# DISABILITY AND LONG-TERM ILLNESS – DEFINING, COSTS AND TASKS FOR LOCAL SOCIAL POLICY

Magdalena Maciejasz Paweł Kubicki

Warsaw School of Economics

# INTRODUCTION

Disability and long-term or serious illness are already some of the main causes for the provision of social assistance<sup>1</sup>. They are also a challenge for social policy because of their scale – according to the National Census, there are at least 4.697.500 disabled people, or 12.2% of Poland's population (GUS 2012a: 63–67). Another key cause of this phenomenon is the scale of expenses (both individual and social) estimated, according to data from 2010, at PLN 64.4 bn, which accounted for 4.6% of the GDP (Piętka-Kosińska 2012: 59).

Both of these tendencies are interrelated – long-term illness can lead to disability. *In wealthy EU countries, the effects of long term illnesses account for over 80% of disabilities; in Poland that share is lower, at over 60%* (Golinowska, Sowa 2012: 11)², which is also associated with the aging of the population (Topór-Mądry 2011: 25). The similarity of both risks is even clearer when, instead of the definition of disability set by the Polish law, we refer to the one which was set out in the UN convention on the rights of disabled people, according to which (article 1) the disabled include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

At the same time, challenges related to disability and long-term illness, including above all those associated with the provision of care on the one hand and rehabilitation and social integration on the other, will intensify due to the aging of Poland's population. Results of the PolSenior survey also underscore the fact that the older the person is, the more frequently he or she is affected by restricted independence, and the need for assistance from other people increases drastically after turning eighty (Błędowski 2011: 33, 35).

Knowing that health problems intensify with age, and keeping in mind the ongoing demographic changes, in particular the lengthening of life expectancy, declining fertility rates as well as the change of the family model, one can expect an increase of benefits related to illness or disability as a percentage of all social assistance benefits disbursed. For institutions responsible for social policy, an increasingly longer lifespan means not just a higher number of beneficiaries, but also an extension of the period in which they receive assistance, which is primarily due to the fact that a longer life does not mean a longer life in good health. Eurostat data for Poland shows that, while the expected average lifespan of men and women at the time of birth is increasing systematically, the number of years in good health is declining<sup>3</sup>.

Considering the above, it becomes clear that the care system for disabled people needs to be considered carefully. Perhaps one should even talk about the creation of such a system, since the existing solutions, in which the family played the role of the primary caretaker, will no longer be accessible to a large part of the Polish society, for demographic and social reasons.

# **DEFINITIONS**

Expert studies (Roulstone and Prideaux 2012: 1–20; Brzezińska et al. 2010: 11–20; Kołaczek 2010: 40–45; Shah and Priestley

2010: 5–22; Woźniak 2008: 36–110) concerning the perception of disability show a visible change from a more medical approach, one that focuses on the lack of ability and deficiency of an individual, to a social approach, one focused on the functioning of a disabled person within the society (see also Kurowski 2012 )<sup>4</sup>. Precisely because of this change, the starting point for theoretical discussions in the Calculator of Costs of Inaction project was the definition of a disabled person compatible with the above UN Convention on the rights of disabled persons. However, in practice, at a local level and in everyday work of social services, this definition plays a lesser role; the predominant definition is the legal one, according to which a disabled person is someone who possesses an appropriate disability certificate issued by an authorized institution, which typically in the case of social assistance means county-level teams for disability certification.

At this point it is worth noting that the law on social assistance does not include any definition of disability. It does, however, refer to the law on professional and social rehabilitation of disabled persons, which defines disability as a permanent or temporary inability to fulfill social roles due to permanent or long-term bodily impairment, in particular one which leads to an inability to work.

Due to the need to operationalize the issue of disability for the purposes of the Social Calculator, the project distinguishes between three levels of disability (Table 1). This division was made because of the scale and scope of support required by recipients of social assistance centers.

Table 1. Definitions of levels of disability

Level	Characteristics of people assigned to specific groups				
Level 1	A person who requires minor, temporary support in selected tasks th go beyond activities of daily living or rehabilitation/therapy over a limit timeframe. This person can participate in social life independently or wi little support.				
Level 2	A person who requires daily support at their place of residence, consisting of caregiver (home assistance <sup>5</sup> and nursing) services or daily therapy/rehabilitation. This person requires support in order to participate in social life.				
Level 3	A person requiring regular support at their place of residence for activities of daily living or intensive daily therapy/rehabilitation. person is only able to participate in social life with the assist of another person. The person fulfills the criteria for being place a 24-hour residential facility.				

Source: proprietary research.

The law on social assistance<sup>6</sup> also does not define the term long-term or serious illness. It merely lists it as one of the reasons for the provision of assistance to individuals and families (article 7). In health-related nomenclature, we are more frequently seeing use of the term 'chronic disease'. The World Health Organization describes it as a disease with a long duration and a slow course<sup>7</sup>.

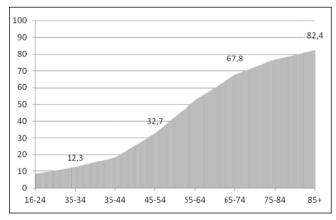
A more extensive but similar definition is given by the *Lexicon* of gerontology, where a chronic disease is defined as an aliment or a pathological state, which persists over a long time and which will continue to persist [...]. The main features of

a chronic disease are: long-term duration, milder course than at an acute stage, deterioration of patient's performance and their dependence on a caregiver, irrevocability of pathological changes and negative prospects as well as psychological and social consequences. Persons suffering from a chronic disease require long-term care — medical, nursing and/or rehabilitation (Zych 2010: 318).

At the same time Nitecki describes the disease not based on its features, but on its impact. A long-term illness will apply to people who are certified or diagnosed as suffering from a longterm illness by doctors authorized to make such diagnosis: such an illness will cause increased spending on medicine or food products required with the recommended diet, or will cause restrictions in the opportunities to find employment. [...] Not every long-term illness will be treated as a reason to receive financial benefit from social assistance, only the ones which contribute to an increase of the individual's or family's expenses related to the treatment of such illness, or potentially reduce chances to gain employment in the labor market in order to meet the essential needs of the individual or a family (Nitecki 2008: 169)9. However, discussions with practitioners show that possession of the medical certificate referred to above is not a prerequisite to receive assistance due to a chronic or serious illness.

Due to the absence of a definition of long-term or serious illness in the law on social assistance - which often makes the interpretation difficult [refers to the causes entitling one to the provision of social assistance benefits - author's note]; at the same time it allows flexibility in their use and facilitates the fulfillment by the administration of the goals and tasks put forward by the law (Nitecki 2008: 159-160)<sup>10</sup> - for the purpose of this project, we have adopted a very general description of persons suffering from longterm or serious illness, which says that it extends to persons who require the assistance of other people, due to their age or an illness and the associated life difficulties, but are lacking such help. Old age is not tantamount to dependence on the assistance of other people (Błędowski 2012: 55), but the definition does incorporate age mainly due to the fact that older people are more often affected by long-term health problems than younger ones (Figure 1). Discussions with experts indicate that often it is difficult to state clearly whether the difficulties in life are caused by the illness, or due to the advanced age of the given person and the associated limitations.

Figure 1. Percentage of people suffering from long-term health problems in Poland by age (2011)



Source: proprietary, based on Eurostat data (hlth\_silc\_05).

Just as in the case of disability and other social problems, persons suffering from long-term or serious illness were divided into three subgroups (levels) shown in Table 2.

Table 2. Definitions of levels within long-term or serious illness

Level	Characteristics of persons assigned to specific groups		
Level 1	A person who, because of the state of their health, requires minor, temporary support in selected tasks, which go beyond the basic daily activities. This person can participate in social life independently or with little support.		
Level 2	A person who temporarily, because of the state of their health, required daily or almost daily assistance consisting of caregiver (assistance a nursing) services. This person requires support in order to participate social life.		
Level 3	A person who temporarily, because of the state of their health, requires regular support in most daily activities. This person is only able to participate in social life with the assistance of another person.		

Source: proprietary research.

# TASKS OF THE LOCAL GOVERNMENT

The law on social assistance defines which tasks are carried out at the level of commune and the county and also divides them into own (mandatory and optional) and assigned tasks (articles 17–20). These tasks can be divided into financial, material and service-based (Table 3). The law on communal government contains no direct references to persons with disabilities.

Analyzing the above list of services, it is clear that most of them are interventionary in nature. The vast majority of people with disabilities and those suffering from long-term or serious illness are receiving financial assistance (Błędowski 2012: 58). Analysis shows that [financial] benefits distributed by social assistance have a negligible impact on limiting poverty (Wóycicka 2011: 131)<sup>11</sup>, therefore one can assume that the amount of benefits is also insufficient to cover the cost of treatment, therapy and care.

On the other hand, care services, particularly specialized caregiver services which could help both ill and disabled people, retain their independence for a longer period of time [...], are not fully utilized by the interested parties and their families and above all by the assistance centers (Deja 2006: 2)12. It is also essential to define specific standards of caregiver services (see for example the standards of caregiver services developed by WRZOS) (Starega--Piasek et al. 2011) and the benefits' catalogue (Wyrwicka, Łukasik 2010: 90)13, since right now the scope of support available in various counties differs, which is due not just to the varied needs, but also to the different financial capacities of the various local governments. At this moment, it is also worth noting the contradiction between the expectation for individualized support, adapted to specific needs of an individual and therefore far from being uniform, and the need to offer a certain standard, averaging the assistance that is being provided.

One solution which could help raise the quality of services being provided and increase the number of organizations that offer these services would be to provide caregiver services in the form of a coupon or a service voucher, which the recipient could claim at a facility of their own choice (Wyrwicka, Łukasik 2010: 90): (draft law on assistance to disabled persons). While definitely desirable, the development of a system of community caregiver services would first require change in the financing of these benefits within the framework of the social assistance system, since in practice, the present level of communal spending on caregiver services does not allow more people to be covered by such services without limiting spending on other goals related to social assistance (Błędowski 2011: 35). The fact that people affected by long-term illness and the disabled account for nearly one third of the recipients of social assistance is a testimony to the scale of essential support for such people. One must also emphasize that the overwhelming majority of nursing home residents comes from these two groups.

Table 3. Responsibilities (tasks and services) of county and the commune (institutions of self-government) in the area of disability-related assistance

Institution	Legal basis	Task	Туре	Mandatory
Commune	Article 17 par. 1 point 4 UoPS	Granting and disbursement of temporary benefits	Proprietary	Yes
Commune	Article 17 par. 1 point 5 UoPS	Granting and disbursement of designated benefits	Proprietary	Yes
Commune	Article 17 par. 1 point 9 UoPS	Payment of pension and disability insurance premiums on behalf of a person who gives up work due to the need to provide direct, personal care to a family member suffering from long-term or serious illness and assistance to non-resident mother, father or siblings	Proprietary	Yes
Commune	Article 17 par. 1 point 11 UoPS	Organizing and provision of care services, including specialist inhouse services, with the exclusion of specialist caretaker services for people suffering from psychiatric disorders	Proprietary	Yes
Commune	Article 17 par. 1 point 12 UoPS	Conducting and ensuring accommodation at protected accommodations	Proprietary	Yes
Commune	Article 17 par. 1 point 15 UoPS	Arranging a funeral	Proprietary	Yes
Commune	Article 17 par. 1 point 16 UoPS	Referral to a residential and nursing home and paying for the stay of a communal resident at that facility	Proprietary	Yes
Commune	Article 17 par. 1 point 19 UoPS	Granting and disbursement of regular welfare benefits	Proprietary	Yes
Commune	Article 17 par. 2 point 1 UoPS	Granting and disbursement of special, designated welfare benefits	Proprietary	No
Commune	Article 17 par. 2 point 2 UoPS	Granting and disbursement of assistance to facilitate economic emancipation in the form of benefits, loans and material help	Proprietary	No
Commune	Article 17 par. 2 point 3 UoPS	Managing and providing accommodation at residential and nursing homes and commune-level support facilities and referring people who require care to these facilities	Proprietary	No
Commune	Article 18 par. 1 point 3 UoPS	Organizing and provision of specialized in-house care services for people suffering from psychiatric disorders	Contracted	Yes
Commune	Article 18 par. 1 point 5 UoPS	Managing and development of the infrastructure of community self-help homes for people suffering from psychiatric disorders	Contracted	Yes
Commune	Article 18 par. 1 point 6 UoPS	Executing tasks which arise from governmental social assistance programs, designed to safeguard the living standards of individuals, families and social groups and the development of specialized support services	Contracted	Yes
Commune	Article 16 par. 1 UoŚR	Nursing benefits	Contracted	Yes
County	Article 4 par. 1 point 5 UoPS	Support of disabled people	Proprietary	Yes
County	Article 19 par. 1 UoPS	Preparation and execution of the county strategy to resolve social problems, with a particular focus on social assistance programs and support of disabled people	Proprietary	Yes
County	Article 19 par. 2 UoPS	Offering specialized advisory services	Proprietary	Yes
County	Article 19 par. 6 UoPS	Granting of financial assistance for the emancipation and the continuation of education to people, who leave residential and nursing homes and to mentally challenged children and young people	Proprietary	Yes
County	Article 19 par. 7 UoPS	Assistance in community integration of people facing difficulties in the adaptation to life, young people leaving residential and nursing homes and mentally challenged children and young people	Proprietary	Yes
County	Article 19 par. 10 UoPS	Management and development of the infrastructure of supra-communal residential and nursing homes and providing accommodation to people referred to these facilities	Proprietary	Yes
County	Article 19 par. 11 UoPS	Managing protected housing for persons from more than one commune and from county support centers	Proprietary	Yes
County	Article 19 par. 12 UoPS	Managing crisis intervention centers	Proprietary	Yes
County	Article 20 par. 2 UoPS	Management and development of the infrastructure of support centers for people with psychiatric disorders	Contracted	Yes
County	Article 6 UoRZiSoZON	Management of county-level teams charged with issuing disability certificates	Contracted	Yes
County	Article 10b par. 6a UoRZiSoZON	Inspecting occupational therapy workshops at least once a year	Contracted	Yes
County	Article 10b par. 1, 2; Article 29 par. 1 UoRZiSoZON	Opportunity to set up and conduct occupational therapy workshops and institutions of professional motivation (including the obligation to participate in expenses referred to in article 10b, par. 2a)	Proprietary	No

Abbreviations: UoPS – law on social assistance, UoŚR – law on family benefits, UORZiSoZON – law on professional and social rehabilitation and the employment of disabled person. Source: proprietary based on review of relevant laws, legal status as of Dec. 31, 2013.

Although people suffering from long-term illnesses and the disabled usually rely on help of their closest ones (Hrynkiewicz 2012: 13), there is a shortage of services addressed directly towards these informal caregivers. Considering the declining care-giving potential of the family, it is essential to provide support to caregivers at an early stage of the performance of care services. Unfortunately, this aspect is often overlooked in the current support system at the local level, which may lead to premature burnout and exhaustion of family caregiver resources.

Table 4. Number of families who received assistance in 2013

Social problem  - basic cause for the provision of assistance	Number of families who received benefits of social assistance
Poverty	754 726
Unemployment	685 993
Long-term or serious illness	429 704
Disability	412 880
Inability to perform guardianship and educational duties and managing a household	241 652
Protection of motherhood	127 184
Alcoholism	89 647
Homelessness	37 317
Difficulty in adapting to life after release from a penal institution	21 284
Family violence	20 187
Crisis situation	10 666
Random event	8 594
Drug abuse	3 808
Natural or ecological disaster	2 132
Orphanhood	1 985
Difficulty in integration of people who were granted refugee status or subsidiary protection	567
Protection of victims of human trafficking	62

Source: proprietary, based on MPiPS-03 report.

# **COSTS OF ILLNESS AND DISABILITY**

One of the key elements analyzed as part of the Social Calculator was the cost of support being provided. Traditionally, at the local level, these costs are included in the budget spending by institutions of the local government. However, they can be classified not only by the type of payer, but also by the type of expenditure:

- 1) costs incurred individually by the disabled or ill person and their family, and the general social expenses,
  - 2) economic and non-economic costs and
- 3) direct and indirect costs, with the latter used primarily in the economics of health care (Piętka-Kosińska 2012: 7).

Foreign literature, particularly in the US, contains numerous studies which estimate costs of an illness<sup>14</sup>. Below is a description of some of the methods used to calculate the costs of illness (*The Global Economic*... 2011):

- 1) cost of illness this approach consists of adding up the various direct and indirect costs, such as personal, related to medical diagnosis, cost of medicine, non-medical (e.g. transporting the sick person). Also included are the costs associated with lost wages as well as non-measurable costs (pain and suffering);
- 2) value of lost output this method estimates the impact of an illness on the GDP by examining the impact of a disease on contraction of the labor market, capital and other production-related factors;

3) value of statistical life – this method reflects the amount that the society is ready to pay in order to reduce the risk of a disability or death related to long-term illness.

Disability and long-term illness are also associated with a number of non-measurable costs, i.e. those that are difficult to value in monetary terms and ones that have no market value. These include, among others, pain, suffering, bitterness and grief. These are the so-called emotional costs (Olcoń-Kubicka, Kubicki 2012: 55). However, there are methods that can be used to incorporate these costs as part of total costs of an illness (for example the Health Related Quality of Life – HRQL) (Muennig 2008: 251).

Another factor to which it is difficult to assign a specific monetary value is time. In Poland, disabled persons are usually cared for by their families and care is mistakenly treated as being "free" (Jurek 2007: 112). In reality its value is huge, but there is a lack of consensus on how to measure its economic worth (Faria et al. 2012: 22). If we treat the time as a resource, which the informal caregiver could spend on some other purpose, for example paid work, it would turn out that the time devoted to care can be treated in the calculations as the value of lost financial gains, or the value of lost free time, if the caregiver was able to spend that time according to their own need.

Analysis of the amount of time devoted to adults requiring care conducted as part of the "Analysis of selected aspects of the current and future situation on the labor market — Barriers to professional activity among women and people in older groups of the productive age" project has shown that 39% of women and 38% of men devote up to 10 hours a week to care, 33% of men and women between 11 and 30 hours and 28% of women and 29% of men spend over 30 hours a week (Kotowska, Wóycicka 2008: 134).

There are several methods of valuing the cost of this time. For example, the alternative cost method, or the self-evaluation method in which the caregiver estimates the value of time devoted to care (in monetary units). Researchers in Australia, based on time spent on care by informal caregivers and treating this time as lost financial opportunities, have calculated the alternative cost of all caregivers in 2010 at AUD 6.5bn, or 0.5% of the GDP and 9.5% of the value of formal health care (*The economic value*... 2010: 18).

Another possible method is the method of replacement valuation, which consists of calculating the cost of purchasing the equivalent number of hours of care provided by informal caregivers from the formal care sector. Using the same values as in the previous method, the researchers have calculated the costs of care in 2010 at AUD 40.9bn (an equivalent of 3.2% of the GDP and 60% of the value of formal health care) (*The economic value*... 2010: 20).

Table 5. Cost of selected benefits granted as part of social assistance

Form of assistance	Number of people who received the benefit	Value of benefits over the year, in PLN	Value of benefits over the year per person, in PLN
Temporary benefit related to long-term illness	45 089	44 600 611	989
Temporary benefit related to disability	52 381	51 390 383	981
Care services (total)	86 967	370 800 615	4264
Specialized care services	4 191	13 805 642	3294
Payment by commune for the stay at a residential and nursing home	43 464	896 666 263	20 630

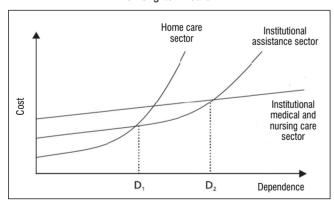
Source: proprietary, based on MPiPS-03 report for 2013.

In the Calculator of Costs of Inaction project, costs of illness or disability itself have not been calculated using the above methods; it does not incorporate non-measurable costs either. However, it does include expenses paid by the institution of local government on measures related to assistance to disabled and sick persons. This limitation is a compromise between the theoretical approach, which would suggest or even require incorporating all the costs and empirical knowledge. One of the limitations is the absence of appropriate data to make an accurate estimate of all the costs incurred by families and institutions in connection with an illness and disability.

Another limitation, more important for design reasons, is the expectation of the project leader and the local authorities regarding the potential utility of the tool. In this case, a more practical tool is one which would facilitate the calculation of costs and expenses paid from the budget of local government organization. Hence, the majority of data used in the project is official statistics and only when those are missing, is the project based on interviews with experts. Table 5 contains a list of selected benefits provided as part of social assistance and their costs shown as part of MPiPS-03 reports for the year 2013.

Practical experience shows that the costs of assistance offered as part of institutional care are much higher than the costs of community-based assistance. We are ignoring here the guestion of quality of care services provided inhouse. The fact that, in Poland, more people who are dependent on others receive help in residential facilities than use these services at home (Błędowski 2012: 61)<sup>15</sup> is even more worrisome. Jackson has tried to determine the optimum model of the "balance of care" using economic analysis technique. Researching the relationship between the degree of a person's dependency and the cost of care required by that person, he has found that home care is the most effective at a low level of dependency, at the medium level it is the care provided the by institutional social assistance sector. while hospital care is the most effective at a high level of dependency (Figure 2). This conclusion should serve as an argument supporting care services provided in-house, which over a longer period of time would help reduce expenses of the entire long-term care system.

Figure 2. Level of dependence and the cost of long-term care



Source: Jurek 2007: 114.

If not just the financial matters are considered but also, or perhaps above all, the negative consequences associated with the stay at residential long-term care facilities (e.g. social, physical and emotional deprivation), deinstitutionalization of care may prove essential<sup>16</sup>. Undoubtedly however, the best investment is the prevention of disability rather than restoration (Piętka-Kosińska 2012: 60), which is yet another argument for a policy of prevention and activation.

### **SUMMARY**

Recent protests by parents and caregivers of the disabled<sup>17</sup> and the so-called round table organized on April 30, 2014 by the Ministry of Labor and Social Policy to discuss systemic solutions concerning the support for the disabled<sup>18</sup> and the already announced future proceedings as part of topical discussions devoted to selected areas of support have shown that, on the one hand there are strong social expectations versus the state and on the other they have revealed the existence of key areas in need of improvement, according to both the protesters and the experts. One of these areas is definitely the system of community support and the care services provided within the family or in replacement of family care.

At the same time, analysis as part of the Calculator of Costs of Inaction project has shown that there is a shortage of tools which would allow estimates of the costs of support measures, including the costs of inaction. As an aside, it is worth mentioning that most often these "immeasurable" costs are borne by women who offer "unpaid" work and are plugging the holes in the support system set up as part of the social policy. The evidence includes experiences of families with disabled children (Kubicki 2014), where it is women that provide the majority of caregiver functions, as well as studies on the issue of valuation of care services (Benoit, Hallgrimsdottir 2011). That feminization of care and domination of family care over alternative forms of support will need to change in Poland, if only for demographic and social reasons.

While it goes beyond the scope of this article, it is also worth considering changing the method of calculating costs of certain measures.

The whole calculation might have changed significantly if we included the benefits associated with the reduction of costs paid by other organizations because of the provision of care services or nursing assistance. For example, with a changed perspective and valuation method, cessation of the provision of care services, which are an expense from the point of view of local government budget, while taking into consideration expenses paid by the family or by the health care system might have led to a situation where actions seen as a burden for the local budget would be recognized as a high-return social investment.

According to the MPiPS-03 report, disability and long-term or serious illness accounted for approximately 30% of all the causes for the disbursement of assistance in 2013 in Poland.

<sup>&</sup>lt;sup>2</sup> Translation ours.

In Poland, women's average life expectancy at birth rose from 79.3 years in 2005 to 81.1 years in 2012, while the number of years in good health declined from 66.9 in 2005 to 62.9 in 2012. Among men, average life expectancy at birth rose from 70.8 years in 2005 to 72.7 years in 2012, while the number of years in good health declined from 61.2 in 2005 to 59.2 in 2012 (Eurostat, tsdph100; http://appsso.eurostat.ec.europa.eu/ [accessed on October 3, 2013]).

The issue of defining as well as the change in the paradigm of disability will be discussed more broadly by Kubicki (2015).

Assistance in household management and the fulfillment of the needs of daily life (i.e. cleaning, washing, shopping, meal preparation, assistance in eating the meals, assistance in washing, help in official matters etc.).

<sup>&</sup>lt;sup>6</sup> Journal of Laws no. 64, item 593 as amended, 2004.

http://www.who.int/topics/chronic\_diseases/en/ [accessed on October 3, 2013].

<sup>8</sup> Translation ours.

<sup>&</sup>lt;sup>9</sup> Translation ours.

<sup>&</sup>lt;sup>10</sup> Tranlation ours.

<sup>11</sup> Translation ours.

<sup>12</sup> Translation ours.

- 13 For more about standardization of caregiver services see Szarfenberg 2011
- For example: The cost of disease and illness in the United Sates in the year 2000, Public Services Laboratory of Georgetown University and with the Division of Program Analysis of the National Institutes of Health, Public Health Service.
- <sup>15</sup> Translation ours.
- For more about de-institutionalization please see: Ogólnoeuropejskie wytyczne dotyczące przejścia od opieki instytucjonalnej do opieki świadczonej na poziomie lokalnych społeczności, http://deinstitutionalisationguide.eu/wp-content/uploads/2013/05/Common-European-Guidelines Polish-version.pdf [accessed on October 5, 2013].
- See social media website for care givers at https://pl-pl.facebook.com/pages/Forum-Rodzin-Os%C3%B3b-Niepe%C5%82nosprawnych-Rodziny-ON/105429839513829 i osób dorostych: https://pl-pl.facebook.com/OpiekunOsobyNiepelnosprawnej.
- 18 See: http://www.mpips.gov.pl/aktualnosci-wszystkie/swiadczenia-rodzinne/art,6673,okragly-stol-jak-wspierac-osoby-niepelnospraw-ne.html [accessed on May 29, 2014].

### REFERENCES

- Benoit C., Hallgrimsdottir H. (2011), *Valuing Care Work. Comparative Perspectives*, University of Toronto Press, Toronto.
- Błędowski P. (2011), *Sytuacja ekonomiczna i potrzeby opiekuńcze osób starszych w Polsce*, "Polityka Społeczna" nr 4T pt. "Aspekty medyczne, psychologiczne, socjologiczne i ekonomiczne starzenia się ludzi w Polsce. PolSenior".
- Błędowski P. (2012), *Zaspokajanie potrzeb opiekuńczych ludzi starych*, in: B. Szatur-Jaworska (ed.), *Strategie działania w starzejącym się społeczeństwie. Tezy i rekomendacje*, RPO, Warszawa.
- Brzezińska A.I., Rycielski P., Sijko K. (2010), Wyzwania metodologiczne. Diagnoza potrzeb i ewolucja wsparcia wśród osób z ograniczeniami sprawności, Wyd. Naukowe SCHOLAR, Warszawa.
- Deja A. (2006), Wykorzystanie specjalistycznych usług opiekuńczych jako jednej z form wsparcia dla osób z autyzmem, Fundacja Synapsis.
- Faria R., Weatherly H., van den Berg B. (2012), *A review of approaches to measure and monetarily value informal care*, in: L. Curtis, *Unit Costs of Health & Social Care 2012*, PSSRU.
- GUS (2012), Narodowy spis powszechny ludności i mieszkań 2011. Raport z wyników, Warszawa.
- Golinowska S., Sowa A. (2012), *Zdrowie i sprawność. Przemiany w Polsce*, "Polityka Społeczna" nr 2T pt. "Zdrowie, sprawność i aktywność starzejącej się populacji".
- Hrynkiewicz J. (2012), *Los starca zależny od kontekstu społecznego*, in: J. Hrynkiewicz (ed.), *O sytuacji ludzi starszych*, RRL, Warszawa.
- Jurek Ł. (2007), Sektory opieki długoterminowej analiza kosztów, Gerontologia Polska, tom 15, nr 4, za: W.A. Jackson (1998), The political economy of population ageing, Edward Elgar Publishing Limited, Cheltenham i Northampton.
- Kołaczek B. (2010), *Polityka społeczna wobec osób niepełnosprawnych*, IPiSS, Warszawa.
- Kotowska E., Wóycicka I. (2008), *Sprawowanie opieki oraz inne uwarun-kowania podnoszenia aktywności zawodowej osób w starszym wieku produkcyjnym, Raport z badań*, Departament Analiz Ekonomicznych i Prognoz MPiPS, Warszawa.
- Kubicki P. (2015), Rodzice dzieci z niepełnosprawnością. Analiza polityk publicznych we współczesnej Polsce, in: R.E. Hryciuk, E. Korolczuk (eds.),

- Niebezpieczne związki: macierzyństwo, ojcostwo i polityka, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa.
- Kurowski K. (2012), *Niepetnosprawność i osoba niepetnosprawna od medycznego do społecznego modelu niepetnosprawności*, Biuletyn RPO nr 10, Biuro Rzecznika Praw Obywatelskich, Warszawa.
- Muennig P. (2008), Cost-Effectiveness Analysis in Health: a practical approach, Jossey-Bass.
- Nitecki S. (2008), *Prawo do pomocy społecznej w polskim systemie prawnym*, Wolters Kluwer Polska, Warszawa.
- Ogólnoeuropejskie wytyczne dotyczące przejścia od opieki instytucjonalnej do opieki świadczonej na poziomie lokalnych społeczności (2012), Europejska Grupa Ekspertów ds. Przejścia od Opieki Instytucjonalnej do Opieki świadczonej na poziomie Lokalnych Społeczności, Bruksela [online].
- Olcoń-Kubicka M., Kubicki P. (2012), *Analiza kosztów ponoszonych przez rodziców dzieci z orzeczoną niepełnosprawnością*, "Polityka Społeczna" nr 2T pt. "Zdrowie, sprawność i aktywność starzejącej się populacji".
- Piętka-Kosińska K. (2012), Koszty niepełnosprawności, "Polityka Społeczna" nr 2T pt. "Zdrowie, sprawność i aktywność starzejącej się populacji".
- Roulstone A., Prideaux S. (2012), *Understanding disability Policy*, The Policy Press, Bristol.
- Shah S., Priestley M. (2010), *Disability and social change private lives and public Policies*, The Policy Press, Bristol.
- Staręga-Piasek J., Balon K., Rutkiewicz G., Stec K., Szmaglińska I., Zielony M. (2011), Standard usług opiekuńczych dla osób starszych świadczonych w miejscu zamieszkania, wersja robocza z dnia 1.06.2011 r., WRZOS, Warszawa [online], http://www.wrzos.org.pl/projekt1.18/download/3.%20STANDARD\_OS\_3p.pdf [dostęp 10.10.2014].
- Szarfenberg R. (2011), Krajowy raport badawczy. Pomoc i integracja społeczna wobec wybranych grup – diagnoza standaryzacji usług i modeli instytucji, Wrzos, Warszawa.
- The economic value of informal care in 2010, Report by Access Economics Pty Limited for Carers Australia [online], http://carersaustralia.com.au/storage/Economic-Value-Informal-Care-Oct-2010.pdf [dostep 10.10.2014].
- The Global Economic Burden of Non-communicable Diseases (2011), World Economic Forum and the Harvard School of Public Health [online].
- Topór-Mądry R. (2011), Choroby przewlekte. Obciążenie, jakość życia i konsekwencje ekonomiczne. "Zdrowie Publiczne i Zarządzanie", tom IX, nr 1.
- Woźniak Z. (2008), Niepetnosprawność i niepetnosprawni w polityce spotecznej – spoteczny kontekst medycznego problemu, Wyd. SWPS "Academica", Warszawa.
- Wóycicka I. (2011), Czy zasiłki z pomocy społecznej skutecznie redukują ubóstwo dochodowe?, in: A. Hryniewicka (ed.), Różne wymiary skuteczności w pomocy społecznej, Warszawa [online] http://irss.pl/2011/ 06/publikacja-rozne-wymiary-skutecznosci-w-pomocy-społecznej/ [dostęp 5.10.2013].
- Wyrwicka K., Łukasik J. (2010), Opieka długoterminowa w systemie ochrony zdrowia, stan obecny zadania na przyszłość, in: Opieka długoterminowa w Polsce. Opis, diagnoza, rekomendacja, Grupa robocza ds. Przygotowania Ustawy o Ubezpieczeniu od Ryzyka Niesamodzielności przy Klubie Senatorów Platformy Obywatelskiej, Warszawa.
- Zych A.A. (2010), Leksykon gerontologii, Impuls, Kraków.

# **WEBPAGES**

http://appsso.eurostat.ec.europa.eu/ [access 03.10.2013] http://deinstitutionalisationguide.eu/ [access 05.10.2013]

http://www.mpips.gov.pl/ [access 29.05.2014]

http://www.mpips.gov.pi/ [access 29.00.2014]

http://www.who.int/topics/chronic\_diseases/en/ [access 03.10.2013]

# SUMMARY

The article addresses issues related to the definition of disability and long-term illness, tasks associated with them, costs of individual actions and consequences of the lack of support. This description was developed within the framework of the *Calculator of Costs of Inaction* project, which means taking into account local and institutional perspective in the analysis and focusing on activities carried out and funded by local government units. The text points out various approaches to defining both social problems, including similarity of disability and long-term illness due to the form of received support for people with limited independence. The predominant intervention support as well as the limited forms of assistance for informal caregivers are pointed out. The text also refers to the issue of calculating the costs of inaction itself and the phenomenon of so called "passing-on" of the costs between family, local government and the state budget.

Keywords: disability, long-term illness, local social policy, costs of support.