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Mateusz BIEŃKOWSKI[*]
Anna Monika KRUK[**]

Community support for seniors with impairments in cognitive abilities, and their families, through an assistant social service

Środowiskowe wsparcie seniorów z ograniczeniami zdolności poznawczych i ich rodzin poprzez usługę asystencką

Abstract

Aim. The aim of the article is to present a new social service in Poland, consisting of the assistance of people with neurodegenerative health problems, and to present the forms and scope of support within the assistance service, as well as a research analysis devoted to the assistance service project within the program implemented by the Support Foundation.

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[*] **e-mail: mbienkowski@aps.edu.pl**
The Maria Grzegorzewska University, Institute of Philosophy and Sociology, Szczęśliwicka 40, 02-353 Warszawa, Poland
Akademia Pedagogiki Specjalnej, Instytut Filozofii i Socjologii, Szczęśliwicka 40, 02-353 Warszawa, Polska
ORCID: 0000-0003-0703-8514

[**] **e-mail: akruk@aps.edu.pl**
The Maria Grzegorzewska University, Institute of Education, Szczęśliwicka 40, 02-353 Warszawa, Poland
Akademia Pedagogiki Specjalnej, Instytut Pedagogiki, Szczęśliwicka 40, 02-353 Warszawa, Polska
ORCID: 0000-0003-3165-1319

The text consists of three parts, an introduction and a summary. The first part of the article presents the social services implemented for the senior community in Poland, in particular those that can be performed for people with cognitive problems and selected instruments of social assistance for seniors in their own living environment. The second part refers to an attempt to search for a theoretical framework for personal assistance services for people with cognitive problems. The personal assistance service can be modelled on the profession of an assistant for a disabled person. The third part is the result of a qualitative study.
Methods and materials. The first two parts of the text have been produced by theoretical analysis methods in social sciences: "desk research" and "discourse analysis". The research part of the article was based on two methods: "individual in-depth interview" and "desk research" analysis which belong to the qualitative research trend.
Results and conclusion. Personal assistance of a person with dementia and their family is a new model of support for seniors in Poland, implemented based on the original concept of the "Wsparcie" Foundation. It can be implemented on the basis of existing organizational and legal instruments within social assistance and on the basis of the experience of various entities within the so-called good practices. Personal assistants of seniors with neurocognitive problems use professional techniques to support people with disabilities.

***Keywords*:** disability, cognitive disorders, personal assistance for seniors and their family, social services, social strategy.

Abstrakt

Cel. Celem artykułu jest ukazanie nowej usługi społecznej w Polsce polegającej na asyście osób z neurodegeneracyjnymi problemami zdrowotnymi, zaprezentowanie form i zakresu wsparcia w ramach usługi asystenckiej, a także analiza badawcza projektu usługi asystenckiej w ramach programu realizowanego przez Fundację „Wsparcie". Tekst składa się z trzech części, wprowadzenia oraz podsumowania. Pierwsza część artykułu przedstawia realizowane usługi społeczne na rzecz środowiska seniorów w Polsce, w szczególności dla osób z problemami poznawczymi, oraz wybrane instrumenty pomocy społecznej dla seniorów w ich środowisku zamieszkania. Część druga jest próbą określenia ram teoretycznych usług osobistej asysty osoby z problemami poznawczymi. Usługa osobistej asysty może być wzorowana na zawodzie asystenta osoby niepełnosprawnej. W części trzeciej znajduje się rezultat badania jakościowego.
Metody i materiały. W dwóch pierwszych częściach tekstu przedstawiono badania zrealizowane za pomocą metodyki analiz teoretycznych, charakterystycznych dla nauk społecznych, w tym *desk research* oraz analizy dyskursu. Część badawczą artykułu oparto o dwie metody: indywidualnego wywiadu oraz analizę dokumentów zastanych, czyli *desk research*, a obie należą do nurtu badań jakościowych.
Wyniki i wnioski. Osobista asysta osoby z problemem demencji i jej rodziny jest no-

wym modelem wsparcia seniorów w Polsce, stworzonym na podstawie autorskiej koncepcji Fundacji „Wsparcie”. Może być realizowana na bazie istniejących instrumentów organizacyjnych i prawnych w ramach pomocy społecznej oraz na podstawie doświadczeń różnych podmiotów w ramach tzw. dobrych praktyk. Asystenci osobiści seniorów z problemami neuropoznawczymi stosują profesjonalne techniki wsparcia osób z niepełnosprawnościami.

***Słowa kluczowe*:** niepełnosprawność, zaburzenia poznawcze, osobista asysta seniorów, usługi społeczne, strategia społeczna.

Introduction

The paper aims to present a new social service – personal assistance – intended for people with dementia and their families, against the background of existing forms of community support for the elderly in Poland. The text presents selected social assistance instruments for the elderly in their home environment. The personal assistance service can be modelled on the profession of disability assistant. Selected legal instruments within the framework of state social policy were analysed, and the model of existing social services supporting people with disabilities was used. The research part presents a scientific evaluation of the practical project: including its objectives, forms and scope of support for individuals, and families with cognitive impairments, as well as an assessment of the possibilities for the practical use of this programme. The text draws attention to the activities of specialists supporting social units in the community and the need for the gradual deinstitutionalisation of social assistance for beneficiaries to directly use these services in their environment.

The first two parts of the text present research carried out using the methodology of theoretical analyses characteristic of social sciences, including *desk research* and discourse analysis. The research part is an attempt to learn about the existing goals, forms and scope of services provided by assistants to neurodegenerative patients and their families based on an ongoing and completed social project.

Social services as a form of community support for dependent persons as part of the deinstitutionalisation of social services

Polish social welfare includes support instruments for people requiring care or support services, both in institutions and in their environment. So-called “good aid practices” and innovative programmes to support people in health crises are constantly being developed. Identifying needs and coordinating social services in institutions are becoming the leading tasks of the modern social worker. Other specialists in this field are also involved in the provision of social services for dependent persons. These include family assistants, disability assistants, social and medical carers, psychologists and physiotherapists.

Social services have developed strongly as a result of the decentralisation of state social policy. As a result, greater responsibility for social problems has been taken on by citizens themselves, as well as by organisations within the local government structure. Mirosław Grewiński and Joanna Lizut draw attention to the 3xDE principle, which is important for the state's social policy, especially for social services. It consists of the decentralisation of social policy, demonopolisation, and deinstitutionalisation of social services (Grewiński, Lizut, 2021). The authors describe the emergence of the deinstitutionalisation concept in the 1970s in the USA and its current successive implementation also in Poland. It applies, among other things, to work for the benefit of people with disabilities (Grewiński, Lizut, 2021). The deinstitutionalisation of services can benefit all customers with disabilities who do not require assistance provided in medical facilities or directly related to social welfare. However, some services should be provided in institutions to ensure access to qualified specialists and rehabilitation equipment, as well as for people with neurodegenerative problems.

In our interpretation, deinstitutionalisation means providing social services to citizens outside of institutions, in the environment of the people requiring support. Such assistance is more individualised, focused on meeting the social needs that are different for each dependent person. People requiring care and support services include people with disabilities, including seniors with neurodegenerative problems.

In Polish literature on the subject, there are many interpretations of the issues of deinstitutionalisation and social services implemented in the deinstitutionalisation model of social policy (Rymsza, 2023). Marek Rymsza defines deinstitutionalisation as follows: "Deinstitutionalisation of assistance practices is the process of moving from organising support based on institutional solutions, in which 24-hour long-term residential facilities have a key role, to organising support in a community-based manner, using the infrastructure of social services and other resources of local communities" (Rymsza, 2023, p. 7). The above definition draws attention to the gradual shift away from social support in organisations established for this purpose so that a person with a disability and their family can function in inclusion and integration with their environment. This ensures that these people are not uprooted from their environment and that the potential of the environment is used as part of the assistance.

The assistance provided by institutions is criticised in the literature for poor coordination and communication between entities, organisational chaos and problems in the standardisation of social services, as pointed out, among others, by Bohdan Skrzypczak (2022).

According to M. Rymsza, facilities are a kind of segregation institution, and social services provided in the community have an "integrative and inclusive character" (Rymsza, 2023). Activities undertaken in a family environment undoubtedly contribute to a higher level of social integration with the environment and a reduced sense of rejection due to illness. It can be argued that community-based support is a type of social service that is extremely beneficial for people in need, including those with conditions that cause cognitive problems. Supporting people with disabilities in their environment, especially their family environment, is undoubtedly a better form of assistance in many cases in terms of health and social care than institutional support.

For families of people with disabilities, including neurodegenerative problems, respite care, implemented under the programme of the Minister of Family and Social Policy from 2022 (Grabowska, 2023), is an important form of support. It enables carers to distance themselves from the illness of a close relative and gather strength for the struggle ahead.

The families of elderly people with cognitive impairments do not have to take care of the sick themselves but can use the services of various home support specialists. One of these is the personal assistant for people with disabilities. The personal assistant can combine various social professions: assistant for the disabled, medical caregiver, and caregiver in a social care home. The supervision and coordination of this special service can be carried out by a social worker and a family assistant. Cooperation between the various specialists is advisable to make the assistance more effective.

As part of the state's social policy, additional legal instruments have recently been created to enable more assistance for people with disabilities. This includes the possibility of providing neighbourhood services to people who need assistance in their living environment. Neighbourhood assistance was introduced by an amendment to the *Ustawa o pomocy społecznej* [Act on social assistance] *of 28 July 2023* (*Ustawa*, 2023). It concerns the provision of care services outside social welfare facilities, in the place of residence of the person receiving the service. In this legal act, in article 36 of the previous version of the act, the wording about neighbourhood services was added (*Ustawa*, 2023, art. 1, p. 2, 1.1). In turn, paragraph 1a was introduced to article 50, point 2 of the *Ustawa* o pomocy społecznej, which reads: "Care services at the place of residence may be provided in the form of neighbourhood services" (*Ustawa,* 2023, art. 50, p. 1a). In the 2023 amended version of the Act, a definition of what is understood by neighbourhood assistance was added to Article 50, paragraph 3a of the previous version of the Act: "Neighbourhood services include assistance in meeting basic needs, basic hygiene and care, which should be understood as forms of support that do not require specialised knowledge and skills, and, as far as necessary and possible, ensuring contact with the environment" (*Ustawa,* 2023, art. 50, p. 3a). According to the amendment to the *Ustawa o pomocy społecznej*, neighbourhood services are organised and financed by the municipality or another entity authorised to carry out such activities (*Ustawa,* 2023, art. 50, p. 3b). People with neurodegenerative disorders could easily benefit from neighbourhood support (*Ustawa,* 2023, art. 50, p. 3a), according to their individual needs. Facility-based support can include the use of short-term services in social care homes, especially on a day-care basis, as highlighted on the website of the Ministry of Family, Labour and Social Policy (*Nowe usługi społeczne…*, 2023) and the amended *Rozporządzenie Ministra Rodziny i Polityki Społecznej z dnia 27 października 2023 r. zmieniające rozporządzenie w sprawie domów pomocy społecznej* [Regulation of the Minister of Family and Social Policy of 27 October 2023 amending the regulation on social welfare homes] (*Rozporządzenie*, 2023). Social services can also be provided by social economy organisations. This includes comprehensive support for modern families, people with disabilities, social reintegration, including professional reintegration, and a range of other services listed in the *Ustawa o ekonomii społecznej* [Act on the social economy]. The list of social services existing in law is defined by Article 2, paragraph 1, points 1–14 of the *Ustawa z dnia 19 lipca 2019 roku o realizowaniu usług społecznych przez centrum usług społecznych* [Act of July 19, 2019, on the provision of social services by the social services centre] (*Ustawa*, 2019).

According to the *Ustawa o ekonomii społecznej*, Article 4, Paragraph 1, one of the entities of the so-called social economy in the form of a social enterprise serves the local community through social services or "[...] social and professional reintegration of people at risk of social exclusion" (*Ustawa,* 2022, art. 4, p. 1). The legislator excludes the category of professional reintegration from the category of social reintegration. In practice, professional reintegration is part of social reintegration, as the two forms of client work should not be separated. In the case of people with dementia-related health problems, professional reintegration is extremely rare.

An important social programme for the elderly is the *Senior Support Corps Programme*, which is planned to run throughout 2024. Municipalities have joined this government programme, which receives 80% public funding, to help senior citizens who have health problems that affect their daily functioning and live alone or with relatives who cannot support them. The programme consists of two modules: one related to care or neighbourhood services, and the other to ensuring the safety of seniors in their social environment and raising the level of quality of their social functioning (*Programme Senior Support Corps...*, 2023). Public and private systems can interact with each other in the context of social services. Personal assistance for people with cognitive disabilities can become a common and accessible form of support.

Personal assistance for people with dementia and support for their families

The health and social problems of people with dementia are similar to those of other patients with neurological conditions, such as multiple sclerosis. For this reason, this text draws certain analogies between neurodegenerative diseases and other neurological conditions unrelated or only partially related to the occurrence of cognitive disorders.

In multiple sclerosis, there is a problem with the white and grey matter of the brain, which causes a decrease in cognitive performance in some patients (Seniów, 2003). In addition, a whole range of cognitive impairments can occur in this disease, including problems with long-term memory, impaired access to the so-called memory trace, attention disorders, and problems with memorising and learning (Seniów, 2003). Supporting people with multiple sclerosis and the cognitive problems that occur in this disease can be a model for assistance in other neurodegenerative diseases, especially for memory problems in the elderly. Many tips for the practice of assisting seniors with dementia-type problems can be obtained by analysing the work and professional standards of disability assistants.

When supporting a person in need of assistance, attention should be paid to their dignity and sense of agency. In the introduction to the materials published with the European Commission grant on assistance for people with multiple sclerosis, Izabela Odrobińska emphasises the need for the person with a disability to make decisions in a similar way to healthy people (Odrobińska, 2003). The assistant of a disabled person should have a partnership relationship with them, not a caregiving one (Odrobińska, 2003). The principles of the work of a disability assistant, established by the United Nations, stem from the desire to create opportunities for these people on an equal footing with non-disabled people (Odrobińska, 2003). Assistance for people with dementia should function similarly. It is crucial to ensure the patient's sense of dignity and their sense of agency in their daily functioning.

The personal assistance model has been in use for a long time in other countries. The Swedish model, in which a person with a disability can use public funds to secure a professional assistance service, is widely described in the literature on the subject (Szeroczyńska, 2003; *Asystent osobisty...*, 2014). In Sweden, the *personal assistance allowance* is dependent on the health status of the person receiving support. In particular, it covers support for chronic illnesses for people up to the age of 65, and if they are already receiving support, it also covers support for people over the age of 65 (*Asystent osobisty…*, 2014). Patients with brain damage causing significant and permanent disability receive publicly funded assistance for more than 20 hours a week. Standard funding for assistance services in Sweden is up to 20 hours a week (Szeroczyńska, 2003; *Asystent osobisty…*, 2014).

Support initiatives for assistants also exist in Poland. An example of good practice in this field is a pilot project carried out in Warsaw from December 28, 2001, to August 28, 2002, concerning personal assistance for people suffering from multiple sclerosis (Doraczyńska, 2003). Professional support for people with disabilities is provided by, among others, family assistants or disability assistants. The profession of disability assistant was introduced into Polish social legislation in 2001 by the *Rozporządzenie Ministra Gospodarki i Pracy z dnia 8 grudnia 2004 r. w sprawie klasyfikacji zawodów i spe-*

cjalności dla potrzeb rynku pracy and zakresu jej stosowania oraz *Rozporządzenie Ministra Pracy i Polityki Społecznej z dnia 1 czerwca 2007 r. zmieniające rozporządzenie w sprawie klasyfikacji zawodów i specjalności dla potrzeb rynku pracy oraz zakresu jej stosowania* [Regulation of the Minister of Economy and Labour of December 8, 2004, on the classification of occupations and specialisations for the needs of the labour market and the scope of its application and the Regulation of the Minister of Labour and Social Policy of June 1, 2007, amending the regulation on the classification of occupations and specialisations for the needs of the labour market and the scope of its application] (Fajfer-Kruczek, 2013).

In turn, the professions of community carer and caretaker in a social care home, which are also important caregiving professions, were introduced in Poland by the *Rozporządzenie Ministra Edukacji Narodowej z dnia 26 czerwca 2007 r. w sprawie klasyfikacji zawodów szkolnictwa zawodowego* [Regulation of the Minister of National Education of 26 June 2007 on the classification of vocational education occupations] (Fajfer-Kruczek, 2013). Support is also provided to families with a disabled child (Wrona, 2013), so it does not only cover senior citizens and their families.

Another example of good practice based on the Eudaimonia Foundation was described by Marta Gawryluk and Anna Puławska-Rodzik in the text *Asystencki system wsparcia dla osób z niepełnosprawnościami na przykładzie działań Fundacji Eudajmonia* [An assistant support system for people with disabilities based on the activities of the Eudajmonia Foundation]. (2013). The Eudajmonia Foundation has introduced three types of assistance, two of which in particular can be a model for working with seniors with dementia-type problems, namely:

- functional assistance, helping to overcome limitations, which is also important for dementia patients,
- social assistance, meaning the exercise of soft skills, which could help seniors with dementia to communicate with their environment and help the environment to recognise and understand the disease,
- supporting assistance in the labour market, which affects the elderly to a much lesser extent (Gawryluk, Puławska-Rodzik, 2013).

The Eudajmonia Foundation has applied a model based on personal assistance for people requiring support, job coaching and activity coaching for these individuals, as well as care services provided when needed (Gawryluk, Puławska-Rodzik, 2013).

The FAOn Association, another example of good practice, offers the following services for people with disabilities in Katowice (Zarzycka, 2013):

- assistance service,
- accompanying service,
- transport service (transport),

- rehabilitation and treatment support service,
- advisory service (official matters, documents),
- home assistance,
- educational assistance support,
- vocational support at the workplace, including assistance in getting to and from work (Zarzycka, 2013).

There are many works in Polish literature on the subject of the profession of disability assistant (e.g., Cervinkova, 2014; Żukiewicz, 2010; Mirewska, 2010), which have been developed in terms of pedagogy, occupational science, as well as in the context of social assistance.

One of the social support models described in books is the so-called Model III – personal assistant for the disabled. In this model, the disabled person decides what the assistant's role is about them (Flak, 2011). Another model of disability assistant combines two professional roles, namely that of a personal assistant and a job coach (Juchnicka ed., Prystrom, Pogorzelski, & Siderska, 2015). This combination is undoubtedly more necessary in younger age groups than in older ones. It is assumed that the personal assistant of a person with a disability should be physically fit and know the principles of first aid (*Asystent osobisty...*, 2014). The ability to provide first aid can be useful not only in the case of a basic dementia-type disease associated with brain damage but also in the case of other diseases occurring in patients. The physical fitness of the personal assistant is useful in any disability situation, especially during uncontrolled social behaviour, particularly in the advanced stages of neurodegenerative disease.

These universal principles of social support can work well for people with neurodegenerative health problems. For people with severe and moderate disabilities, this can give them the chance to live independently with assistance in their daily lives without having to involve family members. This is particularly important for patients with cognitive problems as well as for their families.

Research analysis of assistance services at the "Wsparcie" [Support] Foundation

The system of care for seniors with cognitive impairments covers three basic areas. The first is family care, the second is care provided by specialised personnel employed by the family of a senior with cognitive impairments, and the third is institutional support (Kruk, 2010).

Statistics show that around 90% of people affected by cognitive impairment are cared for by their families (Sędzicki, 2020). The growing number of elderly people forces us to look for new tools to support family carers. Personal assistance is a form of service that supports both seniors with dementia and family carers.

Aim of the survey and research methodology

The aim of this paper is not only to present the forms and scope of support within the framework of the assistant service but also to conduct a research analysis of the assistant service project as part of the programme implemented by the "Wsparcie" Foundation. The foundation was chosen due to the implementation in 2019 of an innovative project *Przywrócić do świata – asystent rodzin żyjących z demencją* [Restore to the world – assistant to families living with dementia].

The research part of the thesis formulates three questions:

- What is the availability of the assistance service?
- What are the forms and types of support for the family of a senior with dementia?
- What are the results of the assistance service for the families of people living with dementia?

In the research part, to broaden knowledge, it was decided to triangulate the research methods (Flick, 2010). Two methods were used, both of which belong to qualitative research. The choice of methods was dictated by the desire to understand the phenomenon, not to measure its intensity. Thanks to the triangulation of methods, the phenomenon under study can be analysed from different perspectives and, as a consequence, better understood.

The research results were based on two research methods. The first one was an individual interview (Kvale, 2010) using a scenario with five assistants working on the project *Przywrócić do świata – asystent rodzin żyjących z demencją* [Restore to the world – assistant to families living with dementia], implemented by the "Wsparcie" Foundation. The second method is the analysis of existing materials (Babbie, 2003). In this part, reference was made to the evaluation report and the document summarising the project.

The interviews were conducted between April and June 2024. The study aimed to try to understand the specifics of the services provided by a family assistant caring for a senior with dementia. The questions in the interview scenario concerned the role of the family assistant in supporting seniors with cognitive impairments, tasks and objectives in working with the families of seniors affected by dementia. In addition, the research tool included questions about the forms and instruments used in the activation of seniors with cognitive impairments. The scenario also included questions about the practical aspects of working with the families of seniors with dementia. Quotes from the interviews are presented verbatim to preserve the originality of the respondents' statements. It should be emphasised that the research material collected does not allow for universal conclusions to be drawn.

Project description

The project, carried out by the “Wsparcie” Foundation, lasted from March 2019 to December 2019 in Warsaw. It was co-financed as part of the programme for the Social Activity of the Elderly in 2014–2019, implemented by the Ministry of Family, Labour and Social Policy. As part of the project, *Przywrócić do świata – asystent rodzin żyjących z demencją* [Restore to the world – assistant to families living with dementia], specialists trained by the foundation, who have several years of experience in working with seniors, offered support, education and information to families of people with dementia. The assistants knew pedagogy, psychology and social work. The work with the family of a senior citizen affected by cognitive limitations was based on home visits. During the meetings, the assistant worked with the person “[...] through memory training, multisensory therapy, reminiscence therapy (relying on the person’s history and experiences), orientation training, music therapy, art classes, and daily activities training” (Korycki, 2020, p. 152). The work with the carer, by contrast, was based on education, motivation and respite care.

Service availability

Information about the assistance service project appeared on the websites of district offices in Warsaw. A poster was created to provide information about the programme and better reach families of seniors with dementia. The campaign encouraged people to contact the organisation by phone (alternatively by email), which seems reasonable given the age of the carers. The elderly are more likely to use the telephone, especially landlines, and less likely to use the internet. Participation in the project was free of charge. Families caring for an elderly person who is dependent due to cognitive impairment could apply to participate in the programme. Priority was given to families not covered by other assistance programmes, childless senior couples without family support, whose disability prevented them from moving outside their place of residence. People with dementia who exhibited aggressive behaviour were excluded from the project.

To join the programme, “[...] the family usually contacted the Foundation, which then qualified the person for the project” (Respondent 3). The prerequisite for receiving support was that the carer agreed and was willing to meet with the assistant, that the carer and the patient lived together, and that the patient was able to participate in activities with the assistant.

The project provided 2,038 hours of support, care, education, information and therapy in the families’ homes. The assistance service was provided to 42 senior citizens with dementia and 42 carers. It should be emphasised that during the project, five carers died, one was placed in a nursing home, and three withdrew from participation at the initial stage (after the first meetings). As the respondents point out, individual goals were set with the families at the first meetings based on the family's needs. The overarching goal of the entire project was "[...] to maintain the cognitive/manual resources of seniors with dementia, despite the progression of the disease. Certain changes in the brain are irreversible, so I remember that the focus should have been on the resources of the Care Recipient and exercising and improving them" (Respondent 3).

The formal framework of the assistants' work cannot be ignored. They were employed by the Foundation on the basis of civil law contracts. As the assistant respondents emphasised, working on the project was a part-time job for them. They often visited their charges after their full-time work. The assistants had full-time jobs as social workers or geriatric therapists, which gave them the necessary experience to join the project. As one of the respondents pointed out, "[...] I am a psychologist, but I know that the assistants at the Foundation have different specialisations" (Respondent 1). Employees of Warsaw social welfare centres very often became assistants. Empathy, kindness, the ability to adapt to sudden changes in the situation and patience were considered important qualities of an assistant. The surveyed assistants expressed the hope that such a service would be available in every municipality. The availability of external funds (from the European Social Fund), the deinstitutionalisation programme, as well as the transformation of social welfare centres into social service centres, will increase the availability of assistance services in the future (Respondent 4).

Forms and scope of support

The support for families with a member suffering from a neurodegenerative disease took the form of visits from assistants. The assistants in question emphasised that the duration and scope of the visits were determined on a case-by-case basis. "The assistants worked with the carers to determine the schedule. Some wanted the assistant to come for shorter but more frequent visits, while others preferred less frequent but longer visits, e.g. for the whole day, when they needed to run errands in the city" (Respondent 5). Sometimes the visits were limited to two-hour meetings once a week. During these meetings, the assistants would first have a short conversation with the senior citizens, drink tea together, and then work. One form of work is to do various memory training exercises: cognitive training, music therapy, gymnastics, and bibliotherapy. In addition, crosswords, board games, puzzles and manual exercises are used to improve motor skills. If intellectual exercises were not possible, the assistants read books to the patients or went for walks with them. Another form of activation was the joint preparation of a meal, combined with the naming of individual activities and dishes. One of the basic criteria for the selection of activities was that, in addition to the rehabilitative function, the meetings and exercises had to be pleasant for the senior citizen. The assistants made sure that the activities were in line with the patient's interests and previous professional life. They emphasised that they brought to their work with the families not only their skills and enthusiasm but also the support tools provided by the foundation. These included "[...] all kinds of jigsaws, matching games, art materials, puzzles, aids in the form of photos, letters, numbers, captions, books, songbooks, prayer books, spiky rubber balls" (Respondent 5). The forms of support within the framework of the assistance service were in line with the theory of social services intended for the elderly (Naegele, 2013), according to which senior citizens are not only the recipients of the service, but also its animators.

Working with a carer for a senior with dementia focused on two basic dimensions: respite care and education. According to the Polish Association for Assistance to People with Alzheimer's Disease, the average care time in the first year after the onset of dementia symptoms (regardless of the type of dementia) is about two hours a day, in the second year, it is four hours a day, in the fifth year, about nine hours a day, in the seventh year, about fourteen hours a day, and in the tenth year, almost around the clock (Bidzan, Rasmus, & Gruzińska, 2012). Thanks to respite care, carers "[...] have the opportunity to take care of their own affairs, rest and meet other people. The assistant also acts as a confidant, can listen to the carer and give them someone to talk to. The assistant brings good energy, a fresh perspective and understanding to the home" (Respondent 5). Because "[…] they could have used the three hours of our work to take care of their things, for example, I think it was a big help" (Respondent 3).

Another area of assistance was the educational function. After training, the assistants provided advice on how to deal with the person who is ill and shared knowledge about the disorder and ways to communicate without triggering aggression. In the project, caregivers could also "[...] gain knowledge about the disease, often participating in support groups or lectures for people living with Alzheimer's disease" (Respondent 3). In the family support system for seniors with cognitive impairments, their life partners are most often involved, followed by children (Korycki, 2020). In 70% of cases, women become family carers for dementia patients. In addition, there is an asymmetry in the relationship between the carer and the patient. The fact that the spouse of the patient often becomes the closest carer contributes to an imbalance in the marital relationship. The carer becomes the active party (this is usually a woman), while the patient becomes the passive party. A marriage based on equality and the subjectivity of the parties under such conditions is weakened. Assistants in their work tried to strengthen the bond between the carer and the patient by involving carers in therapeutic activities.

The key factor hindering the care of a person with cognitive impairment is the stress resulting from the hardships of work and the progressive illness of a family member. Under the influence of stress, the so-called "caregiver syndrome" appears (Pąchalska, 2008). A carer affected by this syndrome experiences chronic fatigue and hyperactivity. Caregiver syndrome leads to cognitive (e.g., impaired memory), emotional (e.g., decreased self-esteem), and vegetative (e.g., sleep disorders) disorders (Bidzan, Rasmus, & Gruzińska, 2012). The first interviewee drew attention to the problems associated with caregiver syndrome, emphasising that "[...] caregivers struggle with burnout, which we understand as care overload. Caregivers can experience emotional exhaustion and loss of interests and relationships. Long-term care often leads to caregiver depression" (Respondent 1). The foundation has addressed these risks and has connected carers with mental health specialists.

Pauline Boss introduced the term "ambiguous loss" in the 1970s in the literature on caring for elderly people with dementia (Boss, 1999). The disease makes the senior with dementia both present (physically) and absent (mentally) in the family at the same time. Under the influence of dementia and the resulting memory loss, the patient loses the shared narratives that form the essence of family ties. This loss and the resulting gradual loosening of the bond is a source of suffering for those around the patient. The loss of the bond is not sudden, as in the case of death. It is a process in which the relatives say goodbye to the patient many times, experience trauma and gradually part with them. "At the beginning, there was fear mixed with the hope that the patient would, for example, recover or that their behaviour would change. Then, as the relationship deepened, we set small goals together and rejoiced when the illness did not worsen or the patient had a few better days. We learned to notice them and to be happy about them" (Respondent 2). Being in a group of people struggling with the same problems allows you to release negative emotions and experience support. In addition, "[...] it is important to notice this subtlety, the moments when the patient comes back, even for a moment. It is very important" (Respondent 2).

Project results

One of the research questions was about the evaluation of the assistant service in terms of the results of the activities, including their potential benefits. In the evaluation of the results, reference should be made not only to the knowledge of the respondents but also to the survey summarising the project. The survey was completed by 33 supervisors. A five-point rating scale was used. In addition, the supervisors were able to give a descriptive evaluation of the assistants' work.

The supervisors rated the assistants' work highly in the survey. The average rating was 4.97 points on a five-point scale. The assistants' work contributed to an improvement in the well-being of the supervisors (4.27/5 points). After participating in the project, the carers felt that they had more knowledge about dementia (4.45/5 points), which shows that the educational and informative impact of the assistant in the environment was effective.

In addition, the carers rated the support they received from the assistant in the areas of modelling work with the patient and providing knowledge and information about dementia as high. In their descriptive evaluation, the carers rated respite care highly. The recommendation for the future, in the opinion of the carers, was to "increase the number of hours and the frequency of the assistant's visits."

The project *Przywrócić do świata – asystent rodzin żyjących z demencją* [Restore to the world – assistant to families living with dementia] was also highly rated by the assistants themselves. One of the assistants wrote in the evaluation survey: "I have very fond memories of working on the project, I learned a lot. I also think that working with other families affected by the disease allowed me to take a step back and look at my problems as a caregiver – thank you very, very much. I think the project was great, very necessary, and I really hope it will continue." The project was also positively evaluated in interviews with assistants four years after the project ended. Despite the good ratings, the project was not continued. "As far as I know, the project was not continued, but working as a social worker, I see that the need for this kind of support is increasing. I think that with an ageing population, this kind of support will be needed" (Respondent 3).

Within the family, support and care for senior citizens with cognitive impairments is most often provided by older people of a similar age to the patient. This is confirmed by the study, as 32 of the 42 carers supported by the project *Przywrócić do świata – asystent rodzin żyjących z demencją* [Restore to the world – assistant to families living with dementia] were of senior age. These people have health problems and limited physical, and often mental, capacities. This thesis is confirmed by the words of the person interviewed in the second interview, who pointed out the advanced age of the carers and their fears about the situation of the senior citizen with dementia at the time of the carer's death. These fears are justified, as during the project, five participating carers died and one was placed in a nursing home. Based on research from the Journal of the American Medical Association, P. Boss emphasises that the mortality rate among carers is 63% higher than among their peers who do not care for someone with dementia (Boss, 1999).

Caring for a senior with dementia increases the risk of the carer developing a disease, especially cardiovascular diseases and mental disorders. Challenges related to organising medical assistance and care often exceed their capabilities. The deteriorated emotional state of the family carer can result in improper care and mistreatment of the senior with cognitive disorders (Sędzicki, 2020).

Conclusion

Personal assistance for people with neurodegenerative diseases and their families is a new instrument for supporting individuals in a particular health crisis, namely cognitive impairment. This type of service is an excellent complement to social assistance instruments, including facilities and so-called "good practices of assistance," most often provided by non-governmental organisations and foundations.

The need for assistance services for elderly people with dementia is not only written about in the Polish discourse on senior citizen policy but also in the German one (Naegele, 2013). Assistance services provided by the third sector are an attractive alternative form of support.

The aim of the study was to determine the forms and scope of support within the framework of assistance services provided by third-sector entities. In the words of the assistants surveyed, the thesis that support for families with a member suffering from dementia should be highly individualised was a recurring one. The assistant of such families supports people struggling with neurodegenerative diseases through cognitive stimulation and engaging the senior in mental exercises, including memory games that help maintain cognitive functions. The support also includes the caregivers themselves through education and respite care.

References

Asystent osobisty osoby niepełnosprawnej: Rozwiązania w wybranych państwach europejskich [Personal assistant for the disabled: Solutions in selected European countries]. (2014). Warszawa: Ministerstwo Pracy i Polityki Społecznej.

Babbie, E. (2003). *Badania społeczne w praktyce* [Social research in practice]. Warszawa: Wydawnictwo Naukowe PWN.

Bidzan, M., Rasmus, A., & Gruzińska, K. (2012). Pomoc rodzinie chorego z otępieniem czołowo-skroniowym [Supporting the family of a person suffering from frontotemporal dementia]. In: M. Pąchalska, L. Bidzan (Eds.), *Otępienie czołowo-skroniowe: Ujęcie interdyscyplinarne* (pp. 293–322). Kraków: Krakowska Akademia im. Andrzeja Frycza Modrzewskiego.

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief.* Cambridge: Harvard University Press.

Cervinkova, H. (2014). *Jesteśmy sobie potrzebni: Asystent osobisty osoby niepełnosprawnej w ramach projektu* „Sprawni w pracy" [We are needed: Personal assistant for disabled people as part of the project "Healthy at work"]. Wrocław: Urząd Marszałkowski Województwa Dolnośląskiego we współpracy z Wydawnictwem Naukowym Dolnośląskiej Szkoły Wyższej.

Doraczyńska, E. (2003). Doświadczenia Oddziału Warszawskiego w realizacji projektu „Osobisty asystent osoby chorej na SM" [Experiences of the Warsaw Branch in the implementation of the project "Personal assistant for a person suffering from MS"]. In:

I. Odrobińska (Ed.), *Osobisty asystent osoby niepełnosprawnej: Materiały poseminaryjne* (pp. 46–49). Dębe: Rada Główna Polskiego Towarzystwa Stwardnienia Rozsianego.

Fajfer-Kruczek, I. (2013). Prawne i organizacyjne aspekty systemu kształcenia asystentów osoby niepełnosprawnej w Polsce [Legal and organisational aspects of the system of training assistants for disabled persons in Poland]. In: J. Rottermund, I. Fajfer-Kruczek (Eds.), *Rozwój usług asystenta osoby niepełnosprawnej w Polsce* (pp. 33–43). Kraków – Katowice: Oficyna Wydawnicza Impuls.

Flak, B. (2011). Asystent osoby niepełnosprawnej [Assistant for people with disabilities]. In: A. Górak et al. (Eds.), *Nowatorskie instrumenty w pracy z klientami pomocy społecznej: Asystent rodziny, trener pracy, klub integracji społecznej, asystent osoby niepełnosprawnej* (pp. 163–227). Wrocław: Grupa Ergo.

Flick, U. (2010). *Projektowanie badania jakościowego* [Designing a qualitative survey]. Warszawa: Wydawnictwo Naukowe PWN.

Gawryluk, M., Puławska-Rodzik, A. (2013). Asystencki system wsparcia dla osób z niepełnosprawnościami na przykładzie działań Fundacji Eudajmonia [An assistant support system for people with disabilities based on the activities of the Eudajmonia Foundation]. In: J. Rottermund, I. Fajfer-Kruczek (Eds.), *Rozwój usług asystenta osoby niepełnosprawnej w Polsce* (pp. 93–104). Kraków – Katowice: Oficyna Wydawnicza Impuls.

Grabowska, I. (2023). Deinstytucjonalizacja praktyk pomocowych wspierających osoby z niepełnosprawnościami: Między koniecznością a wyborem [Deinstitutionalisation of support services for people with disabilities: Between necessity and choice]. In: M. Rymsza (Ed.), *W stronę środowiskowych usług społecznych: Deinstytucjonalizacja praktyk pomocowych w Polsce i Europie* (pp. 53–80). Warszawa: Wydawnictwa Uniwersytetu Warszawskiego.

Grewiński, M., Lizut, J. (2021). Idea, definicje i teoretyczne aspekty deinstytucjonalizacji w polityce społecznej [Idea, definitions and theoretical aspects of deinstitutionalisation in social policy]. In: M. Grewiński, J. Lizut (Eds.), *Deinstytucjonalizacja w polityce społecznej: Szanse i zagrożenia* (pp. 11–30). Warszawa – Radom: Ministerstwo Rodziny i Polityki Społecznej, Uczelnia Korczaka, Instytut Naukowo-Wydawniczy Spatium.

Juchnicka, M. (Ed.), Prystrom, J., Pogorzelski, M., & Siderska, D. (2015). *Przekroczyć granice: Wsparcie doradczo-edukacyjne osób dotkniętych chorobą nowotworową: Modelowa asysta osobista* [Transcending boundaries: Counselling and education for cancer patients: Model personal assistance]. Białystok: Białostocka Fundacja Kształcenia Kadr.

Korycki, A. (2020). *Aktywizacja społeczna i przeciwdziałanie wykluczeniu społecznemu seniorów z niepełnosprawnościami: Wyzwania dla współczesnej polityki społecznej* [Social activation and counteracting social exclusion of seniors with disabilities: Challenges for contemporary social policy]. Warszawa: Wydawnictwo Difin.

Kruk, A. M. (2010). *Instytucje społeczne: Organizacja, zarządzanie, wybrane aspekty prawne i gospodarcze* [Social institutions: Organisation, management, selected legal and economic aspects]. Warszawa: Wydawnictwo Akademii Pedagogiki Specjalnej im. M. Grzegorzewskiej.

Kvale, S. (2010). *Prowadzenie wywiadów* [Conducting interviews]. Warszawa: Wydawnictwo Naukowe PWN.

Mirewska, E. (2010). Miejsce asystenta osoby niepełnosprawnej w systemie pomocy społecznej [The role of the disability assistant in the social care system]. In: A. Żukiewicz (Ed.), *Asystent osoby niepełnosprawnej: Nowy zawód i nowa usługa systemu pomocy społecznej* (pp. 21–30). Kraków: Oficyna Wydawnicza Impuls, Miejski Ośrodek Pomocy Społecznej.

Naegele, G. (2013). Usługi społeczne dla osób starszych [Social services for the elderly]. In: A. Evers, R. G. Heinze, & T. Olk (Eds.), *Podręcznik usług społecznych – przykład Niemiec* (pp. 457–482). Warszawa: Dom Wydawniczy Elipsa, Wydawnictwo Wyższej Szkoły Pedagogicznej im. Janusza Korczaka.

Nowe usługi społeczne od 1 listopada: Pytania i odpowiedzi [New social services from 1 November: Questions and answers]. (2023). Retrieved from: https://www.gov.pl/web/rodzina/nowe-uslugi-spoleczne-od-1-listopada-pytania-i-odpowiedzi.

Odrobińska, I. (2003). Wstęp [Introduction]. In: I. Odrobińska (Ed.), *Osobisty asystent osoby niepełnosprawnej: Materiały poseminaryjne* (pp. 3–4). Dębe: Rada Główna Polskiego Towarzystwa Stwardnienia Rozsianego.

Pąchalska, M. (2008). *Rehabilitacja neuropsychologiczna: Procesy poznawcze i emocjonalne* [Neuropsychological rehabilitation: Cognitive and emotional processes]. Lublin: Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej.

Program Korpus Wsparcia Seniorów na rok 2024 [Senior Support Corps Programme]. (2023). Retrieved from: https://www.gov.pl/web/rodzina/program-korpus-wsparcia-seniorow-2024.

Rozporządzenie Ministra Rodziny i Polityki Społecznej z dnia 27 października 2023 r. zmieniające rozporządzenie w sprawie domów pomocy społecznej [Regulation of the Minister of Family and Social Policy of 27 October 2023 amending the regulation on social welfare homes]. (2023). Dz. U. 2023.2355.

Rymsza, M. (2023). Polityka deinstytucjonalizacji profesjonalnych praktyk pomocowych w perspektywie socjologicznej [The sociological policy of deinstitutionalising professional aid organisations]. In: M. Rymsza (Ed.), *W stronę środowiskowych usług społecznych: Deinstytucjonalizacja praktyk pomocowych w Polsce i Europie* (pp. 7–30). Warszawa: Wydawnictwa Uniwersytetu Warszawskiego.

Seniów, J. (2003). Zaburzenia poznawcze i emocjonalne w stwardnieniu rozsianym [Cognitive and emotional disorders in multiple sclerosis]. In: I. Odrobińska (Ed.), *Osobisty asystent osoby niepełnosprawnej: Materiały poseminaryjne* (pp. 11–16). Dębe: Rada Główna Polskiego Towarzystwa Stwardnienia Rozsianego.

Sędzicki, M. (2020). O konieczności wsparcia seniorów z chorobami otępiennymi (i ich rodzin) [About the necessity of supporting senior citizens with dementia (and their families)]. In: A. Korycki (Ed.), *Przeciwdziałanie wykluczeniu społecznemu osób z chorobami otępiennymi i ich rodzin jako wyzwanie dla pracy socjalnej i polityki społecznej* (pp. 167–169). Siedlce: Wydawnictwo Uniwersytetu Przyrodniczo-Humanistycznego.

Skrzypczak, B. (2022). Standaryzacja placówek i usług społecznych – rozwój instytucjonalny w czasach deinstytucjonalizacji [Standardisation of social facilities and services – institutional development in times of deinstitutionalisation]. In: M. Zima-Parjaszewska, & B. Skrzypczak, *Standaryzacja usług społecznych w organizacji pozarządowej* (pp. 93–135). Lublin: Wydawnictwo Muzyczne Polihymnia.

Szeroczyńska, M. (2003). Prawo Unii Europejskiej a instytucja asystenta osobistego dla osoby niepełnosprawnej [European Union law and the institution of a personal assistant for a disabled person]. In: I. Odrobińska (Ed.), *Osobisty asystent osoby niepełnosprawnej: Materiały poseminaryjne* (pp. 5–10). Dębe: Rada Główna Polskiego Towarzystwa Stwardnienia Rozsianego.

Ustawa z dnia 19 lipca 2019 roku o realizowaniu usług społecznych przez centrum usług społecznych [Act of 19 July 2019 on the provision of social services by the social services centre]. (2019). Dz. U. 2019.1818.

Ustawa z dnia 28 lipca 2023 roku o zmianie ustawy o pomocy społecznej oraz niektórych innych ustaw [Act of 28 July 2023 amending the Social Welfare Act and certain other acts]. (2023). Dz. U. 2023.1693.

Ustawa z dnia 5 sierpnia 2022 r. o ekonomii społecznej [Act of 5 August 2022 on the social economy]. (2022). Dz. U. 2024.113.

Wrona, S. (2013). Assistant of family in the process of early intervention. In: J. Rottermund, I. Fajfer-Kruczek (Ed.), *Rozwój usług asystenta osoby niepełnosprawnej w Polsce* (pp. 73–82). Kraków – Katowice: Oficyna Wydawnicza Impuls.

Zarzycka, J. (2013). Stowarzyszenie FAOn – „Pogotowie Asystenckie" w Katowicach [FAOn Association – "Assistance Emergency Service" in Katowice]. In: J. Rottermund, I. Fajfer-Kruczek (Eds.), *Rozwój usług asystenta osoby niepełnosprawnej w Polsce* (pp. 165–170). Kraków – Katowice: Oficyna Wydawnicza Impuls.

Żukiewicz, A. (2010). Asystent osoby niepełnosprawnej – nowy obszar działania społecznego [Disability assistant – a new area of social engagement]. In: A. Żukiewicz (Ed.), *Asystent osoby niepełnosprawnej: Nowy zawód i nowa usługa systemu pomocy społecznej* (pp. 9–13). Kraków: Oficyna Wydawnicza Impuls, Miejski Ośrodek Pomocy Społecznej.