picture of a social well-being [8].

To sum up, W. Kuklys found that the measurements by the means of social functioning differ significantly from the results measured by income or expenditure. Not all who are income-poor are also poor with regard to social functioning, which can have important implications for policies aimed at poverty reduction. She was trying to develop a methodology that takes into account the variable factors affecting the well-being of the individual and at the same time establishes conditions under which Sen's capabilities can be measured. The measurement focused at capabilities is significantly different from the traditional measurement by income; also, it differs from the subjective feeling of well-being. However, it still measures the well-being of the affected individuals using income. Kuklys considers her research to be a first step in the measurement of capabilities of the persons with disabilities. For further analysis, she recommends more accurate indicator of disability. While her data surveyed only the number of disabled members of the household, the author also recommends considering the extent, respectively, the degree of disability. Combined with regularly recurring long-term measurements, it is expected that this method should lead to precise results with regard to the rate of poverty among this group of people with special needs.

Considering the level of poverty, which W. Kuklys found among people with disabilities, one should note that the author proposes certain assumptions without which it would not be possible to express capabilities by income. These should be taken into account when interpreting the results. For example, the second assumption states that the same product has the same characteristics for all individuals, which can overestimate the welfare of the disabled people and hence underestimate the rate of poverty among the affected population. As mentioned above, a healthy person obtains the function of mobility by buying a bicycle or by the use of public transport. The disabled person is often dependent on the individual transport by a car. Hence, when replicating this study in Slovak conditions as a basis of the social policy, it is necessary to collect a new data set. We see two reasons for this: First, research must work with the up-to-date data in order to consider the latest political developments. Otherwise, the measured well-being might not show the real standard of living in Slovakia, the influenced of the current legislation, etc. Second, a new data set would also allow one to include a wider range of living standard indicators that would capture the quality of life in Slovakia in a greater detail.

4. The right of all persons with disability to lead an independent life and their right to be included in the community

The Europe 2020 strategy, introduced in the year 2010, commits the European Union and its member states to make the best use of public funds to promote the social inclusion of

the most vulnerable groups in terms of poverty reduction, expansion of employment opportunities, promoting lifelong learning and decent housing for all and to overcome all forms of discrimination [9]. These objectives cannot be achieved without addressing the situation of more than 1.2 million Europeans who spend their lives in institutions, excluded from society. The tendencies to strengthen the protection of human rights of the EU citizens are already reflected in the formulation of a specific catalogue of human rights in the Charter of Fundamental Rights of the European Union, which combines a system of civil, social, economic and political rights. Respect for fundamental rights such as respect for human dignity, the right not to be subjected to inhuman or degrading treatment, the right to liberty and security, the right to respect for private and family life, the right to education, the right to work, the right to health, the right to equality and the right not to be discriminated are integral parts of the general principles of law. The Charter of Fundamental Rights of the European Union, moreover, explicitly recognises the rights of those who are usually placed to institutional care: the right of children to protection and care in their best interests (Article 24), the right of older people to live a dignified and independent life (Article 25) and the right of persons with disabilities to participate in social life of the community (Article 26) [10]. A fundamental document governing the right to independent living and the right to live in the community comes from the UN Convention on the Rights of Persons with Disabilities (2006) (the Convention) [11]. By ratification of the Convention, the EU in 2009 committed to ensure that all relevant legislation, programmes and funding will respect and promote the equal opportunities for people with disabilities and the right to independent living and inclusion in the society. The whole Convention is based on the principle of independence, which is the basic building block for all rights of people with disabilities. Independence is presented as the first general principle of the Convention. Likewise, the preamble recognises the importance of individual autonomy and independence, including the freedom of choice for persons with disabilities. The right to independent living and inclusion in society is explicitly guaranteed under Article 19 of the Convention. However, Article 19 does not define the right to independent living. This article defines only the right to live in the community: 'The parties recognise the equal right of all persons with disabilities to live in the community...', while the aspect of choice is emphasised [11]. Persons with disabilities must be able 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 environment' [11]. The Convention explicitly emphasises that people with disabilities have the right to choose from a wide range of support services, whether domestic or residential, and other community support services, including personal assistance necessary for independent living in the community and integration into it and prevent their isolation and segregation. This right includes the right to access and benefit from health and social services, which should enable people to become independent and socially integrated. Herewith, an independent way of life and freedom of choice should be ensured to the recipients of these services (the Convention). However, the right to independent living is broader than the right to life in the community. As we had shown above, independent living, the combination of factors of the environment, human, relationships, etc., leads to the fact that a person has control over his/her own life. The realisation of the right to independent living and inclusion in the community requires adequate social services, which must follow a number of other operating services (employment services, medical care, housing, legal protection, etc.).

Independent living for people with disabilities also requires architectural accessibility of buildings, environment, accessible transportation, availability of the compensation funds and access to personal assistance to all those in need. The condition of independent living is a certain standard of living. This brings us to the issue of social security for people with disabilities (the amount of pension contributions for care) as well as the right to work, which is important not only in terms of financial independence but also because of the meaning of life. It is similar with the right to education, which is associated with the right to work, because education determines your career prospects. The right to live independently includes in itself a number of sub-rights, including the right to life in the community.

5. Deinstitutionalisation of the social services in Slovakia: the lack of discussion

The Convention clearly prohibits forced institutionalisation of people with disabilities, regardless of the extent of disability. Deinstitutionalisation of social services is defined in the Convention as a key legal right of the recipients of social services to the highest attainable standard of physical and mental health [11]. The process of deinstitutionalisation is going on in the EU countries since the 1970s. In the Slovak Republic, as in other post-communist countries, the issue of dealing with the human rights of persons with disabilities and the transformation of social services was addressed with a delay of several decades when compared to other countries of the European Union. In 2011, the government adopted a strategy of deinstitutionalisation of social services in order to foster the social care in the Slovak Republic (strategy for deinstitutionalisation of the social service system and alternative child care in Slovakia) [12]. Actually, it is a political statement which emphasises the essentiality of the deinstitutionalisation, summarises the recent developments in the European Union's strategy and commitments of Slovakia as well as describes the current state of the social services and child care. The strategy was further developed into the National Action Plan, where this National Action Plan foresees the transition from the institutional to community-based social care between the years 2012 and 2015 (the National Action Plan for the transition from institutional to community-based care in the social services system (2012–2015) [13]. There have been several social service centres selected by the government offices for a pilot project of deinstitutionalisation. These centres are supposed to go through the transformation process without prior considerations about the impact of this process on the social service recipients, on their families or on the staff employed by these centres. The term deinstitutionalisation is often simplistically understood as the closure of large residential social service facilities (health and social centre) and their transformation into an institution with a maximum capacity of 40 people.

The process of transformation of institutional care in Slovakia brings with it a number of serious problems. It is a long and complex process in which there is no general and clear instruction on how to transform institutional care to community. Each country must find its own variant of community care and develop a strategy for the transformation of institutional care with careful consideration of all the risks associated with this process taking into account the specificities of various groups of citizens with disabilities. To prepare the reform

of long-term care is important to clarify the basic concepts and identify the nature and essence of the process, its positives, problems and risks. While at the European level, there is a lot of debate about what a transformation of social services must be, in the Slovak context is a totally unexplored area with major consequences for the existence and life of persons who are reliant on care. The literature lacks elaboration on the issues, conceptual analysis and comparative and empirical research. One of the key problems of the transformation of the institutional care process is that there is no clearly defined concept of an institution. In theory, institutions are analysed in terms of their historical development, in terms of structure and character as well as in terms of their social function. One of the most quoted meanings was formulated by D. North in the year 1991. The term institution refers to the established standard procedures to organise political, economic and social interaction. They consist of informal rules (customs, traditions and codes of conduct) as well as of formal rules (e.g. laws) [14]. For example, economic institutions determine how the material resources are distributed and produced in the culture to ensure a certain level of prosperity. Political institutions regulate the public life. In the conditions of a modern society, there is a special type of institutions that for a longer or shorter period of life affect specifically defined groups of citizens. Such institutions include prisons or social service for people with disabilities. These institutions are by their nature different from the ordinary life in the community. A common feature of these institutions is bringing together under one roof of activities such as housing, work and leisure activities, which are usually in modern societies done separately and in different places. Not only are all of these activities performed in one area, but in addition they are carried out according to a well-defined and strictly adherent plan for all.

An American sociologist E. Goffman shifted the problems of this type to sociological and philosophical level. He characterises these institutions as total institutions. This term refers to those institutions that for their members make up an environment that is fundamentally different from the life of the world in which ordinary people live. Goffman totally defines the institution as a place that serves as a residence and workplace, in which a greater number of similarly situated individuals are for a long time (some lifetime) cut-off from the outside community and collectively leads externally closed and formally administered life. Among total institutions, he places such institutions that are established for the purpose of providing care to those who have a problem to take care of themselves due to age or severe disability. Furthermore, he places there such institutions designed to re-educate people threatening others (e.g. prison facility for minors), for risk groups (e.g. detention centres), equipment related to the functioning of society (e.g. military barracks) and, finally, centres creating special environment (e.g. monasteries) [15]. Similarly, a Czech sociologist Keller characterises institutions for people with disabilities, who points out that this type of institutions requires special attention because the latent tendency of all bureaucracies is realised that there is an attempt to look at the clients as not fully equal and inscrutable, as the objects require a certain distance [16]. Further analysis of the institutions established for the provision of care focused on the institutional culture of these institutions. British researchers J. Tizard, R. D. King and N. V. Ravnes, who focused on the interactions between staff and children in various types of social care facilities, report that institutional care is characterised by depersonalisation (removal of signs and symbols of our individuality), the rigid routine (fixed given time of getting up,

meals and activities not respecting personal preferences or needs) and overall collective treatment (people were treated in groups, with no respect for individuality and privacy) and social workers keeping distance from the recipients [17]. Adapting to such routines and a lack of meaningful activities lead clients to passive or institutional behaviour. This is a phenomenon in which a person will behave in a manner which they are attributed by others. Unless prejudices are prevalent among employees about the inability of clients, respectively, that they pose a threat to their families and the wider community in the institution, this creates an atmosphere that basically leads them to such behaviour. For example, by J. Huber and S. Hollins, who observed the lives of 20 men living in closed long-stay institutions, concluded that over the years, the social invisibility of these men contributed not only to their de-socialisation but also to a degree of dehumanisation [18].

It follows that the concept of a total institution refers to some institutional culture and deinstitutionalisation of social services is not just a question of restrictions on investments in existing large residential institutions. Closing of institutions and developing community-based services are aspects of this process. The part of this process is to change the paradigm of care: the transition from the medical model to the social, from patient to citizen and from the care facility to the right holder. There is often a view that the above-described problems can be solved by improving the material conditions [13]. As we showed above, the problematic characteristics of institutional care are not exclusively linked to poor material conditions. Favourable staffing and clients as well as the emphasis on meaningful activities could of course improve the quality of care. However, the problems associated with depersonalisation, overall procedures, rigid routines and social distance keeping persist in establishments where the overall material conditions are good. To overcome institutionalisation is not enough to reduce the number of beneficiaries of social services, increase the number of employees and geographically place the institution to some community or its modification into an ordinary house that does not look from the outside as an institution. Even the smallest residential services can reproduce the institutional culture. There is a whole range of other factors such as choice, which recipients of services have the level and quality of support, involvement in the community and various forms of pressure on recipients to undergo drug treatment, psychiatric evaluation and therapy, etc., which show that in small institutions there can be a significant institutional character of care. As long as characteristics typical of total institutions predominate, there is a group of second-class citizens without a right to independent living as this group of persons is subject to the system, which modifies most or all of their life.

Total institutions derive their strength and longevity not only from their compactness and closeness before the community but also from other pitfalls of deinstitutionalisation. Following on human rights documents, the term institutionalisation refers to a process which transforms the institution both in terms of formalised structure of rules and philosophy of social services as well as produces a wide range of services in the community, including the prevention of institutionalisation, through obviating the need for an institutional care [19]. From this perspective, the process of deinstitutionalisation requires to adopt measures to ensure that the public services, such as social and health care, education, housing, transport and culture, are accessible to all, regardless of age or disability. The process of deinstitutionalisation, however, has been criticised for underappreciation and underestimating the risks that it entails. While this

process should bring improved quality of life to clients of these institutions, the experience of other countries in recent decades has shown that it was accompanied by insufficient development of alternative care, which meant that beneficiaries were left without access to social services. These ambiguous deinstitutionalisation processes have been reported in the UK, in the US and also in Italy [20]. Unrealistic expectations and deadlines, as well as the lack of financial resources, prevented this process from being transformed in a manner that each recipient has ensured access to appropriate services. Deinstitutionalisation is often interpreted as a threat to the social state, in the sense that the main purpose of this process is to reduce public spending on social welfare [21]. The analyses of public spending on community-based care showed that for most beneficiaries, this form is less expensive than care in residential facilities (if one disregards the cost of inputs), but for certain categories of beneficiaries who require a 24-hour assistance to community care, it is more expensive [22]. Recent economic developments mentioned dilemma between costs and results in a new perspective. The economic crisis is associated with the risk that the government and the municipalities want to keep the budget balanced by reducing expenditure on public services, of which the largest part is the cost of staff salaries. Therefore, there is the risk of cutting the number of employees to the number of recipients of services and redundancies of employees in both residential and community services.

An important subject to the process of deinstitutionalisation is that it can affect the development of new forms of exclusion, including poverty. Independent living for people with disabilities depends on their economic status in society. Persons with disabilities constitute a significant proportion of people at risk of poverty, and the need for income is higher for them than it is with the non-disabled, precisely because of the necessary support, which enables them to lead a normal life [23]. Many cannot afford to leave the institute because their incomes are insufficient to cover the necessary costs of living in a normal environment. This situation is in our view reinforced by the current interpretation of the Slovak law on the social security, which promotes the dependency on charity. An example for this may be the effort of the Ministry of Health of the Slovak Republic to reduce the costs within the so-called consolidation of the public finances by avoiding reimbursement of an electric or mechanical wheelchair from public health insurance (through health insurance companies). For people with severe physical disabilities, this means a serious interference with their independence and autonomy. Similarly, the requirement towards the recipient to financially contribute towards the cost of the mobility aids implies the dependence of these recipients on the charity, as the pension of these recipients is often insufficiently high for this. Another example of an attempt to redirect the social service provision towards the charity was the draft amendment to Act No. 580/2004 body of law, on health provisions, which requires the recipients to contribute towards the cost of the personal assistance, which was currently set at 1.39% of the subsistence minimum, i.e. 2.76 € per hour plus the tax payments. This meant destruction of personal assistance as a kind of social service. It should be mentioned that the vague definition of the right to social services determines the direction of the transformation of social services. The tension between private and public sector opens up a space for discourse on the nature of the social policy of the government and state functions.

Another serious problem is related to the question of deinstitutionalisation of social services—the problem of strengthening the competencies of persons dependent on the assistance of

another person, so that each individual can choose for himself the most effective and most appropriate way to ensure needs. Several surveys in Slovakia [24] have been confirming for the long time the poor even critical income situation and financial security of the elderly and persons with disabilities; thus, for a significant part of this population, social services become unavailable. The financial inaccessibility of the social services and their insufficient capacity are explicitly mentioned as one of the biggest challenges by a tenth of the elderly [24]. At the same time, social services are defined as services of general interest. This implies a policy orientation, which goes beyond the interests of one group. In other words, it contributes to social equality improvement and to reduction of social exclusion and isolation. This task is to be fulfilled by four requirements: universal access, affordability, justice and quality of social services [25]. General availability is obliged to offer defined services according to specified conditions, including complete territorial coverage and affordable prices for all persons. Affordability of services of general interest is defined by reference to the income structure, the cost of living, the structure of the consumer basket and other criteria in a particular state. Based on the understanding of the social services as services of general interest, it is the responsibility of the state power how to fulfil these requirements. The state may impose a variety of ways to ensure the obligation to affordable services for the low-income groups—through price controls, providing the address contribution for care and the like. The principle of affordability may in some cases mean that for everyone, or for specific vulnerable group, the service is free and the state pays a loss to the provider.

Social inclusion of people with disabilities also prevents negative attitudes and prejudices of the majority of the society towards them, as well as against older people. In addition, the form of societal disinterest in these socially excluded, unacceptable nodding to uselessness of a large group of people who have become a social burden can be observed. The denial of their human uniqueness and peculiarity strengthens the enforcement of uniformed institutional care with formal pseudo-individualisation. Deinstitutionalisation is usually also considered to be too utopian social project or a wishful thinking, especially for people with a broader range of disabilities. Transformation projects are generally focused only on people with mild or moderate form of disability [13]. People with severe disabilities or with more complex needs are excluded from this process. An idea that this group of people needs continuous care in institutional facilities prevails. The result is that in such institutions small staff with a large number of severely disabled people remains. The assumption that institutional care is a safer option for those people was questioned by numerous reports and publicised cases which justify the frequent cases of ill-treatment of beneficiaries and the poor quality of care in these facilities (see, e.g. Refs. [26, 27]). This situation can be attributed to a lack of protective mechanisms that would prevent the criminal acting, and the fact that people with severe disabilities are not able themselves to obtain help and support. The needs of recipients must also be taken into account, and an operational support system for these people should be established.

6. Conclusion

The study was devoted to clarifying the concept of quality of life in the context of social services. Using the concepts from the social and political philosophy, we have demonstrated that the

issue of quality of life is an organic part of respect, implementation and enforcement of human rights with an emphasis on the social rights, especially the right to live independently. In the study, we analysed Sen's interpretation of welfare that focuses not only on the achieved results such as income level and material resources but also on the freedom to deal with things in life that one realistically values. We see two benefits of this approach. One of the benefits is that it allows one to focus the attention to the reasons that caused the loss of freedom and, respectively, the capability deficit and thus to help determining the degree of responsibility, which plays a key role in issues of entitlement to compensation from the society. The degree of freedom or the capability provides more information about existing opportunities and possibilities of the individual to make free decisions and allows identifying inequalities caused by the social structure that disadvantages, marginalises or discriminates against certain groups. The second benefit of the approach focused on the capability is that it can reflect the pluralism of human lives. It not only reduces the human achievement to the chosen means (as income) but also takes into account other aspects that make life meaningful and that people consider an achieved success.

In practical terms, the methodology for measuring well-being through the social functioning is used to measure the standard of living and social prosperity of individual countries. These analyses of poverty and inequality are still not included in the evaluation of these components. The practical application of this methodology provides additional information to conventional methods based on the revenues or the gross domestic product. Based on the conceptualisation of the term right to independent living, we tried to identify the specific elements that are essential for the transformation of social care in the Slovak Republic. We have shown that independent living, the combination of factors of the environment and humans, leads to the fact that a person has control over their own lives. In the last part, we analysed the basic problems of transformation of social care from the institutional forms to the community form in Slovakia. This process was evaluated in terms of its impact on the social functioning and capabilities of people with disabilities. We have identified that, in some cases, a lack of capability is due to low economic output and, in others, it may be a weak social security, sometimes social structure or institution or social norms, traditions and customs. We have shown that improving the quality of life of people with disabilities is not only a question of closing institutions. This process includes a change of the paradigm of care and takes measures to ensure that public services such as social and health care, education, housing, transport and culture are accessible to all, regardless of age or disability. It should also be accompanied by measures aimed at fighting poverty, which may be one of the main reasons for the institutionalisation of people with disabilities. Unpreparedness of deinstitutionalisation (material, organisational, legislative, institutional, personal) and the lack of discussion in Slovakia on the new forms of social care keep destroying the current system (even if non-compliant) without adequate substitution.

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Author details

Zuzana Palovičová

Address all correspondence to: palovicz@gmail.com

Philosophy Department of the University of St. Cyril and Metod, Trnava, Slovakia

References

- [1] Sen A Development as freedom. 1st ed. Oxford: Oxford University Press; 1999. 366p.
- [2] Sen A Capability and well-being. In: Nussbaum M, Sen A, editors. The quality of life. 1st ed. Oxford: Clarendon Press; 1993. pp. 30-52.
- [3] Sen A Inequality reexamined. 1st ed. Harvard: Harvard University Press; 1995. 224p.
- [4] Sen A Well-being, agency and freedom: The Dewey lectures 1984. The Journal of Philosophy. 1985; 82(4):169-221. DOI: 10.2307/2026184.
- [5] United Nations Development Programme (UNDP) Human development report 1990. Concept and measurement of human development [Internet]. 1990. Available from: <http://hdr.undp.org/en/reports/global/hdr1990> [Accessed: 16.11.2016].
- [6] Nussbaum M Frontiers of justice: Disability, nationality, species membership (The Tanner lectures on human values). 1st ed. Harvard: Belknap Press; 1997. 512p.
- [7] Nussbaum M Women and human development: The capabilities approach (The Seeley lectures). 1st ed. Cambridge: Cambridge University Press; 2001. 338p.
- [8] Kuklys W Amartya Sen's capability approach. Theoretical insights and empirical applications. 1st ed. Berlin Heidelberg: Springer; 2005. 116p. DOI: 10.1007/3-540-28083-9.
- [9] European Commission Europe 2020. A European strategy for smart, sustainable and inclusive growth [Internet]. 2010. Available from: http://ec.europa.eu/europe2020/europe-2020-in-a-nutshell/index_en.htm [Accessed: 16.11.2016].
- [10] European Union Charter of fundamental rights of the European Union [Internet]. 2000. Available from: http://www.europarl.europa.eu/charter/pdf/text_en.pdf [Accessed: 16.11.2016].
- [11] United Nations Convention on the rights of persons with disabilities [Internet]. 2006. [Updated: <http://www.un.org/disabilities/convention/conventionfull.shtml>]. [Accessed: 16.11.2016].
- [12] Ministry of Labour, Social Affairs and Family of the Slovak Republic Strategy for deinstitutionalisation of the social service system and the alternative child care in Slovakia [Internet]. 2011. Available from: <https://www.employment.gov.sk/sk/rodina-socialna-pomoc/socialne-sluzby/> [Accessed: 16.11.2016].

- [13] Ministry of Labour, Social Affairs and Family of the Slovak Republic National action plan for the transition from institutional to community-based care in the social services system 2012-2015 [Internet]. 2011. Available from: https://www.employment.gov.sk/files/legislativa/dokumenty-zoznamy-pod/narodny-plan-deinstitucionalizacie_en.pdf [Accessed: 16.11.2016].
- [14] North DC Institutions, institutional change and economic performance. 14th ed. Cambridge: Cambridge University Press; 2002. 152p.
- [15] Goffman E. Asylums: Essays on the social situation of mental patients and other inmates. 1st ed. New York: Doubleday; 1961. 386p.
- [16] Keller J Sociologie organizace a byrokracie. 2nd ed. Praha: SLON; 2007. 182p.
- [17] King RD, Raynes NV and Tizard J Patterns of residential care: Sociological studies in institutions for handicapped children. 1st ed. London: Routledge and Kegan Paul; 1971. 255p.
- [18] Hubert J, Hollins S Men with severe learning disabilities and challenging behaviour in long-stay hospital care: Qualitative study. The British Journal of Psychiatry. 2005; 188(1):70-74. DOI: 10.1192/bjp.bp.105.010223.
- [19] European Union Common European guidelines on the transition from institutional to community based care by European Expert Group on the transition from institutional to community-based care [Internet]. 2012. Available from: <http://www.deinstitutionalisationguide.eu/wp-content/uploads/2016/04/GUIDELINES-Final-English.pdf> [Accessed: 17.11.2016].
- [20] European Union Report of the ad hoc expert group on the transition from institutional to community-based care [Internet]. 2009. Available from: <http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=614&furtherNews=yes> [Accessed: 17.11.2016].
- [21] Mansell J Deinstitutionalisation and community living: Progress, problems and priorities. Journal of Intellectual and Developmental Disabilities. 2006; 31(2):65-76.
- [22] Mansell J, Knapp M, Beadle-Brown J, Beecham J Deinstitutionalisation and community living – outcomes and costs: Report of a European Study. Main report. Vol. 2. 1st ed. Canterbury: Tizard Centre University of Kent; 2007. 134p.
- [23] Ministry of Labour, Social Affairs and Family of the Slovak Republic Report on the social situation of the population of the Slovak Republic for 2015 [Internet]. 2016. Available from: <https://www.employment.gov.sk/files/slovensky/ministerstvo/analyticke-centrum/sprava-socialnej-situacii-obyvatelstva-za-rok-2015.pdf> [Accessed: 18.11.2016].
- [24] Guran P Social services for elderly – Evaluation and attitudes. In: Piscova M, editor. Ageing and the elderly: Conditions and context. 1st ed. Bratislava: Institute for Sociology of the SAS; 2014. pp. 104-124.
- [25] European Union Social services of general interest. European Parliament resolution of 5 July 2011 on the future of social services of general interest (2009/2222(INI)) [Internet]. 5.7.2011. Available from: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//NONSGML+TA+P7-TA-2011-0319+0+DOC+PDF+V0//EN> [Accessed: 18.11.2016].

- [26] United Nation Forgotten Europeans – Forgotten rights: The human rights of persons placed in institutions [Internet]. 2010. [Updated: http://www.europe.ohchr.org/Documents/Publications/Forgotten_Europeans.pdf] [Accessed: 18.11.2016].
- [27] ECCL European Coalition for Community Living Wasted Time, Wasted Money, Wasted Lives... A Wasted Opportunity? A Focus Report on how the current use of Structural Funds perpetuates the social exclusion of disabled people in Central and Eastern Europe by failing to support the transition from institutional care to community-based services [Internet]. 2010. [Updated: <http://community-living.info/wp-content/uploads/2014/02/ECCL-StructuralFundsReport-final-WEB.pdf>]. [Accessed: 18.11.2016].