

Creation of dementia-friendly public libraries in Croatia

by Kornelija Petr Balog

Social exclusion of older adults

Social exclusion, the term first used by French sociologists in the 1970s, refers to socially excluded segments of the population (who they are, where they live, what their needs are)¹. It is a multifaceted concept and social inclusion is used as the umbrella term which may include economic exclusion, exclusion from social relations (social resources, social connections, social networks), or civic exclusion (exclusion from engagement with formal civic, political and voluntary groups).

Building on a longstanding focus of European researchers on disadvantages in later life, social exclusion is receiving growing attention from all social agents that are associated with the older population in society (social care institutions, medical institutions, libraries, educational institutions, etc.). Social exclusion is mostly connected with economic instability (or even poverty) and the vulnerability of the older population to increasing inequalities in societies². It is worrying that older people who experience social exclusion tend to do so for a longer part of their lives than is the case with people belonging to other age groups³. Economic inclusion of the older population – adequate incomes in old age and protecting older citizens from poverty – are major challenges for governments and policymakers across the world⁴. The

KORNELIJA PETR BALOG, University J. J. Strossmayer in Osijek, Department of Information Sciences, Croatia, e-mail: kpetr@ffos.hr.

Last website consultation: January 17th, 2023.

The terminology used in this paper is the terminology that can be found in the LIS materials – since the text is written for LIS community the author believes that it is advisable to use the terminology found in LIS related materials and guidelines.

1 Clive Miller, *Managing for social cohesion*. London: Office for Public Management, 2019, p. 38-41.

2 Thomas Scharf, *Between inclusion and exclusion in later life*. In: *Ageing through austerity: critical perspectives from Ireland*, edited by Kieran Walsh, Gemma M. Carney, Áine Ní Léime. Bristol: Policy Press, 2015, p. 113-130, DOI: 10.51952/9781447316251.ch008.

3 Thomas Scharf; Nora C. Keating, *Social exclusion in later life: a global challenge*. In: *From exclusion to inclusion in old age: a global challenge*, edited by Thomas Scharf, Nora C. Keating. Bristol: Policy Press, 2012, p. 1-16, DOI: 10.1332/policypress/9781847427731.003.0001.

4 Jim Ogg; Michal Myck, *Introduction: framing economic exclusion*. In: *Social exclusion in later life: interdisciplinary and policy perspectives*, edited by Kieran Walsh [et al.]. Cham (ZH): Springer, 2021, p. 25-31, DOI: 10.1007/978-3-030-51406-8_2.



problems of economic exclusion have been additionally amplified by the recent Covid-19 pandemic and the Ukraine war. Among the older population, some individuals are more prone to economic exclusion. Older women, for example, are more at risk from poverty than older men. Divorce, separation, or widowhood can very often result in a reduction of income and deterioration of living standards for (older) women⁵. Coupled with declining health, increased likelihood of bereavement, loneliness, and other challenges of old age, economic exclusion poses a significant threat to older people's capacity to lead an independent and full life⁶.

Social relations are considered to be the key determinants of an individual's health, well-being, and feeling of belonging⁷. Therefore, exclusion from social relations of older people reduces the possibility of their being healthy, happy, and well-balanced in old age. However, it is also important to acknowledge the presence of negative social relations – conflicting and/or abusive social relations may have the opposite impact on an older person's health and well-being⁸. One of the critical outcomes of social exclusion may very often be loneliness. Loneliness may have severe consequences – ranging from poor physical and mental health⁹ to increased health care and societal costs¹⁰.

Another significant factor that contributes to the social exclusion of older generations is ageism. Ageism refers to prejudices concerning the elderly, who are seen as hindering productivity and social dynamism. Unfortunately, social stereotypes about ageing can also result in negative self-perception of ageing, reduced self-efficacy and possibly depression¹¹.

Many social agencies are aware of the problems and challenges that face older citizens, which intensify with their age and loss of physical and cognitive faculties. Many institutions offer activities and services that help alleviate some of the problems that contribute

5 Michal Myck [et al.], *Economic aspects of old age exclusion: a scoping report*. In: *Rosenet Cost Action (CA15122). Reducing old-age social exclusion: collaborations in research & policy*, April 2017, <https://www.researchgate.net/publication/325923948_Economic_Aspects_of_Old_Age_Exclusion_A_Scoping_Report>; Toni Calasanti, *Gender and ageing in the context of globalization*. In: *The Sage handbook of social gerontology*, edited by Chris Philipson and Dale Dannefer. Los Angeles: Sage, 2010, p. 137-149, DOI: 10.4135/9781446200933.n10.

6 Elise Whitley; Michaela Benzeval; Frank Popham, *Associations of successful aging with socioeconomic position across the life-course: the West of Scotland twenty-07 prospective cohort study*, «Journal of aging and health», 30 (2018), n. 1, p. 52-74, DOI:10.1177/0898264316665208.

7 John Bowlby, *Attachment and loss: retrospect and prospect*, «American journal of orthopsychiatry», 52 (1982), n. 4, p. 664-678.

8 Karen S. Rook, *Exposure and reactivity to negative social exchanges: a preliminary investigation using daily diary data*, «The journals of gerontology: Series B», 58 (2003), n. 2, p. 100-111, DOI: 10.1093/geronb/58.2.P100.

9 Julianne Holt-Lunstad [et al.], *Loneliness and social isolation as risk factors for mortality: a meta-analytic review*, «Perspectives on psychological science», 10 (2015), n. 2, p. 227-237, DOI: 10.1177/1745691614568352.

10 John T. Cacioppo; Stephanie Cacioppo, *The growing problem of loneliness*, «The Lancet», 391 (2018), n. 10119, DOI: 10.1016/S0140-6736(18)30142-9.

11 Jina Han; Jinhyun Kim, *The impacts of self-perception of aging and self-efficacy on depression among Korean older persons*. In: "Social work research: a world of possibilities. Society for Social Work and Research: 14th Annual Conference" (San Francisco, 14-17 January 2010).

to the social exclusion of this demographic. This paper gives a short overview of public libraries' activities intended to reduce the social exclusion of senior citizens in their midst and presents two projects on the information needs of Alzheimer's patients and their caregivers as well as the creation of dementia-friendly public libraries in Croatia. Those projects have been carried out by the Department of Information Sciences of the Faculty of Humanities and Social Sciences at the University in Osijek, Croatia.

Library contribution to the fight against social exclusion of older adults

Libraries in general, but particularly public libraries, have been collecting evidence of their social impact for some time now. Drawing on that research, it is argued that public libraries represent a broadly positive and valued resource for older people¹². In addition, there is a common perception that public libraries have a long history of provisioning for disadvantaged or excluded individuals, social groups, and social classes. Based on the philanthropy of the Victorian public library and its concern for labouring classes, the provision of free books and access to information by the mid-20th century public library developed through time into the outreach public library services for underserved social, racial, and ethnic minorities by the 1980s¹³.

However, a research project on public library services in the UK at the end of the 20th century found that the provision of services for the disadvantaged members of society might have been of marginal importance for public libraries¹⁴. The research has also indicated that the working class and disadvantaged users have always under-utilized public libraries, whereas other social groups (e.g. Black people) have even experienced exclusion by the public libraries¹⁵. These problems are thought to be partly the result of a failure to establish a policy framework for public library services to socially excluded groups and communities.

Professional library associations have reacted to this obvious gap in theory and practice and created guidelines or tools for addressing the problem of service provision for older citizens. British Chartered Institute of Library and Information Professionals (CILIP) has created guidelines on public library provision in England¹⁶ in which they, among other things, emphasize the need for libraries to reach out to the hard-to-reach members of their communities who are unable or unwilling to visit the library. But most of all, CILIP stresses the importance of having a library strategy that meets the needs of the local community. American Library Association (ALA)¹⁷ has also

12 Rebecca Linley, *Public libraries, older people and social exclusion*. In: *Open to all? The public library and social exclusion*, edited by Dave Muddiman [et al.]. London: Resource: The Council for Museums, Archives and Libraries, 2000, p. 129-143, <<http://eprints.rclis.org/6283/1/lico84.pdf>>.

13 Dave Muddiman [et al.], *Open to all?* cit. p. 1-2.

14 *Ivi*, p. 1.

15 Patrick Roach; Marlene Morrison, *Public libraries, ethnic diversity and citizenship (British Library Research and Innovation Report 76)*. Coventry: University of Warwick. CEDAR, 1998.

16 Chartered Institute of Library and Information Professionals, *What makes a good library service? Guidelines on public library provision in England for portfolio holders in local Councils*. 2009, <<https://modern.gov.sutton.gov.uk/mgConvert2PDF.aspx?ID=15468>>.

17 American Library Association. Office for Diversity, Literacy and Outreach Service, *Keys to engaging older adults*. 2018, <<https://www.ala.org/aboutala/sites/ala.org.aboutala/files/content/Keys%20to%20Engaging%20Older%20Adults-8-19-2019.pdf>>.

taken special care in guiding American libraries in enabling the equity of access for older adults, which focuses mostly on eliminating barriers to access to older adults by providing books-by-mail programmes, home visits, accessible bookmobiles and other outreach programmes for homebound older users; utilizing tools to enlarge texts (e.g. screen magnifiers) and providing accessible collections (e.g. through audio-books, large-print formats or braille); and finally, through designing library spaces for accessibility (e.g. clear aisles and pathways, accessible shelving or easy to navigate entrances). A subsidiary of ALA, the Reference and User Services Association (RUSA)¹⁸ has gone a step further and created *Guidelines for library and information services to older adults*. Those guidelines were first created in 1987, and the last version was adopted in 2008. The guidelines include seven major areas of service planning:

1. Acquire current data about the older population and incorporate it into planning and budgeting;
2. Ensure that the special needs and interests of older adults in your community are reflected in the library's collections, programs, and services;
3. Make the library's collections and physical facilities safe, comfortable, and inviting for all older adults;
4. Make the library a focal point for information services to older adults;
5. Target the older population in library programming;
6. Reach out to older adults in the community who are unable to travel to the library; and finally,
7. Train the library's staff to serve older adults with courtesy and respect.

ALA has also offered a toolkit for engaging older adults¹⁹, which can help libraries in planning their activities.

Croatian Library Association does not have a section that is dedicated to issues concerning only older library users, but there is the Section on Library Services for Persons with Disabilities and Special Needs (founded in 2000), which, among other target groups, also addresses the needs of older adults in nursing homes, people with physical and mental disabilities, as well as older adults that are homebound²⁰.

Library services for people with dementia

According to World Health Organisation²¹, around 55 million people worldwide have dementia and there are 10 million new cases every year. As the proportion of older people in the population is increasing at the global level, the number is expected to rise to 78 million in 2030 and 139 in 2050. Alzheimer's disease (AD) is the most common form of dementia and may contribute to 60-70% of cases. Although dementia (including AD) is generally considered to be an age-related disease, it may affect younger people, as well. The severity of the problem is indicated by the fact that dementia is currently

18 American Library Association. Reference and User Services Association. Management and User Services Section. Library Services to an Aging Population Committee, *Guidelines for library and information services to older adults*, «Reference & user services quarterly», 48 (2008), n. 2, p. 209-212, <<https://journals.ala.org/index.php/rusq/article/viewFile/3692/4026>>.

19 ALA, *Keys to engaging older adults* cit.

20 Hrvatsko knjižničarsko društvo, *Komisija za knjižnične usluge za osobe s invaliditetom i osobe s posebnim potrebama*. 2002, <https://www.hkdrustvo.hr/hr/strucna_tijela/30/plan_i_program/>.

21 World Health Organisation, *Dementia*. 20 September 2022, <<https://www.who.int/news-room/fact-sheets/detail/dementia>>.

the seventh leading cause of death among all diseases and one of the major causes of disability and dependency of older people all over the world. In addition, this irrevocable and incurable disease affects people that suffer from it, but also their families and society at large, on several levels: physical, social, psychological, and economic. In Croatia, it is estimated that approximately more than 100.000 people (2.6% of the population) suffer from dementia, 70% of whom have AD²².

A person suffering from some sort of dementia (e.g. AD or some other related disorder) demonstrates symptoms of impaired memory, thinking processes, and behaviour. Early signs include problems in remembering recent events and difficulty performing routine and familiar tasks. The person may also experience confusion, personality or behaviour change, difficulties in finding words or following directions. Also, it is important to stress that dementia is a disease and not a normal part of ageing²³. Nevertheless, age is the strongest known risk factor for dementia. Other risk factors may include smoking, physical inactivity, obesity, alcohol, high blood pressure, depression, social isolation, or cognitive inactivity²⁴.

Despite various physical and mental limitations, a person suffering from dementia can still benefit from library services and activities. Library services and activities aimed at persons suffering from dementia can be categorized into services and activities for a) prevention and promotion, and b) management and treatment²⁵. In the field of prevention and promotion activities, libraries can achieve a lot in the area of social cohesion, alleviation of social inequalities when it comes to people suffering from dementia and members of their families, raising awareness among the general population about the disease, and lifting the stigma from those affected with this difficult disease. And while library services cannot prevent the disease in the true meaning of its word, they can help manage and treat it (together with other non-pharmacological approaches such as music, dance, painting, etc.). Many types of library services and materials can help stimulate memory and while they cannot stop the disease, they definitely can slow its process.

Intending to raise awareness among library professionals, caregivers, and public policymakers, as well as among families and friends of persons suffering from dementia, IFLA has encouraged the creation of guidelines for library services for persons with dementia²⁶. The guidelines are extremely useful because they give practical recommendations on how to provide materials and services that would stimulate the cognitive processes of people suffering from dementia. Furthermore, they also provide suggestions for library staff on how to tailor library services for this particular group of library users. Danish libraries seem to be particularly active in the area of library services for people with dementia and the guidelines include many interesting examples of those services.

22 Biljana Starči Hina, *Alzheimerova bolest: u Hrvatskoj se 350.000 ljudi nosi s problemima demencije*, «Tportal.hr», 21 settembre 2021, <<https://www.tportal.hr/vijesti/clanak/alzheimerova-bolest-u-hrvatskoj-se-350-000-ljudi-nosi-s-problemima-demencije-20210921>>.

23 Helle Arendrup Mortensen; Gyda Skat Nielsen, *Guidelines for library services to people with dementia*. The Hague: IFLA Headquarters, 2007, <<https://www.ifla.org/wp-content/uploads/2019/05/assets/hq/publications/professional-report/104.pdf>>.

24 WHO, *Dementia* cit.

25 Daisy Fancourt; Saoirse Finn, *What is the evidence on the role of the arts in improving health and well-being? A scoping review*. Copenhagen: WHO Regional Office for Europe, 2019, <<https://apps.who.int/iris/handle/10665/329834>>.

26 H. A. Mortensen; G. S. Nielsen, *Guidelines for library services to people with dementia* cit.

Another useful resource for librarians is a publication entitled *Library dementia services*²⁷ where the author provides useful and practical tips classified into four chapters: customer service and communication, information resources to best meet the reference needs of the community, collection development for ongoing and appropriate mental and social stimulation of those experiencing cognitive decline, and programming ideas.

Library collections for people with dementia should include, among other materials, illustrated books, books for reading aloud, media materials, audiobooks, music, kits of sensory and memory-evoking materials, and books and materials for caregivers and staff²⁸. Topics with universal appeal (such as pets or flowers), or topics that are most likely to bring to the surface older memories (gardening, food, countries of the world) are the best for dementia library users²⁹. Reminiscence kits (also known as memory kits or memory boxes) consist of multimedia objects gathered by theme. The goal of those kits is to evoke positive memories or improve cognitive function and fight depression and apathy in dementia patients³⁰. These kits can include books, sets of pictures, CDs, DVD slideshows, and even tactile objects and realia.

Library programming has a special value because it may have a direct therapeutic benefit to those living with AD and related dementias. Recent research³¹ has shown that greater social contact in midlife correlates with both a lower risk of developing dementia and with higher cognitive performance. Library activities for persons suffering from dementia can therefore boost their cognitive health³².

There are efforts to create dementia-friendly libraries all over the world. In Denmark, three public libraries developed activities based on oral text-reading supported by pictures and/or visits to museums primarily for people with dementia (but some participated with the assistance of relatives)³³. The results were positive, both for the participants (who re-experienced the joy of literature and were stimulated culturally and intellectually) and the staff (who contributed to the creation of dementia-friendly libraries). A feasibility study on the value of book groups for people living with dementia was conducted in 2017³⁴ in New Zealand. It indicated that participants enjoyed those activities, but preferred adaptations where the original texts were shortened,

27 Timothy J. Dickey, *Library dementia services: how to meet the needs of the Alzheimer's community*. Bingley: Emerald, 2020.

28 H. A. Mortensen; G. S. Nielsen, *Guidelines for library services to people with dementia* cit.

29 T. J. Dickey, *Library dementia services* cit., p. 122, 136.

30 Kyongok Park [et al.], *A systematic review and meta-analysis on the effect of reminiscence therapy for people with dementia*, «International psychogeriatrics», 31 (2019), n. 2, p. 1-17, DOI: 10.1017/S1041610218002168.

31 Andrew Sommerlad [et al.], *Association of social contact with dementia and cognition: 28-year follow-up to the Whitehall II cohort study*, «PLoS Medicine», 16 (2019), n. 8, DOI: 10.1371/journal.pmed.1002862.

32 Laura N. Gitlin; Nancy Hodgson, *Better living with dementia: implications for individuals, families, communities, and societies*. London: Elsevier Academic Press, 2018.

33 Anders Møller Jensen; Rikke Gregersen, *Public libraries' involvement in creating a dementia-friendly society: psychosocial factors and environmental design / Living with dementia and quality of life*, «Alzheimer's and dementia», 16 (2020), n. 57, DOI: 10.1002/alz.043128.

34 B. Sally Rimkeit; Gillian Claridge, *Literary Alzheimer's: a qualitative feasibility study of dementia-friendly book groups*, «New Zealand library & information management journal», 56 (2017), n. 2, p. 14-22.

whereas the original lexis and syntax were retained. And whereas more and more New Zealand libraries organize book groups for persons suffering from dementia³⁵, it is first necessary to have ready materials in the country's language. In the 2017 feasibility study, a linguist and a psychogeriatrician adapted five books to be read by dementia patients. They realized that the oversimplification of words and the plot did not work well with their readers, and they had to change their approach in the sense that they only shortened the books, while preserving the original text. Since 2013, an innovative and engaging American library service, Tales and Travel Memories³⁶, has each month been taking residents of six memory care facilities in Illinois on an imaginary trip to another country or a part of the United States. Residents have been allowed to read aloud from a short folktale, myth, or legend from the destination, which has been typed in large font to make it easier to read. This library service is a good example that could be replicated in other countries, and one that does not require a book adaptation by a professional.

The benefits and positive impacts of these library activities are without question but there is a lack of research studies that can confirm this belief. One of the rare studies was carried out in 2015 by Susan Wesner and funded by a grant from the American National Institutes of Health and the National Library of Medicine. The study analysed the therapeutic effectiveness of the Tales and Travel Memories Program and reported the increased social interaction, increased cognitive interaction, and various types of cognitive engagement, including verbalization, memory recall, reading ability, and emotional engagement of people suffering from dementia. In addition, caregivers also reported improved relationships with their loved ones as a result of the program³⁷. Another study examined a social and storytelling program for people with dementia run by a Canadian public library³⁸. The study revealed various benefits of this program - from supporting engagement, fostering relationships, and helping caregivers, to reaching broader communities. This study also emphasized the librarians' diversified roles as demonstrated through their collaboration with professionals, preparation and research, and facilitation of the sessions.

In addition, it must not be forgotten that the biggest burden of care and supervision of people suffering from dementia falls on family members and friends as more than 70% of people with dementia live at home and 75% of necessary care is provided by family and friends³⁹. Since the main carer of the diseased can invest as many as about 70 hours per week in the task of caring⁴⁰, the caregivers are frequently affected by a

35 Alyson Baker; B. Sally Rimkeit; Gillian Claridge, *Promoting dementia-friendly libraries: setting up book groups to encourage reading and community inclusiveness for people living with dementia*, «New Zealand library & information management journal», 57 (2018), n. 1, p. 4-10.

36 *Tales and Travel Memory Programs*, <<http://talesandtravelmemories.com/>>.

37 This study is cited in *Tales and Travel Memory Programs* cit.

38 Jiamin Dai; Joan C. Bartlett; Karyn Moffatt, *Library services enriching community engagement for dementia care: the Tales & Travels Program at a Canadian public library as a case study*, «Journal of librarianship and information science», 2022, DOI: 10.1177/09610006211065170.

39 Manuel Martín-Carrasco [et al.], *Effectiveness of a psychoeducational intervention program in the reduction of caregiver burden in Alzheimer's disease patients' caregivers*, «International journal of geriatric psychiatry», 24 (2009), n. 5, p. 489-499, DOI: 10.1002/gps.2142.

40 Brooke S. Harrow [et al.], *Variation in cost of informal caregiving and formal-service use for people with Alzheimer's disease*, «American journal of Alzheimer's disease and other dementias», 19 (2004), n. 5, p. 299-308, DOI: 10.1177/153331750401900507.

series of negative consequences such as anxiety, depression, social isolation or financial burden. It is therefore important to bear in mind that caregivers also need help – they need information about the best way to help their sick relative or friend, or how to best exercise the social, legal, and medical rights of the sick person, they need activities that will help them get in touch with other people with similar problems, or they just need a respite from their continuous and arduous work. In many ways, libraries can address many of those needs – various library programming for people suffering from dementia usually requires the in-house social gathering of both people suffering from dementia and their caregivers. They help reduce their social isolation, provide enjoyable social interaction, and enable access to helpful library resources on the disease⁴¹.

It is evident that libraries all over the world are starting to rethink their services and tailor them for this particular group of users, however, those efforts are still rare. It is necessary to start planning services for older adults (a part of which will inevitably end up affected by dementia) at a much larger scale. This was the reason which motivated a group of researchers at the Department of Information Sciences of the Faculty of Humanities and Social Sciences, at the University J. J. Strossmayer in Osijek, Croatia, to start investigating, first information needs and information behaviour of people with dementia and their caregivers, then the necessary prerequisites to create dementia-friendly public libraries in Croatia.

Dementia-related projects at the Department of Information Sciences in Osijek

Public libraries in Croatia are quite active in regard to library services and activities for older adults, with Zagreb City Libraries being at the forefront. This library network has been organizing a number of various activities for older citizens of Zagreb ever since 2008: from delivering books to their doorstep, over art workshops, information and digital literacy training, interaction and story-telling to preschool children, educational activities to empower older adults in the area of their human and material rights as well as social and health protection, exhibitions of works of art created by older adults, up to physical exercises for the older generation⁴². Other public libraries in Croatia offer mostly information and digital literacy workshops (e.g. Pula Public Library⁴³ or City and University Library in Osijek)⁴⁴, but also other types of workshops such as language learning (e.g. Dubrovnik Public Libraries)⁴⁵, activities that include

41 T. J. Dickey, *Library dementia services* cit.

42 Sanja Bunić, *Projekt 65 plus Knjižnica grada Zagreba aktivno uključivanje osoba treće životne dobi u kulturna i društvena zbivanja*, «Vjesnik bibliotekara Hrvatske», 53 (2010), n. 2, p. 15-25, <<https://www.hkdrustvo.hr/vjesnik-bibliotekara-hrvatske/index.php/vbh/article/view/428>>; Snježana Erečogovac; Vlasta Šolc; Ira Tuzlančić, *Program za budućnost: deset godina projekta "65 plus" u Knjižnicama grada Zagreba*, «Vjesnik bibliotekara Hrvatske», 61 (2018), n. 2, p. 199-220, DOI: 10.30754/vbh.61.2.700.

43 Vodnjanski Đir, *Radionica digitalne pismenosti za osobe treće životne dobi*. 2 studenoga 2022, <<https://www.vodnjanski.info/radionica-digitalne-pismenosti-za-osobe-trece-zivotne-dobi/>>.

44 Srđan Lukačević; Dino Radmilović; Kornelija Petr Balog, *Digitalne kompetencije i treća životna dob: analiza programa informatičkog i informacijskog opismenjavanja korisnika treće životne dobi Gradske i sveučilišne knjižnice Osijek*, «Vjesnik bibliotekara Hrvatske», 61 (2018), n. 2, p. 123-153, DOI: 10.30754/vbh.61.2.667.

45 Dubrovačke knjižnice, *Informatika i engleski: Besplatne radionice za osobe treće životne dobi*. 7 kolovoz 2020, <<https://www.dkd.hr/novosti/informatika-i-engleski-besplatne-radionice-za-osobe-trece-zivotne-dobi>>.

talking and reminiscing about the hometown or place of living of older adults (e.g. the “Ivan Goran Kovačić” Karlovac Public Library)⁴⁶, or even video-workshops (“Vid Omišljanin” Omišalj Public Library)⁴⁷.

However, although people suffering from dementia (especially in the early stages of the disease) can benefit from library services and activities, in Croatia there are almost no library services aimed at this user group (apart from some library collections for users suffering from dementia such as the collection at the City and University Library in Osijek)⁴⁸. As already mentioned, this particular gap in library services motivated a group of researchers at the Department of Information Sciences in Osijek to start rethinking a project that would bridge that gap. However, it was soon clear that before investigating library services for people suffering from dementia (in particular, Alzheimer’s disease) it is necessary to investigate their information needs (including the information needs of the members of their families, as well). As a result, two research projects were conducted: 2018-2020 Information needs of Alzheimer’s disease patients and their family members (UNIOS ZUP 2018 – 76) and 2021-2024 Creation of dementia-friendly public libraries: theoretical and practical approaches (FFOS-002).

Project 2018-2020 Information needs of Alzheimer’s disease patients and their family members (UNIOS ZUP 2018 – 76)⁴⁹

The project’s goal was to find out about the information needs of Alzheimer’s disease (AD) patients and their caregivers living in Osijek’s wider area as well as the problems they encounter in regulating their financial, social, health, hereditary, retirement, and other rights. The project results were extremely useful to all stakeholders involved in information dissemination and support systems to this demographic group such as:

- AD associations that provide direct support to the patients and their family members;

- Health institutions and schools of medicine that can raise awareness among future medical workers about the changing (information) needs of this population, which requires the adjustment of their approach to the diseased and their family members; and

- Public libraries and other information institutions that disseminate health information to their members within local communities (e.g. acquire materials on this topic, provide information on associations, communal services, and patient rights of this population, raising awareness among the general public through the organisation of various events on dementia such as lectures, exhibitions, workshops, etc.).

This interdisciplinary project included researchers and professionals from various fields because it strived to ensure a holistic approach to this research topic: information sciences, law and medicine. More specifically, the project included researchers working at the Faculty of Humanities and Social Sciences in Osijek (Sanjica Faletar Tanacković, PI, and Kornelija Petr Balog), Simmons College, Boston, USA (Sanda Erdelez), Law School in Osijek (Renata Perić), School of Medicine in Osijek (Sanda Škrinjarić-Cincar,

⁴⁶ Gradska knjižnica “Ivan Goran Kovačić” Karlovac, *Treća dob*, <https://gkka.hr/?page_id=2132>.

⁴⁷ Gradska knjižnica Rijeka, *U Omišlju: video radionica za osobe starije životne dobi*. 14 listopada 2022, <<https://gkr.hr/Magazin/Najave/U-Omislju-Video-radionica-za-osobe-starije-zivotne-dobi>>.

⁴⁸ Gradska i sveučilišna knjižnica Osijek, *Knjižnica – prijatelj demencije*. 14 veljače 2022, <<https://www.gskos.unios.hr/index.php/knjiznica-prijatelj-demencije/>>.

⁴⁹ Project’s web page can be accessed at: <<http://alzheimer.ffos.hr/view/about.php>>.

Silva Butković-Soldo) and Association Memoria Osijek (Silvija Dološić). The project also included two students of information sciences who wrote their final graduation papers as a part of the project topics.

The project members analysed the information needs and information behaviour of AD patients' caregivers that shared their experiences on the Croatian forum. The findings of this study were published in papers presented at international conferences⁵⁰. Also, 12 additional interviews with caregivers were conducted and findings were presented at the 2020 ISIC conference in South Africa⁵¹. Patients' rights were also explored and described in an additional paper⁵². Within the project, several popular lectures were organized on the topic of the human rights of AD patients.

Since the Covid-19 pandemic occurred during the duration of the project, some of the conferences were organised online and therefore some of the project funds were saved; as a result, library materials specially designated for the use by the people with dementia were bought and allocated to the City and Public Library in Osijek. This special collection will be used for educational, research, and therapeutic purposes.

The research findings indicated that there is no systematic and organized system of information provision for AD patients and their caregivers in Croatia. The first contact with the disease and the information about it is in the general medical practitioner's (GP's) office, but for the majority of the participants, this is insufficient and not precise or clear enough. One of the reasons for such a situation may be that the GPs themselves do not have enough knowledge about the disease. At the same time, the GPs seem to be the only source of information from the 'system' that our respondents recognize; all the other actors (e.g., Centre for Social Care, Alzheimer's associations) are almost invisible.

As a result, the most significant contribution of this project was the creation of the *Guide for people suffering from Alzheimer's disease and their caregivers*⁵³, with practical information for the diseased and their families living in Osijek and its wider area. The publication offers, in one place, all the types of information needed by this population – information about exercising their various rights. It also offers an important section where relevant legal mechanisms of protection (e.g. custody or deprivation of legal capacity) are simply and understandably explained. Finally, it contains the

50 Sanda Erdelez [et al.], *The use of online discussion forums by people with Alzheimer's disease and their caregivers*. In: *Proceedings of the XXVII Bobcatsss Symposium. Information and technology transforming lives: connection, interaction, innovation*, edited by Gordana Gašo [et al.]. Osijek: Filozofski fakultet Osijek, 2019, p. 424-434. <http://bobcatsss2019.ffos.hr/docs/bobcatsss_proceedings.pdf>; Sanda Erdelez; Sanjica Faletar Tanacković; Kornelija Petr Balog, *Online behavior of the Alzheimer's disease patients' caregivers on Croatian online discussion forum*. In: *Proceedings of 82nd Annual Meeting of the Association for Information Science & Technology*, edited by Catherine Blake, Cecilia Brown. Silver Spring (MD): Association for Information Science & Technology, 2019, p. 78-88, DOI: 10.1002/pra2.8.

51 Kornelija Petr Balog; Sanjica Faletar Tanacković; Sanda Erdelez, *Information support system for Alzheimer's disease patients' caregivers in Croatia: a phenomenological approach*, «Information research», 25 (2000), n. 4, DOI: 10.47989/irisic2011.

52 Silvija Dološić; Marina Milić Babić; Silvia Rušac, *Alzheimerova bolest kroz prizmu ljudskih prava / Alzheimer's disease and human rights*, «Socijalna psihijatrija», 47 (2019), n. 4, p. 470-496, DOI: 10.24869/spsih.2019.470.

53 Guide can be downloaded from: <<https://www.docdroid.net/ujzMEwk/ab-brosura-tisak-pdf>>.

address book of relevant institutions and non-government associations in Osijek and its area. This guide was distributed widely – among the GP offices in Osijek and wider area because they are usually the patient's first medical contact, but it was also distributed among the non-government associations and libraries. In addition, the publication is accessible in e-form and can be downloaded from the Project's webpage.

The project ended in 2020 and its findings paved the way for the new project that focused on the creation of dementia-friendly libraries in Croatia.

Project 2021-2024 Creation of dementia-friendly public libraries: theoretical and practical implications (FFOS-002)⁵⁴

This project was founded on the findings of the previous project, but the first project focused on the information needs of AD patients and their caregivers whereas its follow-up focuses on the ways libraries can contribute to active ageing and postponing of AD. The project's goal is to look into practical and theoretical approaches to the creation of dementia-friendly public libraries in Croatia.

Literature suggests⁵⁵ that AD patients can preserve their language skills until later stages of the disease whereas cognitive therapy that includes intellectual activities such as reading (silently or out loud) might contribute to slowing down the disease. Older adults in general, and dementia and AD patients in particular, are very often discriminated against and stigmatized in modern society, which results in their isolation and marginalization. This in turn can lead to low self-esteem, depression, low quality of life and, sometimes, even to an untimely demise. The initiatives that contribute to the creation of so-called dementia-friendly communities are therefore of extreme importance. Dementia-friendly communities are communities that are physically and socially friendly to dementia patients who, in turn, feel welcomed, appreciated and involved in the life of those communities.

To achieve the main project's goal, it is necessary to:

- Find out to what degree are librarians and students of library and information sciences informed about AD and how they perceive the role of public libraries in the creation of dementia-friendly communities;
- Raise awareness about AD (with an emphasis on librarians and students of library and information science - LIS);
- Investigate the AD patients' needs in relation to reading materials and encourage the creation of appropriate reading materials in the Croatian language; and
- Contribute to their social inclusion through library activities tailored to the needs of AD patients.

This project is also interdisciplinary in character and includes members from various disciplines. The project partners come from the following institutions: The Faculty of Humanities and Social Sciences in Osijek (Sanjica Faletar, PI, Kornelija Petr Balog and Zoran Velagić), School of Medicine in Osijek (Silva Butković-Soldo), Faculty of Dental Medicine and Health (Štefica Mikšić), Simmons College, Boston, USA (Sanda Erdelez), Clinical Hospital Osijek (Mirjana Vladetić), the City and University Library in Osijek (Dubravka Pađen-Farkaš), Croatian Association for Alzheimer's Disease in Zagreb (Mira Dajčić) and Association Memoria Osijek (Silvija Dološić), and the Library Association of Slavonia, Baranya and Sylvania (Tihonija Zovko).

⁵⁴ Project's web page: <<https://demencija-pnk.ffos.hr/index.html#>>.

⁵⁵ H. A. Mortensen; G. S. Nielsen, *Guidelines for library services to people with dementia* cit.; also T. J. Dickey, *Library dementia services* cit.

The preliminary research into the Croatian public library services for AD patients and their caregivers revealed⁵⁶ that public librarians in Croatia are knowledgeable about AD and believe that libraries can contribute to the development of dementia-friendly communities. However, findings also suggest that the largest portion of studied libraries do not actively seek information about AD patients in their community and offer limited resources, services, and activities for this potential user group. The larger proportion of libraries in the study have dementia-related materials in their collections but Croatian librarians do not perceive themselves as competent to deal with users suffering from dementia and need additional training. As a result of this finding, it was decided to:

- Invest efforts to create dementia-related educational events within the project;
- Include dementia-related topics in the LIS curriculum at the Department of Information Sciences in Osijek;
- Create a continuous professional development course on this topic within the Croatian Centre for Continuous Education of Librarians.

Since this is an ongoing project, so far several educational events were organized, whose purpose was to raise awareness about the disease among the general public but also to inform librarians and LIS students⁵⁷.

In the next two years, it is planned to investigate the reading text features that are required for use by dementia patients and apply those findings in designing and publishing one work of Croatian literature (most likely a book of poetry). In addition, it is planned to obtain rights and translate into Croatian one picture book on dementia.

Concluding remarks

The goal of this paper was to give a short overview of libraries' activities, services, and programming that are specially tailored for the use by older adults, particularly those suffering from dementia (with Alzheimer's disease being the leading dementia disease in the world). Library activities can be categorized into two groups: prevention and promotion, and management and treatment. The former activities are important for lifting the negative perception and stigma from the disease as well as raising awareness among the wider population whereas the latter activities proved to be extremely helpful in slowing down the disease, but also in reducing the social isolation of people suffering from the disease as well as their caregivers.

Two projects presented in this paper are pioneer works of the Department of Information Sciences in Osijek and are currently the only projects on this topic in the Croatian library community.

Upon the finish of the second project in 2024, the intention of project members is to apply for an Erasmus+ project on the topic of dementia-friendly libraries in Europe. In that sense, libraries in Italy that are active in the area of services for patrons suffering from dementia are invited to contact professor Sanjica Faletar (sfaletar@ffos.hr) or Kornelija Petr Balog (kpetr@ffos.hr).

56 Sanjica Faletar Tanacković; Kornelija Petr Balog; Sanda Erdelez, *How can libraries support dementia-friendly communities? The study into perceptions and experiences of Croatian public librarians*, «Education for information», 37 (2021), n. 4, p. 525-543, DOI: 10.3233/EFI-211560.

57 More about the educational activities at the Project can be found at: <<https://demencija-pnk.ffos.hr/assets/pages/edukacija.html>>.

Articolo proposto il 29 novembre 2022 e accettato il 17 gennaio 2023.

ABSTRACT AIB studi, 63 n. 1 (gennaio/aprile 2023), p. 135-147. DOI 10.2426/aibstudi-13790
ISSN: 2280-9112, E-ISSN: 2239-6152 - Copyright © 2023 Kornelija Petr Balog

KORNELIJA PETR BALOG, University J. J. Strossmayer in Osijek, Department of Information Sciences, Croatia, e-mail: kpetr@ffos.hr.

La creazione di biblioteche pubbliche in grado di accogliere persone affette da demenza in Croazia

L'esclusione sociale in età avanzata comporta l'emarginazione degli adulti anziani nella vita sociale odierna e richiede un cambiamento significativo delle politiche pubbliche in società soggette al fenomeno dell'invecchiamento. Particolarmente escluse da tutti gli aspetti della vita sono le persone (anziane) affette da qualche forma di demenza.

I servizi delle biblioteche pubbliche sono concepiti per soddisfare le esigenze informative e ricreative di tutti i gruppi di popolazione e sono particolarmente adatti nell'aiutare a superare i problemi di esclusione. Tuttavia, i risultati della ricerca presentata in questo articolo indicano che i servizi bibliotecari dedicati alle persone affette da un qualche tipo di demenza sono ancora in uno stadio iniziale nella gran parte dei paesi, Croazia compresa.

L'articolo presenta gli obiettivi e i risultati di due progetti realizzati dal Dipartimento di Scienze dell'informazione della Facoltà di Scienze umanistiche e sociali dell'Università J. J. Strossmayer di Osijek, in Croazia. Tali progetti si occupano dei bisogni informativi e dei servizi bibliotecari pubblici per le persone affette da demenza (in particolare quelle affette dalla malattia di Alzheimer) e di chi se ne prende cura.

Creation of dementia-friendly public libraries in Croatia

Social exclusion in later life involves the marginalization of older adults from all aspects of life in today's society and requires a significant change in public and social policy in ageing societies. Particularly excluded from all aspects of life are (older) people suffering from some form of dementia.

Public library services are tailored to meet the informational and recreational needs of all population groups and are particularly suited to help overcome problems of exclusion. However, the research indicates that dementia library services are still in their very beginnings in most countries, including Croatia.

This paper presents the goals and results of two projects carried out by the Department of Information Sciences of the Faculty of Humanities and Social Sciences at the University J. J. Strossmayer in Osijek, Croatia. Those projects deal with information needs and public library services of people with dementia (in particular, Alzheimer's disease) and their caregivers.