



# Sweden

**Population**

10,328,000

**Area**

407,000 km<sup>2</sup>

**Capital**

Stockholm

**3 largest cities**

Stockholm (1,759,000)

Gothenburg (651,000)

Malmö (322,000)

**Neighboring countries**

Denmark, Finland,

Norway

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## 1. Migration history

Sweden has a long history of migration. During the 15th and 17th century larger groups of Roma, Walloons, Jews, and people from Germany, France, and Italy came to Sweden. Between 1850 and the 1930s, 1.5 million people emigrated to America or Australia from Sweden [1]. In the early 20th century, there were also waves of emigration to Denmark and Norway [2]. Through the immigration of about 180,000 refugees from Finland, Norway, Estonia, Denmark, and Germany during the Second World War, Sweden developed into the immigration country it is today [1, 2]. In the 1960s and early 1970s, Sweden actively recruited labor migrants from the Netherlands, West Germany, Italy, Austria, Belgium, Greece, Yugoslavia, and Turkey. In addition, many migrants came from Finland [2]. After recruitment was stopped in 1972/73, many labour migrants (especially from Finland) returned to their home countries, resulting in a negative migration surplus in the early 1970s. In the 1980s and 1990s, refugee flows and family reunification increased significantly. Large groups of migrants came from Iran, Iraq, Lebanon, Syria, Turkey, Eritrea, Somalia, and Chile. During the war in Yugoslavia, about 100,000 Bosniaks were admitted. EU accession in 1995, accession to the Schengen Agreement in 2001, and

especially the EU enlargement rounds in 2004 and 2007 led to a significant increase in immigration from other EU states (especially Romania) [1, 2]. In recent years, immigration of asylum seekers, refugees, family members of existing migrants, and international students has increased. While less than 60,000 people immigrated in 2000, the number of annual immigrants has exceeded 100,000 annually since 2012 [1]. In 2014, 127,000 people moved to Sweden. Most of these immigrants were born in Syria (26,100), Eritrea (5,300), Poland (5,100), and Somalia (4,400). In addition, a large group of people born in Sweden returned from abroad (15,200). In terms of population size, Sweden was the main destination for asylum seekers in the EU in 2014 and 2015. In 2015, approximately 163,000 people applied for asylum [2]. People from Syria (191,500), Iraq (146,000), Finland (144,600), Poland (93,700), and Iran (80,100) were the largest migrant groups (born abroad) in 2019 [3]. Between 1990 and 2019, the migrant population (born abroad) and their proportion in the total population more than doubled (788,800 to 2 million; 9.2 to 20%) [4]. The net migration rate has always been positive in recent decades, and as of 2020 it is 4 [5].



## 2. Estimated number of people with a migration background with dementia

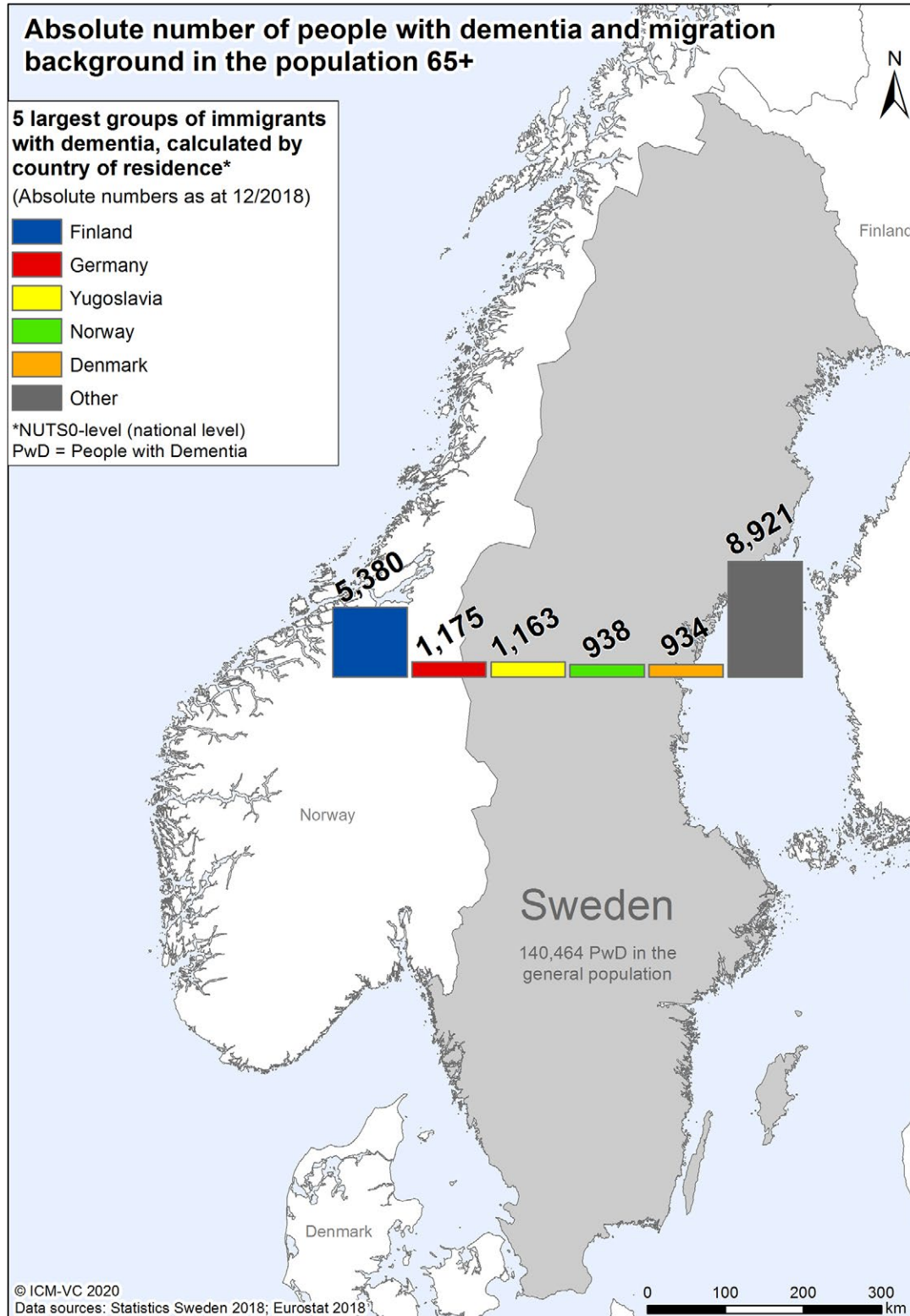


Fig. 3.7.30.1: Absolute number of PwM with dementia aged 65+ (Sweden – Nation)

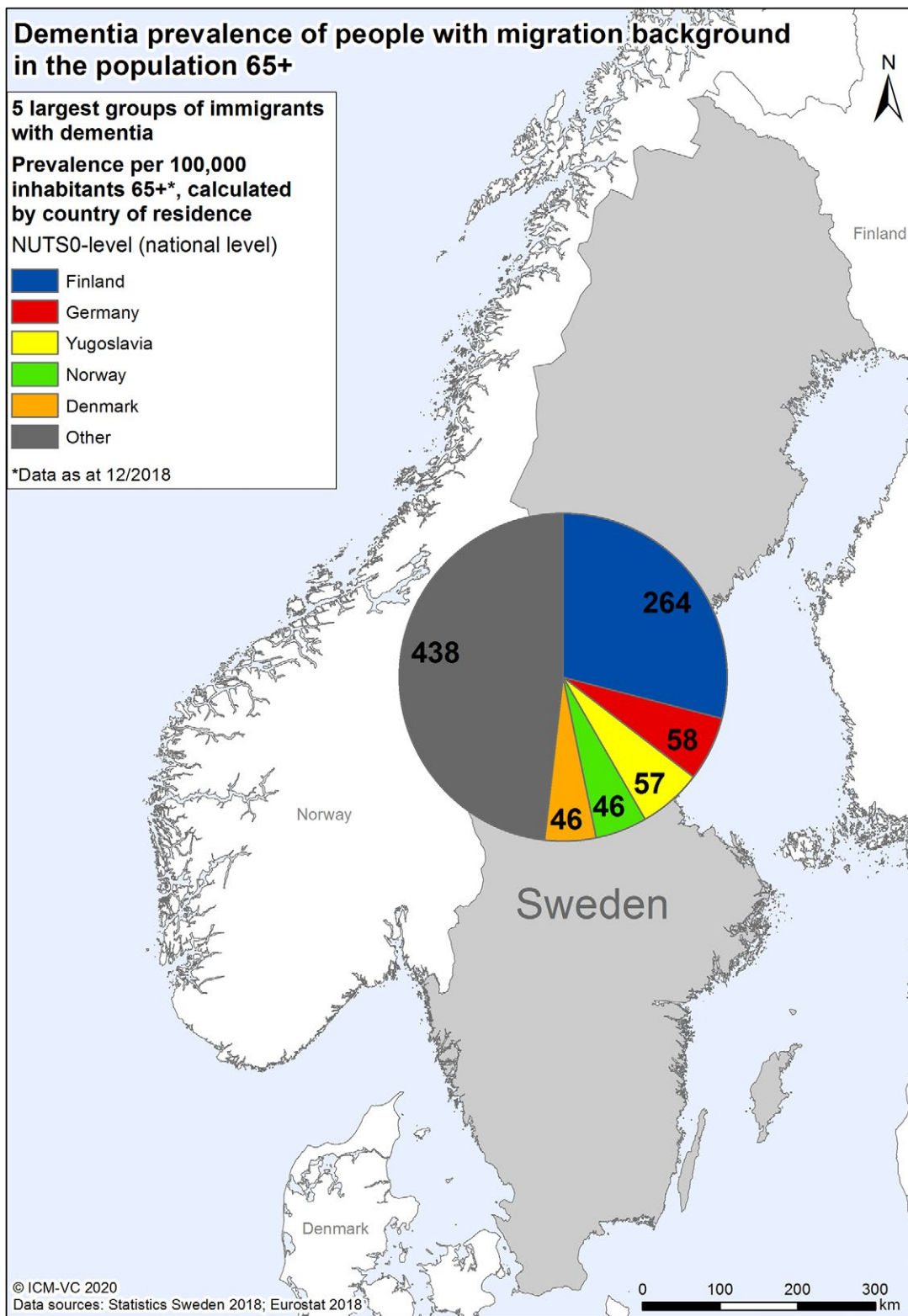


Fig. 3.7.30.2: Prevalence of PwM with dementia among the population aged 65+ (Sweden – Nation)



**Tab. 52: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Sweden – Nation)**

NUTS	Total	SE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Sweden	140,464	121,953	FI 5,380	DE 1,175	YU 1,163	NO 938	DK 934	8,921
Prevalence/10,000 inhabitants with migration background 65+								
Sweden	5,236	-	FI 201	DE 44	YU 43	NO 35	DK 35	332
Prevalence/100,000 inhabitants 65+								
Sweden	6,900	5,991	FI 264	DE 58	YU 57	NO 46	DK 46	438

Data source: Statistics Sweden (2018)

There are 268,300 PwM aged 65 or older. Of those, approx. 18,500 are estimated to exhibit some form of dementia. Figure 3.7.30.1 shows the most affected migrant groups presumably originate from Finland (approx. 5,400), Germany (approx. 1,200), Yugoslavia (approx. 1,200),

Norway (approx. 900), and Denmark (approx. 900). The second graph highlights the number of PwM with dementia in Sweden per 100,000 inhabitants aged 65 or older (figure 3.7.30.2). Table 52 illustrate the values depicted in the maps on the national level [6-8].

### 3. National dementia plan

Currently, no NDP could be identified for Sweden. However, according to a parliamentary speech by Prime Minister Stefan Löfven on 12 September 2017, the publication of a dementia strategy is planned [9, 10]. Furthermore, the National Board of Health and Welfare (Socialstyrelsen) has published the document 'A National Strategy for Dementia: Documentation and Proposal for a Plan for Prioritized Initiatives by 2022' in June 2017.

This document discusses the topic of migration in great detail. In a separate 4 ½ page section ('Foreign-Born People With Dementia'), six main topics ('Working with People With Dementia and a Foreign Background', 'Working with an Interpreter', 'RUDAS', 'Migration School', 'Care for the Elderly in National Minority Languages', 'Translation into other

Languages') and in 16 further text passages in ten chapters/subchapters, various issues related to migration are discussed. In these sections, the increasing need to examine and care for people who speak a language other than Swedish and have dementia is emphasised several times. According to the document, approximately 20,000 of the 160,000 people with dementia living in Sweden were born in another country. By 2036, the number of foreign-born people with a cognitive disease is expected to double. A general problem pointed out in this dementia strategy is that district councils and municipalities have only a few initiatives for people with dementia with a mother tongue other than Swedish. There is a particular lack in the areas of diagnostics and care for people with dementia. Only three dis-



district councils (Stockholm, Skåne, and Örebro) have initiated specific activities in these areas targeting people with a mother tongue other than Swedish. However, it is also stated that the district councils and municipalities need support to increase the willingness to help people who do not speak Swedish. Other major issues, according to a study by the Migration School, Knowledge Centre for Dementia Skåne that is referred to in this document, are that foreign-born people perform worse on traditional cognitive assessment instruments (e.g. MMSE), they receive less dementia-specific medication, and they are prescribed more neuroleptics than domestic-born people. Furthermore, it is repeatedly mentioned that there is a lack of interpreters in Sweden. According to the research findings cited, the quality of interpretation is often unsatisfactory and the communication gaps caused by inaccurate interpretation can have a negative impact on the results of cognitive tests and the subsequent diagnosis. Lack of expertise on the side of interpreters and lack of knowledge regarding how to best use interpretation services are cited as main reasons for this issue. To address these problems, the National Board of Health and Welfare recommends an improvement of recruitment practices and the expansion of training for interpreters in dementia care.

After the description of the key problems related to the care of PwM with dementia, this document also mentions some efforts already made in this field. In this context, the Migration School, Dementia Knowledge Centre in the region of Skåne is mentioned several times. This organisation has been engaged in developing and implementing working methods to improve dementia care for people with a foreign background since 2011. In the dementia strategy, several services already implemented by the Migration School are highlighted, such as online accessible web-based training on dementia in different languages or interpreter

training for medical staff working with people with dementia. In the context of the topic of interpreter utilisation, reference is made to an ongoing study at the Memory Clinic in Malmö, which is researching how the examination of dementia is influenced by the presence of an interpreter. The aim of the study is to identify development opportunities and develop routines for optimised interpreter use in dementia examinations. A service that is already integrated into care is the screening instrument RUDAS, which has been used since 2014 in several memory clinics and health centres in the county of Skåne for cognitive tests of people with a low level of schooling and other language or cultural backgrounds. Another model of good care practice is the cooperation between municipal social services and regional healthcare to support people with dementia from a foreign background, which has been established in a district of Malmö since 2013. Within the framework of this cooperation, various methods have been developed that staff at outpatient care services or inpatient facilities in Malmö and the region of Skåne, which is also involved in the cooperation, use in the case of communication difficulties between the staff and people in need of care who have lost their knowledge of Swedish. One method that has already been implemented is the matching of care recipients to staff members with the same mother tongue during the identification of the contact person. If such a matching is not possible, the staff members are supposed to learn the most important terms for care in the patient's mother tongue. Furthermore, the contact person should also have knowledge of the culture and living conditions of the region in which the care receiver grew up. Another method that has already been used is the maintenance of an action and implementation plan by the staff, in which the individual needs and wishes of the care receiver are described. In addition to these regional models of good



care practice, this document also refers to a few nationally available information and counselling services for PwM. For example, the Swedish Dementia Centre offers multilingual information about dementia through print and online mediums, and Alzheimer Sweden has a hotline that also addresses people who do not speak Swedish.

The dementia strategy also includes a few basic guidelines as well as some detailed recommendations for action for care providers and professionals. First, there is an explanation that a person-centred approach includes special consideration of the needs of people with a different cultural or language background. The staff of health and social services need to consider the cultural and language background while providing guidance and information to persons in need of care and their relatives and use an interpreter if necessary. The use of interpreters can be particularly important in the examination and treatment of persons with a mother tongue other than Swedish. In this dementia strategy, reference is made to the im-

portance of having an external person present during interpreted patient interviews, who has knowledge about the care and the lingo used in care as well as the language of the patient. Regarding support for the patient's relatives, care planners and providers are encouraged to plan and implement interventions based on the individual's needs, ethnicity, and gender. At the end of the document, the measure is recommended to ensure that knowledge about the needs and conditions of foreign-born people with dementia is disseminated in the healthcare system by 2022 [11].

Thus, 'A National Strategy for Dementia: Documentation and Proposal for a Plan for Prioritised Initiatives by 2022' not only presents a detailed thematic introduction and description of the main problems related to dementia care for PwM, but also provides a comprehensive framework for action with recommendations for care planners and service providers as well as references to existing studies, projects, care structures, and care services.

## 4. National dementia care and treatment guidelines

Two documents with national guidelines for dementia care were identified: 1. 'Care and Support for Dementia Patients: Support for Guidance and Management' from 2017, 2. 'Care and Support for Dementia Patients: Summary with Potential for Improvement' the evaluation of the national guidelines from 2018. The first document does not have a separate chapter on migration but makes a brief reference to people with a different linguistic or cultural background in eight sections. These people are identified as a group with special needs in terms of dementia care. In the context of person-centred care, the person with dementia should be given the opportunity to practice their religion, eat culturally adapted food, preserve their cultural traditions and cus-

oms, and have access to staff who speak the same language. Overall, the guidelines seem to identify cognitive assessment and early detection in people with suspected dementia and different linguistic or cultural background as a key challenge. In four passages they recommend the use of the intercultural assessment scale RUDAS, which has already been adapted to this group. In terms of inpatient care, it is recommended that the physical environment should be designed considering the cultural and religious needs of people with dementia. In addition, the guidelines point to the right of linguistic minorities to receive individually tailored information on health status and available care services, and to the need for the adaptation of services to the linguistic background.



Sweden seems to be following an inclusive model of care, where existing healthcare services are adapted to the needs of people with different linguistic or cultural background [12].

The second document from 2018 has a separate chapter on migration ('Needs of People from Other Countries Need Attention'). In addition to this three-page chapter, the topic also plays a role in another separate section and a later chapter. Overall, the evaluated guidelines refer to migration in a much broader sense than the guidelines from the previous year. This indicates that the topic is becoming increasingly more important at the national level. The focus of the content is on raising awareness among providers of dementia care services, and especially among municipalities and districts, of the needs of people from other countries. Communication difficulties are mentioned as a particular challenge, as many people who have a different mother tongue lose their Swedish language skills due to dementia. Further, the problem of traumatic experiences and their effects on psychological symptoms and the validity of results in dementia diagnostic tests for people with a foreign background are addressed. The document assumes that the number of people with dementia born in another country will increase significantly in the coming years (doubling within the next twenty years). Of the current 20,000 people, most were born in Finland or another neighbouring Scandinavian country. Several passages mention the importance of considering the specific needs of people from different linguistic or cultural backgrounds in the provision of care and assistance. With almost the same wording as in the guidelines from 2017, several needs are cited and the implementation of concrete measures such as the use of RUDAS for people with suspected dementia and another mother tongue is recommended. The evaluated version adds that a training program for the use of RUDAS is available to healthcare professionals. The screening tool and the

training program have spread nationally in recent years. At present, half of the districts are already using RUDAS. In addition, two-thirds of the districts stated in a survey that they have developed routines for the use of interpreters. Simultaneously, the guidelines also reveal that there is a shortage of care and assistance for people from other countries. This shortage exists particularly in terms of early detection and screening for dementia, appropriate drug treatment, and specialised post-diagnostic care. Less than one in ten municipalities provides daycare, home care, or family care services adapted to the needs of linguistic minorities. Although the proportion of municipalities with residential facilities that focus on people with a different mother tongue has increased, it was still only 16% in 2017. The geographical distribution of services for linguistic minorities is highly concentrated in large cities. Furthermore, research has shown that people born outside Scandinavia are prescribed less dementia medication. There are large gaps in the knowledge of the needs of cultural and linguistic minorities and the appropriate measures to meet these needs. As a result, foreign-born persons make less use of municipal support services than persons originating from Sweden. The 2018 evaluated guidelines conclude that the districts and municipalities need to work more actively to diagnose dementia in people from other countries and to gain more knowledge about the investigation and treatment of dementia in this group. Prescription of dementia drugs needs to be reviewed and more municipalities need to develop specialised services for people with different mother tongues [13]. The analysis of the documents from 2017 and 2018 has shown that Sweden is paying close attention to the topic of dementia and migration at the national level. The national guidelines give general recommendations to municipal healthcare providers and show them concrete options for actions to address the cur-





rent knowledge and care gaps regarding people with foreign backgrounds and dementia.

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on

written statements and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the expert, PwM are identified as a vulnerable group in the healthcare system. This applies particularly to people born outside Europe, e.g. Asia, the Middle East, or Africa. Still, the topic of dementia and migration is only partly considered to be important at the national level in Sweden. For instance, no national budget for dementia and migration exists. However, some individual experts focus on this topic. In some regions, the topic is very important. The expert noted that PwM are considered vulnerable with regard to the development, process, and consequences of dementia as well as gaps in care, underdiagnosis, and utilisation of formal healthcare services. In general, care is adapted to people born and raised in Sweden. People having other linguistic and cultural backgrounds, and especially migrants with less education, remain deprived of the kind of care they need. In addition, the diagnosis of dementia is less reliable because the tests used are influenced by culture, language, and education and there is a lack of professional interpreters. In Sweden, the concept of person-centred dementia care is pursued. According to the expert, this concept does not work in practice for PwM. Basically, an integrative model of care is used, in which all people have the same right to seek care and support. However, the problem is that healthcare and society are not adapted to everyone. Differences in language, culture, and education, as well as a lack of knowledge about how healthcare works and what society offers in terms of resources, mean that migrants have

fewer opportunities to make use of available services. As an example, the expert cited the day care services for people with dementia that are basically available to everyone in Sweden, but which are not used by many PwM because they cannot interact well with staff or patients. For these reasons, the expert concluded that existing care services are more suitable and adequate for non-migrants with dementia. However, there are also groups of migrants for whom care is more appropriate (people from Finland or Denmark) because they are better integrated into society and there are fewer language and cultural problems. Furthermore, some ethnic groups with a long history of migration have access to healthcare staff who come from the same country or to homes for people with dementia with staff who speak the same language (e.g. the home for Jews, people from Finland, as well as Persian and Arabic speaking people in Stockholm). Measures for intercultural care are local and not nationally distributed or under development. In the county of Skåne in southern Sweden, some information films on dementia, the importance of seeking help at an early stage of the disease, and dementia investigation have been developed in different languages.

The expert identified a great need for improvement in the early diagnosis of dementia in PwM, the use of cognitive screening tools that are less influenced by language, culture, and education, and the use of interpreters during dementia assessment.



### 6. Professional qualification and people with a migration background in healthcare

The expert stated that culturally sensitive care is partly included in the education of healthcare professionals. Reflecting on one's own culture and the prejudices and beliefs about others, as well as its potential impact on treatment, is basically part of the person-centred approach. However, dedicated courses on culturally sensitive care are not available nationwide. In this respect, there are great differences between different universities and colleges. Moreover, the courses are mostly elective and it is not certain that all students attend such courses. The situation is similar for professional training opportunities in intercultural care. In southern Sweden, professional caregivers can attend courses organised by the Knowledge Center of Dementia. There are also small nationwide efforts in this area.

According to the expert, the proportion of PwM among professional caregivers is high in both outpatient and inpatient care, ranging

between 20 and 40%. The proportion is even higher in the elderly care sector. The professional caregivers with a migration background are from many different countries of origin (e.g. Iran, Iraq, Poland, Greece, Bosnia, North Macedonia). This high diversity among professional caregivers has different effects on care. On the one hand, these caregivers provide people in need of care access to language and intercultural care. On the other hand, many of these professionals have the feeling that they are often used as interpreters, which is not acceptable to them, as they do not have additional time or any compensation for these extra tasks. Furthermore, the absence (vacation, illness) of healthcare professionals with a migration background often results in waiting times for patients with the same mother tongue. Overall, the need for culturally sensitive care in Sweden is not being met by sufficiently qualified professionals.

### 7. Support for family caregivers

The expert highlighted that in Sweden, family and care provider networks are very important and migrant organisations have an important role in supporting family caregivers of PwM with dementia. Currently, there are major differences in the suitability of existing information resources and support services for family caregivers of PwM and non-migrants with dementia. The expert pointed out that family

caregivers of PwM with dementia are in great need of specialised services providing support and information. However, the expert could think of only one such specialised service that is currently available: telephone counselling provided by a non-profit association for persons with dementia and their family members in the Persian and Bosnian languages.



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