



CULTURAL SENSITIVITY IN MEMORY WORK: Experiences from Finland

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IN MEMORY WORK:
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This guide has been developed as a part of the Society for Memory Disorders Expertise in Finland's (Suomen muistiasiantuntijat ry) ETNIMU-project which improves the brain health of ethnic minorities. ETNIMU-project has been funded with the support from the Ministry of Social Affairs and Health and the gaming revenue of Veikkaus Oy.

More information: www.muistiasiantuntijat.fi/etnimu

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WORKING GROUP:

Siiri Jaakson, Project Manager, ETNIMU-project, The Society for Memory Disorders Expertise in Finland
Elina Hemmilä, Organization Assistant, The Society for Memory Disorders Expertise in Finland
Urve Jaakkola, Project Coordinator, ETNIMU-project, The Society for Memory Disorders Expertise in Finland
Eva Rönkkö, Coordinator of Multicultural Activities, Eläkeläiset ry
Tiina Auer, illustration, graphic design and edition

COVER:

Tiina Auer, Ene Rönkkö

TRANSLATION BY:

Hanna Rantala

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The Society for Memory Disorders Expertise
in Finland (Suomen muistiasiantuntijat ry)

Fredriksberginkatu 2

00240 Helsinki

Tel. +358(0)9 454 28 48

E-mail: info@muistiasiantuntijat.fi

www.muistiasiantuntijat.fi

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Introduction

The deterioration of brain health and memory disorders can affect us all regardless of our language, culture or nationality. In Finland social and health services are equal for all. Nonetheless, not everyone in need of services can access them or find the kind of services that would meet their needs.

Finland has a population of approximately 5.5 million. 200 000 people are living with mild cognitive impairment and 193 000 with progressive memory disorders (Viramo & Sulkava 2015, 35). According to Statistics Finland, there are approximately 310 000 foreign-language speakers in Finland (Tilastokeskus, 2017). Memory disorders are as recurrent among this population as they are among the ethnic Finns. With prevalence rates adjusted to those of the ethnic Finns, this means that there are 11 200 foreign-language speakers living with mild cognitive impairment and 10 900 foreign-language speakers with progressive memory disorders. These people form a patient group who is easily left out of services, for example, because of their insufficient Finnish language skills. Their brain health, nevertheless, should be taken care of as well. When the baby-boomers reach elderhood and the total number of the elderly increases, this question will become more pertinent.

Whether an ethnic Finn or a minority ethnic person, memory disorders proceed the same. Their treatment is in many ways the same. The aim of this guide is to highlight the issues that we should take into consideration when we meet an ethnic minority elderly person with memory problems. The most important issue is to remember that there is a human being behind her memory problems or memory disorder: this person has her culture, personality and wishes that should be taken into consideration. Such an approach, which respects the person's background and needs, is what we call a cultural sensitivity as a way of work.

The Society for Memory Disorders Expertise in Finland's ETNIMU-project was a development project that took place from 2015 until 2017 with the support of Veikkaus Oy. It sought to increase information about brain health among ethnic minority elderly. The project created materials about brain health, memory and memory disorders in the native languages of the project's participant groups: Finnish, Estonian, Russian and Somali. The project also aimed to strengthen the cultural-sensitive skills of social and health care professionals and students.

This guide discusses the theories and action models behind ETNIMU-project, and reflects upon them in the light of ETNIMU's aims, procedures and results. It seeks to support, among others, the work of social and health care professionals and anyone who may be working with ethnic minority elderly and the topic of memory. This guide represents the core observations of ETNIMU-project.

The observations, cases and examples presented in this guide are based on the activities of ETNIMU-project. These should not be used to generalize the specific groups in question.

We hope you enjoy your reading,

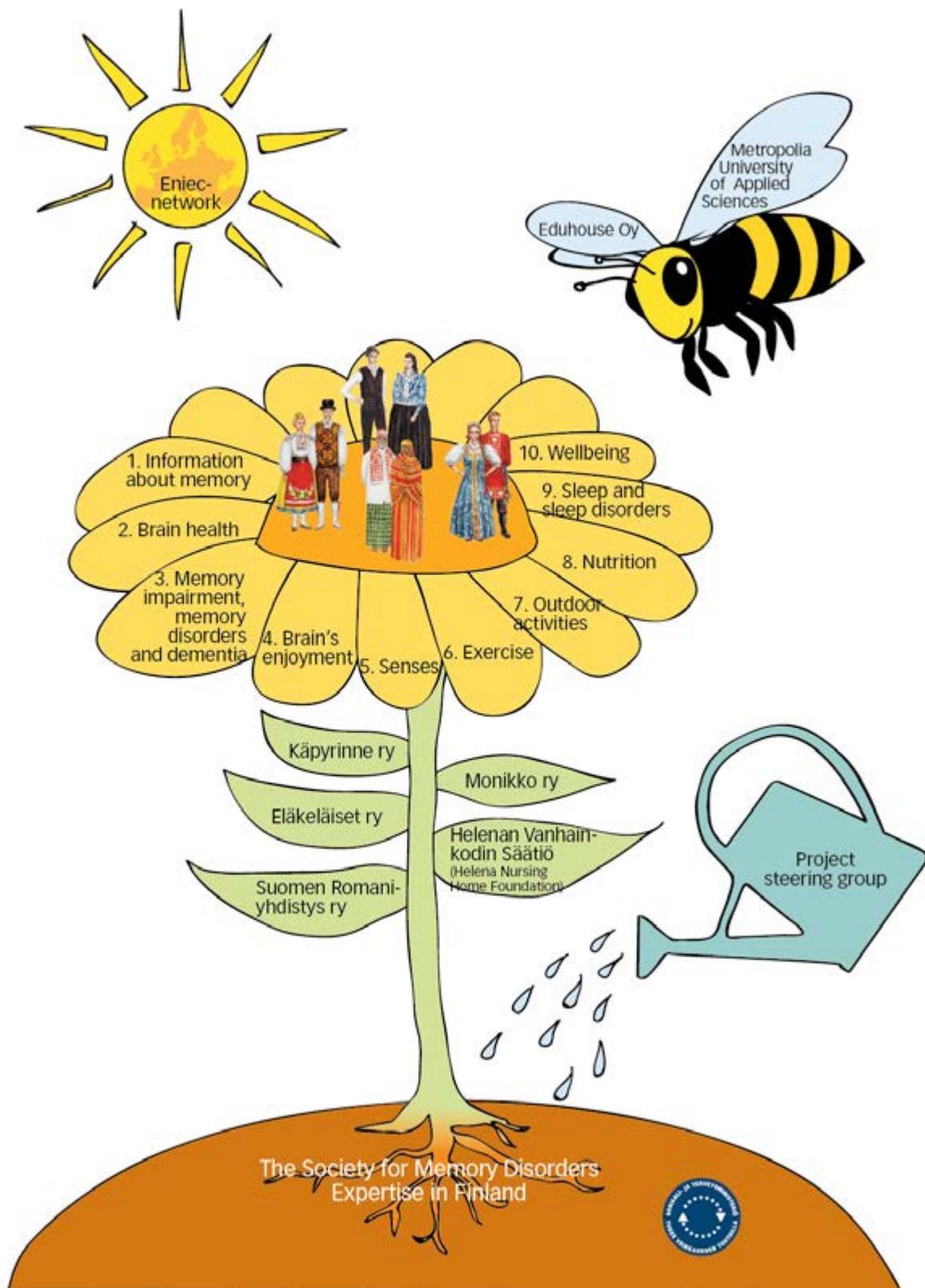
Siiri Jaakson, Elina Hemmilä and Urve Jaakkola

Memory does not go to waste in use, quite the opposite!

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The functioning model of ETNIMU-project



Improving the brain health of ethnic minority elderly (ETNIMU-project) 2015–2017

Project's aims:

- develop customer-centric group meetings with Estonian, Russian and Somali-speaking elderly, Roma people, as well as with their family members
- build a service continuum that takes the backgrounds and needs of ethnic and cultural minority elderly and their family members into consideration and that reaches the social and health care professionals and educational institutions.

The project:

- diffuses information about brain health, memory and memory disorders among different ethnic minorities in their native languages, develops guidance and information services
- promotes cultural sensitivity by diffusing information and sharing the project's good practices among social and health care professionals
- builds a professional, interdisciplinary peer support network, including different multi-cultural communities.

Project functions:

- Organized a course of 10 meetings in groups of ethnic minority elderly from 2015 to 2017. The aim of the course was to provide information about how to improve brain health, memory and memory disorders in the native languages of the participants.
- The course meetings covered the following topics: 1) Information about memory, 2) Brain health, 3) Memory impairment, memory disorders and dementia, 4) Brain's enjoyment, 5) Senses, 6) Exercise, 7) Outdoor activities, 8) Nutrition, 9) Sleep and sleep disorders, and 10) Well-being.
- The course meetings were organized in six different groups: groups of Somali-speaking women, Estonian speakers, Russian speakers, and Roma people in Helsinki, as well as a Russian-speaking group of carers for elderly with memory disorders in Helsinki. There was also a Russian-speaking group in the town of Kotka.

Project's partners:

- Pensioner's Association (Eläkeläiset ry)
- Alzheimer's Association of Helsinki (Helsingin Alzheimer-yhdistys ry)
- Käpyrinne Association, Jade I & II -projects
- Finland's Roma Association (Suomen Romaniyhdistys ry)
- The Helena Nursing Home Foundation, Tsaikka-project
- Eduhouse Vocational School and the Metropolia University of Applied Sciences.

Networks:

- European Network on Intercultural Elderly Care (ENIEC)
- The Society for Memory Disorders Expertise in Finland's regional Alva-network for professionals (Alva-verkosto)
- Memory coordinators' network, coordinated by the Society for Memory Disorders (Muistikoordinaattoreiden verkosto)
- Age-friendly Helsinki (Muistiystävällinen Helsinki)
- The Helsinki Social and Health Office's Network on Multicultural Elderly Care (Mova-verkosto)
- MTÜ 65B -network of memory trainers in Estonia (MTÜ 65B).

Project steering group:

- Lecturer in Social Care, Sari Heikkinen, Laurea University of Applied Sciences
- Senior Medical Officer in Neurology, Senior Lecturer, Kati Juva (MD)
- Expert, developer of memory work, Pertti Riihelä
- Coordinator of Multicultural Activities, Eva Rönkkö, Eläkeläiset ry
- Employee with Muistiluotsi, Paula Tommola, Kymenlaakson Muistiluotsi
- Executive Director of The Society for Memory Disorders Expertise in Finland, Maisa Toljamo
- as well as, the ETNIMU-project employees, the Project Manager Siiri Jaakson and the Project Coordinator Urve Jaakkola.

Project's core deliverables:

- Exercises to Activate the Brain 1. The guide contains 22 exercises for coordination and concentration that support brain health by working together the brain and the muscles.
- Exercises to Activate the Brain 2. The guide contains 26 solving puzzles exercises.
- Improving Brain Health! is an easy-to-understand guide that contains the core issues around the themes of memory and brain health.

The set of the three guides constitutes a tool that can be used by group leaders to direct activities about brain health. The guide and the exercise booklets are targeted primarily at people who are leading groups of ethnic minority elderly, but they can be used to direct all kinds of groups with an interest in improving brain health. The guides have been designed to minimize culture-bound contents. The set of the three guides have been published in Finnish, Estonian, Russian and Somali. Read more about the project's deliverables on page 27.



The ethnic minority elderly groups in ETNIMU-project

The Roma People

The group of Roma people has been an active group already for some time. The group had just over 10 participants, five of whom were men. The average age in the group was between 80 and 90 years. The participants were living with different medical conditions, and many had deteriorated hearing. Many also had problems with their memory. According to the group leader we were fortunate to be able to engage with the Roma of this particular generation: they were the last nomadic generation who had lived “on carriages”.

One of the biggest challenges with the Roma people’s group had to do with the number of cultural manners that we had to learn before we could start the meetings. For example, mentioning any body part from neck below had to be avoided, as the Roma participants would consider it offensive and shameful.

The Estonian Speakers

The group of Estonian speakers in Helsinki had been an active group for a long time and almost all participants knew each other. There were around 15 participants who were between 70 and 75 years of age. All were women. Although many of the participants had been living in Finland already for a long time and knew the Finnish language well, they referred to themselves as “us” and to the Finns as “them”.

The Estonian-speaking group knew a lot about memory and the group had covered memory issues already during the previous years. Nonetheless, memory impairment and the behavioural changes related with it were viewed with shame. The participants would not seek medical attention to discuss their memory problems and they believed that having your memory impairment diagnosed in Finland would lead to institutionalisation.

During the course meetings it became evident that the participants had not been accustomed to dialogue as the group’s work method. They were nervous when responding to our questions. It is also possible that the participants were nervous because one of us was typing on a computer during

the meetings, taking notes about observations. The participants might have interpreted the situation more serious than it actually was.

The Russian Speakers in Helsinki

The Russian-speaking group in ETNIMU consisted of two groups that had been running for a long time in Helsinki. There were approximately 30 participants, between 65 and 75 years of age. All participants were women. The group also had one Russian-speaking student who was writing her final thesis.

The Russian-speaking group leaders were strong personas and the groups had become molded after their styles. The elderly were active participants who knew a lot about their well-being. The Russian-speaking group stood out for its hierarchical way of working and its group leaders enjoyed strong authority. The participants expected us to be similar, more lecturer-like leaders. It was a surprise that we would emphasize dialogue and interaction as our main approach.

The Russian speakers in Kotka

Kotka has a large Russian-speaking population, but there were no existing group activities for Russian-speaking elderly. We had to start by reaching out to the elderly, a process in which we received help from a memory work specialist from the Memory Association in the Kotka region. A group of Russian-speaking students from the Eduhouse vocational school also helped us to form the group, while they could gather data for their final assignments. In the end, we started a group of seven to eight Russian-speaking elderly. They were between 65 and 75 year-old women.

The elderly who took part in the course meetings did not know each other from before and they felt somewhat embarrassed to speak about themselves with strangers. However, they could speak about their experiences with immigration openly and with humour. All participants had put the needs of their closed ones before themselves. Their own needs had received only little consideration.

Russian-speaking carers for elderly with memory disorders

The Russian-speaking group of carers for elderly with memory disorders had been running already for a number of years and many of the participants knew each other from before. This was a small group of only four to five participants, one of whom was a man. The participants were around 60 years of age. The new group members had many questions about being a carer, care pathway and memory disorders.

In the group of carers our plan, as with the others, was to focus on the participants' brain health and how to improve it. Nonetheless, the group concentrated mostly on the issues that had to do with the family members who had memory disorders. The carers simply did not think about improving their own brainhealth or well-being, but rather put the needs of their closed ones first. The situation improved over the course of the meetings, and towards the end, the carers started to think also about their own health.

The Somali-speaking women

The Somali-speaking women have had group activities in Helsinki already for a number of years: they took part in ETNIMU-Project through Käpyrinne ry's Jade project. The number of participants varied between 8 and 12. The participants were between 55 and 65 years of age.

In the group's culture the concept of time was understood different from the Finnish way. The participants were not very punctual and they came to the meetings if they did. Another challenge with time had to do with prayer times which we had to be taken into consideration when planning the group meetings.

The participants in this group communicated with us with the help of an interpreter. Getting feedback from the interpreter was at times challenging, as every once-in-a-while even a simple Finnish word required a long explanation in Somali. This in turn started out conversations between various participants, of which the interpreter translated to us only the essential. Sometimes only a single sentence or a word.



Background information to understand cultural-sensitivity

Immigration in Finland

Finland has always been a country of many kinds of peoples. In addition to the Finnish-speaking population, Finland's inhabitants include the indigenous Sami people, and Swedish-speaking and Roma minorities (Eläkeläiset ry, 2017).

Although Finland has yet to ratify the United Nation's Declaration on the Rights of the Indigenous Peoples, Finland has long supported diversity through various acts and decrees; for example, Freedom of Religion Act dates to 1923, Constitutional Reform to 1990, and Non-Discrimination Act to 2015. Despite the legal support, Finland is not an easy country to settle for immigrants. A dress code that stands out from the mainstream, different cultural customs or visible signs of non-mainstream religions, for example, may be used as causes to express doubt and to prompt demands, such as, "when in Rome, do as the Romans do". Although there is support for diversity there is also pressure to live like the majority (Eläkeläiset ry, 2017).

Over the past few years immigration has become a recurrent topic in the Finnish media and public discourse. Diversity and immigration, however, are no novel phenomena. Many people emigrated from Finland in the 19th century to settle, for example, in North America. Finland has also been a destination for migrants throughout the times, especially from the neighbouring regions of Russia and the Baltic states (Eläkeläiset ry, 2017).

At the end of 2016 there were approximately 354 000 foreign-language speakers living in Finland, that is people whose native language is some other than Finnish, Swedish or Sami (Tilastokeskus, 2016). That comprises 6.4% of the total population. In 2015, 28 746 people moved to Finland, while 16 305 people moved out of Finland (Tilastokeskus, 2015). Throughout the 2000s only a small part of immigrants have been asylum-seekers or refugees: the main reasons for immigration to Finland are family ties, work or studies. Between 2006 and 2014 Finland granted between 2000 and 3000 residence permits a year to asylum seekers, refugees or their family members. These constitute about one-eighth of all immigration (Pakolaisneuvonta ry, 2016).

It is also important to remember that the major-

ity of the people who move to Finland every year are returnees, which means that they are Finnish-born (Eläkeläiset ry, 2017). Finland has also populations of so-called traditional cultural and linguistic minorities, including the Swedish-speaking Finns, the Roma people, the Ingrian Finns, the Karelian speaking Finns, the Jews and the Tatars. Of these the Roma people constituted one of the participant groups in ETNIMU-project. The number of Roma people in Finland has been estimated at approximately 10 000–12 000 (THL, 2017).

At the end of the year 2016, there were over 42 000 elderly migrants in Finland (people over 55 years of age). In addition, there were over 21 000 migrants between 50 and 54 years of age (Eläkeläiset ry, 2017). The aging ethnic minorities constitute thereby a significant group of people: this is why we decided to put our efforts to improving brain health among this group in particular. Through our previous work experiences with Helsinki Alzheimer's Association's memory clinic, we had also noticed that the general level of knowledge about memory and memory disorders among the ethnic minority elderly was poor. We also knew that the elderly needed information in their native languages. The latter two factors provided the impetus to start ETNIMU-project.

Culture, multiculturalism and ethnicity

Culture is used to denote to the shared views and beliefs through which a particular group of people, who belong to the same community, group or nation, interpret the world. Shared views or cultural signifiers steer societal behaviour and provide a feeling of belonging within a particular culture (Hall 2003b, 85). In standard language, culture is often used to refer to the customs, practices, values and worldviews that define a particular group of people according to their nationality, ethnicity, region or a shared point of interest (Benjamin 2014, 60-61).

Culture can be divided into two dimensions: a deep structure and an operational level in which actions and operations are conditioned by the deep structure (Immonen 2001, 21-22). We can compare



culture symbolically with an iceberg: the deep structure constitutes the biggest part of the iceberg, which is hidden under the water. Only the iceberg's peak, the operational level, is visible. These are the parts of culture that we easily conceive as "cultural". The visible parts on top of the water include dress codes and different behavioural rules, such as regulations and customs, as well as food, music, and language. Our value judgments tend to be based on these visible parts. They also create expectations in us and can even ignite prejudices. The visible parts of the culture help us determine whether someone belongs to "us" or to "them" (Benjamin 2014, 61-62).

Culture is not inherited but learned: its sources are in social settings rather than in the genetic matter (Hofstede 1993, 21). Nowadays we are no longer touched by only one culture and its circle of influence. Instead, we live, operate and move in and through multicultural settings, crossing over the borders of different cultural communities in many ways, both locally and globally (Korhonen & Puukari 2013, 35). Culture shapes us and we shape culture. We are constantly surrounded by culture and cultures, and our relationship with our own as well as with other cultures is shaped by these multidimensional interactions (Korhonen & Puukari 2013, 12).

All societies are more or less **multicultural**. Multicultural can be defined as linguistic, religious, ethnic and other cultural diversity (Saukkonen, 2016). This means that people speak different languages, take part in different religious communities, maintain alive different cultural customs and heritage, and have different understandings of what good life constitutes. **Multiculturalism**, in turn, refers to the ways in which societies exist and live. It is a strategy that keeps diversity and difference under control (Hall 2003a, 234). In the Finnish context, multiculturalism denotes to the coexistence and co-actions of different cultures based on mutual understanding and respect. As part of it not only the minorities but also the Finnish majority is constantly redefining itself and its place. Multicultural societies are thereby in a state of flux, because the meanings of both the majority and the minorities are constantly shifting (Hiltunen 2017, 10-11).

Societies are also multiethnic. Ethnicity can be defined in various ways, but it can be used to denote people's community or nationality and the identities that come with it. Ethnicity is often linked with specific cultural traits, such as language or traditions. An ethnic group can be defined as a group of people who share, for example, specific

cultural or linguistic traits, who share at least partly the same origin and identify themselves as part of the same group (Saukkonen, 2016). Ethnic minorities, however, do not consist only of immigrants; indeed, Finland has also traditional linguistic and cultural minorities, such as the Roma people, the Tatars and the indigenous Sami people (Sarvimäki, 2015).

The term immigrant is generally defined as a foreign citizen who has moved to Finland with the plans of living in the country for a longer time (Väestöliitto, 2017). We will not refer to the ETNIMU-participants as immigrants, however, but rather as ethnic minorities given the diverse backgrounds of the elderly participants. Some have moved from Estonia, Russia and Somalia, while others were Finnish Roma.

Cultural sensitivity in memory work in Finland

Pilots on Finnish memory work with ethnic minorities started in 2003 as a part of the IkäMAMU-activities of the Finnish Association for the Welfare of Older People. IkäMAMU mapped the situation of brain health among the Russian and Estonian-speaking residents of Helsinki. IkäMAMU-activities also applied existing memory materials to work with the Russian-speaking elderly with memory disorders and their family members.

In 2004 services began for the Estonian and Russian-speaking customers at Kamppi service centre in Helsinki, where the Memory Clinic of the Helsinki Alzheimer's Association operated. The memory clinic screened for memory impairments through assessment tests. Then, for the first time, a care pathway was created for the Estonian and the Russian-speaking elderly and their family members with social and health care professionals. At the time also a peer support group for Russian-speaking carers for elderly with memory disorders was started.

The IkäMAMU-project was ended in year 2005, and since then also the Memory Clinic of the Helsinki Alzheimer's Association has stopped its services. Need for memory services in different languages, however, has not gone away – rather the opposite. Based on the feedback from different ethnic minority groups, the elderly would need and want to improve their brain health and gain more information about memory disorders in their native languages. In order to meet such needs, **Improving the Brain Health of Ethnic Minority Elderly, ETNIMU-project** [Etnistaustaisten ikääntyvien ihmisten aivoterveysten edistäminen] was started. In addition to the Estonian and Russian-speaking groups, that had already existed, new target groups included older Somali women and the Roma people.

Ethnic Minorities and Memory Disorders

General aging changes in memory function across different cultural backgrounds

Humans are holistic beings – everything affects everything. Our health is influenced by the genetics we have been passed on, environment, as well as the choices we make during our lives. Social surroundings and the culture in which we live and grow up strongly influence us in addition to our physical and psychological health. Social surroundings constitute an asset for us, but when we become separated from it and find ourselves within the domains of a foreign culture we may often face heightened risk of disease (Jaakson & Jaakkola 2017, 10).

All memory problems and lapses are not signs of memory disorders. Slight changes start to happen at the age of 40, while clearer changes occur only after the age of 75. Aging is always an individual process. The following age-related changes, however, can be regarded as normal:

- Ability to learn continues.
- Abilities to memorize and to retrieve decline.
- Environmental interferences grow stronger, the ability to concentrate may decline.
- Ability to maintain memories does not decline.
- Knowledge and skills from before maintain.
- Recognition and recall based on tips maintain.
- Abilities to remember details, such as names and telephone numbers, decline.
- Abilities to perform actions that require effort and efficiency decline.
- Interferences of contextual factors, such as fatigue or stress, grow stronger.

Sometimes the changes may be a sign of a progressive memory disorder. You should be worried when the following symptoms appear:

- You or your family members are concerned about your short-term memory.
- You often forget appointments.
- You have difficulties following care instructions.
- You forget words frequently.
- Your abilities to deduct and to solve problems have declined. You have difficulties taking care of basic financial functions, and tasks such as

paying bills or performing simple banking tasks are more difficult than before.

- You cannot find your purse, phone, keys or other familiar objects and they are lost almost all the time. Objects seem to disappear suddenly and you may have difficulties understanding how to use them.
- Your mood changes often, you feel anxious or apathetic, and cannot get anything done.
- Memory symptoms get in the way of performing your daily tasks.
- Often you may not notice the changes that are happening in your personality yourself, e.g. incoherence, paranoia or fear. Your family members may notice that you are becoming withdrawn and seek to be left alone. (Jaakson & Jaakkola 2017, 13-14.)

Memory impairment among ethnic minorities here and elsewhere

The World Health Organization WHO estimates that there are approximately 47 million people around the world living with a memory disorder. Approximately 60% of them live in low and middle income countries (WHO, 2017). Memory disorders thereby exist around the world and they are not bound to specific cultures.

According to the researcher Peter Bekkhus-Wetterberg we should remember that despite the similarities between customers, from a professional point of view, an ethnic minority elderly person is also different from a mainstream elderly customer. The cultural and educational background, possible trauma and other factors that may separate the ethnic minority elderly from the majority elderly should be taken into consideration when we plan and deliver care. Early diagnosis is important so that the customer herself can understand what the nature of her disorder is and what are its prognosis and care like (ENIEC Suomi, 2014).

The ways in which facts are understood and conceptualized may differ on a general level between different ethnic minorities. There may be differences between individuals as well as groups.

These may be one of the reasons why ethnic minority elderly do not always know how to access health services. For example, the term dementia is recurrently used but often poorly known among various groups. Levels of knowledge about memory disorders also vary between different linguistic and cultural groups, and facts about memory disorders may be limited. Memory disorders are often considered a taboo, a shameful issue that should not be talked about. In other cases, they may be perceived as signs of normal aging process or as "old age senility", thereby requiring no medical care. Fear may also put a stop to the process of accessing care: a minority ethnic elderly person might be scared that she would be committed to a mental institute or be forcibly returned to her country of origin, if diagnosed with an irreparable disease (ENIEC Suomi, 2014).

Differences between cultures, countries and languages have mostly to do with the ways in which memory disorders are perceived, how they are talked about, and how they are treated. Although the disorder in itself does not differ across cultures, the ways in which it may be approached, accepted and treated diverge. For us to be able to address such differences we need to apply a cultural-sensitive approach to our work. Most importantly we should be able to see the human being, the individual, behind cultural differences.

The Danish researcher Rune Nielsen conducted a dementia research study among migrants in which two issues stood out: middle-aged immi-

grants were more frequently diagnosed with dementia than middle-aged Danes. The difference was significant. The elderly immigrants, in turn, received less dementia diagnoses than the elderly Danes. The contradictory results were explained, firstly, with the fact that the elderly migrants do not access services. This results from lack of familiarity with the Danish service systems and language difficulties among the elderly migrants. Secondly the research mentions "wrong diagnoses"; this means that there is both overdiagnosis and underdiagnosis of memory disorders that depend on cultural factors (Nielsen et al., 2011). The same phenomenon can be observed also in Finland. We mentioned earlier that we had previous work experience with the Helsinki Alzheimer's Association's Memory Clinic. There we came across with an Ingrian man who had had a cerebral infraction, but who was suspected of having a memory disorder. The reason had been that the staff and the man did not share a language in common and they had communication difficulties. Employees have, indeed, faced situations in which an elderly person has been diagnosed with an incipient memory disorder, whereas after a holistic assessment of the customer, the memory care workers have reached the conclusion that the elderly person has mostly been stressed out because she has not been understood (Törmä et al., 2014, 104-105). Such problems do not exist only elsewhere, but are part of the daily challenges also in Finland.



The participants' thoughts in ETNIMU course meetings: **MEMORY PROBLEMS, MEMORY DISORDERS, DEMENTIA**

THE GROUP OF ROMA PEOPLE: The participants described dementia mostly as a time when “you start to be out of it” and cannot really get anything done - even your clothes don’t fit right. Some participants told us that their siblings were getting close to such state. The Roma participants, however, were also able to joke with the topic.

THE GROUP OF ESTONIAN-SPEAKING ELDERLY: The participants thought that memory disorders have to do with your entire system slowing down and when you no longer can hold onto new things the way you can onto the old. The participants had some information about the effects of healthy lifestyle and recognized stress as a risk factor. The participants, however, avoided seeking medical assistance because of memory problems; they

feared that they could become labelled weird or crazy.

THE GROUP OF RUSSIAN-SPEAKING ELDERLY: Memory disorders were thought to be a sign of old age senility and the participants asked if this wasn’t just normal. Russian speakers called memory impairments sclerosis.

THE GROUP OF SOMALI-SPEAKING ELDERLY WOMEN: The participants told us that although some members of the community would have problems with their memory, they would be looked after and be called upon. The participants also believed that even if their mind and memory would start to play tricks, prayer would help them cope with their daily tasks.

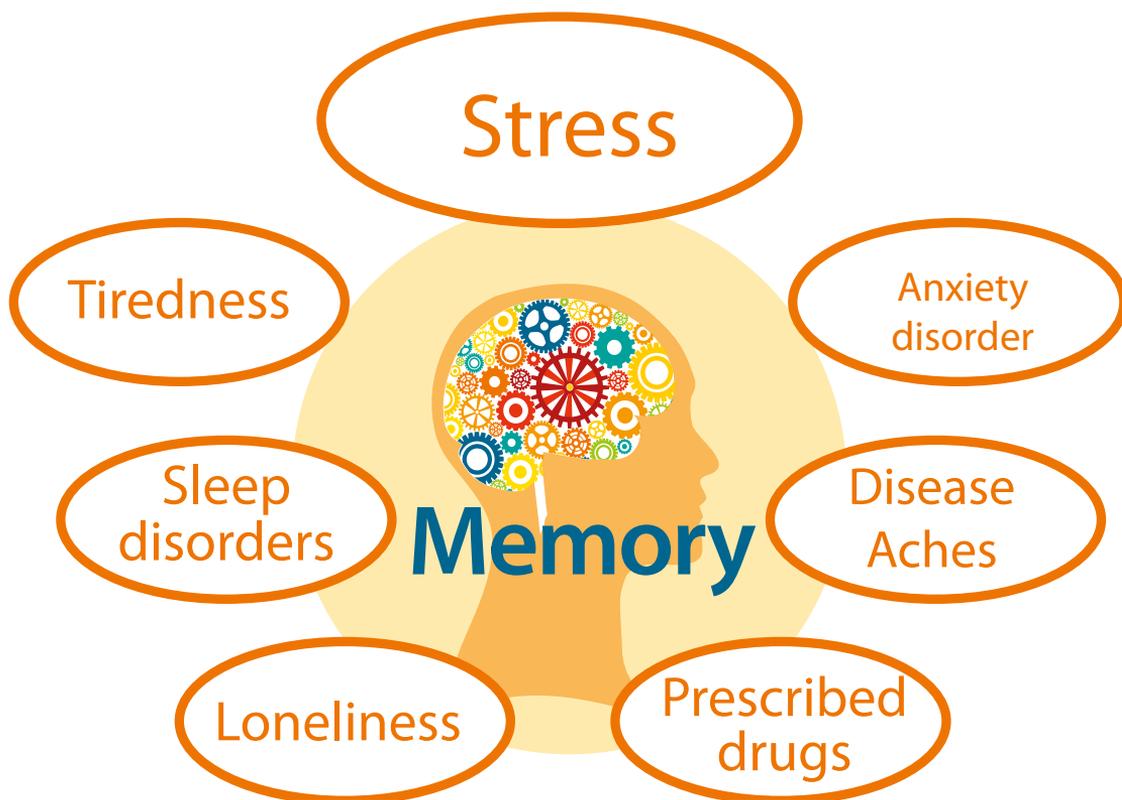
The concept of dementia raised confusion in all ethnic minority participant groups. The participants thought dementia was a disorder on its own and they had difficulties understanding it only as a symptom of memory disorders. However, the terminology of memory disorders may be foreign also among the majority population. The term dementia, in particular, can still be heard mentioned in standard speech and in the media instead of memory disorder, even though the former is considered outdated. Thereby, it is difficult to conclude whether the terminology was foreign to the participants because of their cultural backgrounds or because of a more general unfamiliarity with memory disorders.

Ethnic minorities and factors affecting memory

Memory function is influenced by the same set of factors among all humans, regardless of the ethnic background. Certain risk factors, however, tend to be elevated among ethnic minority individuals. For example, immigrants' lives contain stress, such as, concern about seeing their families dissolve, parents getting sick in their countries of origin and loneliness in the new home country. Being able to recognize the causes of stress can help doctors, among others, to grasp better the situation of their customers (Oroza 2007, 444). Stress, however, may also be a natural reaction to changes in culture and surroundings. It can be either short-term or long-term. When short-

term, stress has no effect on memory: at best, it may even boost memory function. Long-term stress, in turn, may cause distress and memory problems. Also other factors, such as anxiety, loneliness, sleep disorders and tiredness affect memory function (Jaakson & Jaakkola 2017, 7-8).

Many diseases and aches affect memory function and medications may also have side effects that affect memory function (Jaakson & Jaakkola 2017, 7). Drug misuse is quite common among certain ethnic minorities. For example, many Russian speakers continue to order prescribed drugs from their countries of origin, because they trust the doctors there more than the ones in Finland. Also among the Roma people there is misuse of prescribed drugs: drugs are taken in abundance or "just in case".



Migration as a cause of stress

Migration is a life altering event that provokes different kinds of emotions and reactions in people. The more different the new surroundings, the bigger the change: when this is the case, the person has to get used to new customs, language, people and even climate. Migration is an individual process that every migrant must go through. The way in which the process proceeds is individual but it is affected, for example, by the individual's previous experiences, age, social networks and the way in which the practical matters fold out (Mielenterveystalo, 2017).

Although an individual might be well adapted into her new surroundings, has learned the new language and taken on new habits, she may not know her way around the practices at doctor's appointments or know how to run daily errands. The word health centre [terveysasema], for example, may provoke confusion if a similar term is not used in the person's country of origin. The changes and reforms that the Finnish health care system has gone through may also prove burdensome for immigrants. For instance, the participants in the group of Russian-speaking carers told us that they felt anxious about the constant changes in the care system: as soon as they had gotten used to the arrangements, these would be replaced by new ones. What also caused confusion in the group was the fact that different health care districts referred to the same issues with different terminology. The carers found it hard to get peer support from one another, because they were not certain that they were talking about the same issues.

The participants' thoughts in ETNIMU course meetings: **STRESS**

THE GROUP OF ROMA PEOPLE: The participants thought that stress is simply a part of life - it comes and it goes. Being in good spirits, however, was very important to them.

THE GROUP OF ESTONIAN-SPEAKING ELDERLY: The Estonian-speaking participants thought that stress is a disease, and that although it is a frequently used word in Finland it does not exist in Estonia. The Estonian way of life was perceived different from the Finnish and stress was considered too big a word to describe many different emotions, such as sadness or distress. According to the participants the case, however, could be different in a welfare country such as Finland.

THE GROUP OF RUSSIAN-SPEAKING ELDERLY IN HELSINKI: The participants told us that they suffer from stress every once in a while. When this happened their appetite, for example, would increase. Many of them said that exercising out in the nature provided relief.

THE GROUP OF RUSSIAN-SPEAKING ELDERLY IN KOTKA: The participants in the Russian-speaking group in Kotka described stress as something that made it burdensome to live and which even affected their will to live. They recognized, nonetheless, that the effects of stress were individual.

THE GROUP OF RUSSIAN-SPEAKING CARERS IN HELSINKI: The participants described many types of stress symptoms, some of which were highly intense. The participants told us that when they felt stressed out they could experience rage and anger, go through memory lapses and have physical symptoms. When overwhelmed by stress, they could feel the urge to break everything around them and even their will to die increased. They told us that they took medication to help them cope.

THE GROUP OF SOMALI-SPEAKING ELDERLY WOMEN: The topic of stress provoked contradictory reactions. The participants thought that stress in itself does not exist, but that everything happens because the God has so intended. Everything happens for a reason, and everyone's life has been predetermined.

Because of such differences across the groups, we had to find new ways to address the topic of stress. Not all participants recognized the term or the phenomenon, and we noticed that we would have to refer to stress using other expressions: when things start to pile up, when you feel distressed, when all sort of things seem to happen at the same time,...

Minority ethnic elderly in medical appointments and in diagnosis

Ethnic minority elderly can constitute a challenging group for diagnosis, because even the term memory disorder is foreign to many. In addition, in many cultures memory disorders are considered to be a sign of old age senility or a shameful matter that should be concealed. For example, the elderly who come originally from the old Soviet regions told us that there have been cases in which the elderly with memory disorders had to be hidden away, so that the government officials would not close them up in asylums. Such experiences shape the lives of the elderly until today. The Estonian-speaking participants in ETNIMU-project, for instance, mentioned that for them the threshold to seek medical attention for memory issues was high even though they are living in Finland.

The most trustworthy picture of the ethnic minority elderly person's state of health can often be drawn in her natural surroundings, for instance, through a home visit. There you can observe how orderly the home is, what the functional abilities of the person are, the body language, and other factors that may not easily be observed during a medical appointment. The proceedings during the medical appointment and Finnish language may also be new to many ethnic minority elderly and inflict confusion and fear (Malinen & Lindholm 2014, 4). It is also important to find out from what kind of circumstances the ethnic minority elderly person comes and what is her past like. There may be experiences of war, flight, life in poor conditions and even torture or other trauma. All of these will affect the care relationship and provide a reason for you to become familiar also with your customer's past (Malinen & Lindholm 2014, 6).

The significance of native language and the role of interpreter in medical appointments

Communication is one of the founding principles for our well-being and a fundamental right. When a person has a memory disorder, her native language plays an important role during the care assess-

ment and care. When memory disorders progress, bilingual people forget first what they have learned during their adulthood. In practice, this means that the acquired language will deteriorate (Pohjois-Suomen sosiaalialan osaamiskeskus, 2016). This is why memory assessment tests should always be conducted in the person's native language. Language, overall, poses its own set of challenges during medical appointments with doctors, neurologists and memory workers. In the absence of a common language and/or an interpreter, it is often the spouse, child or other family member who has to perform as an interpreter. This may not be the best solution since the family member may be as confused and ashamed about the symptoms as the person who is being assessed. It may also lead to circumstances in which valuable information is retrieved. The presence of a family member in appointments, however, can also help in receiving supportive information about the assessed person's background and lifestyle, which in turn may affect care positively (Linderborg & Jaakkola, 2012). It can be beneficial to understand what you can expect of a person of certain age in her community. Finally, it is important to book sufficient time for appointments with ethnic minority elderly, even if family members who lead the process were present (Juva, 2016).

Whether you are dealing with professional interpreters or with family members who act as interpreters, you should remember that interpreters might

In which floor
are we?

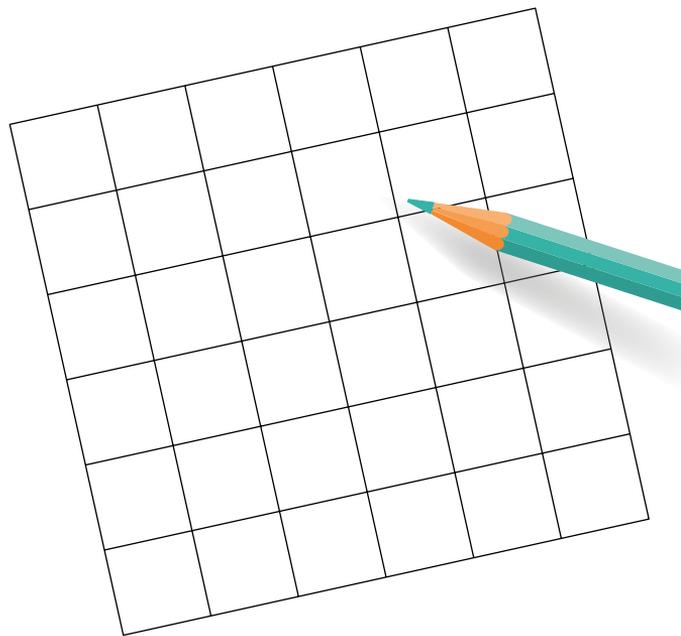
Viidental
korrusel.

unintendedly complicate the diagnosis. An interpreter or a family member may unconsciously make the speech more comprehensible than it actually is. Therefore, it would be important to inform the interpreter in advance about the purpose of the appointment. It would also be beneficial to go through the interpretation after the appointment and make sure that you have understood everything correctly (Linderborg & Jaakkola, 2012).

Memory disorder screening and assessment tests

When you suspect a memory disorder, it is important that you monitor for the changes in the state of the ethnic minority elderly person - do not only evaluate how well or poorly the person is doing right now. The basic screenings of memory disorder, laboratory tests and head scans are exactly the same as across the majority population (Juva, 2016).

Memory assessment includes filling out a memory questionnaire. If the person being assessed has come to the assessment with a family member, they should also fill in a specific family questionnaire which screens for observed symptoms. After the memory questionnaire, an MMSE assessment test is performed. MMSE scale is a largely used early stage assessment instrument that is conducted when there are suspicions of memory disorder. It provides broad measures of possible cognitive impairment. MMSE assessment test contains several short tasks that provide measures of cognitive functions: orientation, concentration, memory, linguistic function and perception. An even broader assessment is the CERAD neuropsychological battery, of which the MMSE assessment test constitutes one part. CERAD battery screens for cognitive functioning in nine domains: 1) language functions, 2) naming, 3) MMSE, 4) verbal learning (immediate retrieval), 5) copying, 6) delayed recall of a word list, 7) recognition of a word list, 8) delayed recall of images, and 9) clock drawing test (Hänninen, Paajanen & Kuikka 2015, 362-362). The acquired total score helps establish whether there is need for further examination, later assessment, or whether the person is not likely to have a memory disorder (Hänninen, Paajanen & Kuikka 2015, 366). As part of ETNIMU-project, we produced early stage memory assessment tests in Estonian and Russian: a memory assessment test for customer and the family questionnaire in Estonian, as well as the



MMSE assessment test in Russian. These and other assessment tests can be found on the website of the Society for Memory Disorders Expertise in Finland [Suomen muistiasiantuntijat].

Cognitive screenings, however, contain challenges when they are performed with ethnic minority individuals who come originally from highly different settings. The following challenges, for example, may come up during the screening:

- Poor language skills of the customer. The screening should always be conducted in the person's mother tongue.
- The jargon used in the screenings, as well as the predetermined wordings of the test may complicate the customer's comprehension. The questions are worded strictly, and the interviewer ought to follow through the guidelines, which means that she cannot, for example, respond to any clarifying questions.
- The concepts and terminology may have different meanings in the customer's culture of origin: do your questions have significance in your customer's life and culture, and is the customer familiar with them from before (Juva, 2016)? For example, with the Russian-speaking customers the question in the MMSE test "In which province [maakunta] are we?" may prove too challenging, because the customer may

not be familiar with the term province. If so, this will misguidedly lead to minus points (Suomen Alzheimer-tutkimusseura et al., 2017).

- The settings of the screening in which the customer is alone in a room with a stranger. The situation and the isolated settings may create difficulties with some customers from different cultural backgrounds.
- The rapidness of the screening: the time available for the test is limited. The meaning of time, however, varies between cultures, and in some cultures it may not be customary to hasten.
- Religious and cultural reasons, perception and experiences (ENIEC Suomi, 2014). For example, prayer times may prove a challenge during the screening.

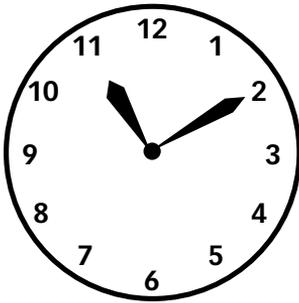
The same challenges should be considered also when you are dealing with the families of the ethnic minority elderly. Moreover, the screenings should be repeatedly yearly, in order to monitor for possible changes (Juva, 2016).

When you evaluate the results of the assessment tests, you should pay attention to several limitations. For example, the results in the MMSE assess-

ment test tend to correlate with age, culture, level of education, and social status. Education provides not only factual information, but it also improves cognitive function and collaborative skills, increases the skills to take different tests and helps to make sense of the test structure and the meaning of taking a test (ENIEC Suomi, 2014). Having limited or no education or work experience may affect, for example, the following:

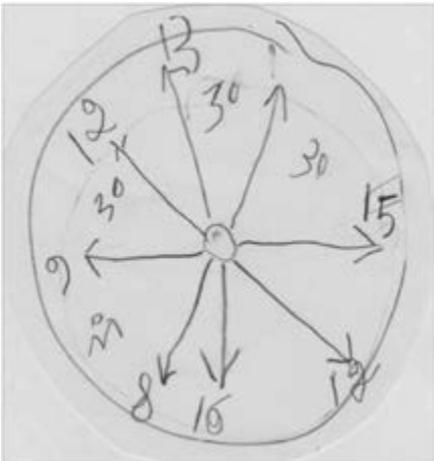
- Copying an image. Limited educational background may make it harder to draw images.
- Naming months. In many cultures months are named by serial numbers, which means that the logic is not consistent with the Finnish naming of the months.
- Categories. The customer must name as many words as possible in the same semantic category. This task may not be automatically clear for all customers.
- Numbers may have different lengths in different countries and languages.
- The verbal learning tasks may pose challenges.
- Drawing a clock may be difficult if the customer does not have sufficient schooling background, is not used to watches, or the time has no real significance in the customer's culture (ENIEC Suomi, 2014).

Ethnic minorities and the interpretation of memory problems: EXAMPLE OF THE CLOCK-DRAWING TEST

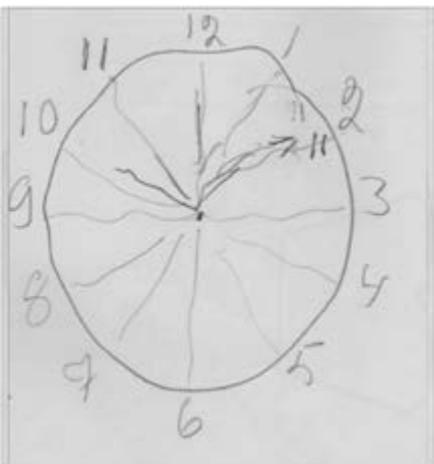


Kuvassa oikeaoppisesti piirretty kellotaulu.

In order to get the full six points in the clock-drawing test, which is part of the CERAD battery, you have to draw the following items into the clock: 1) the clock is more or less shaped as a circle, 2) the clock contains the numbers from 1 to 12, 3) the numbers are ordered correctly on the clock, 4) one of the clock hands points at the correct direction, 5) also the other clock hand points at the correct direction, and 6) the length of the clock hands is drawn correctly (only when each points at the correct direction) (Pulliainen et al., 1999 and 2011).



Clock drawn by a 57 year-old Somali woman who took part in the ETNIMU-project. The woman has not gone to school and she has been living in Finland for 18 years. In Somalia, the sense of time differs significantly from the Western concept of time.

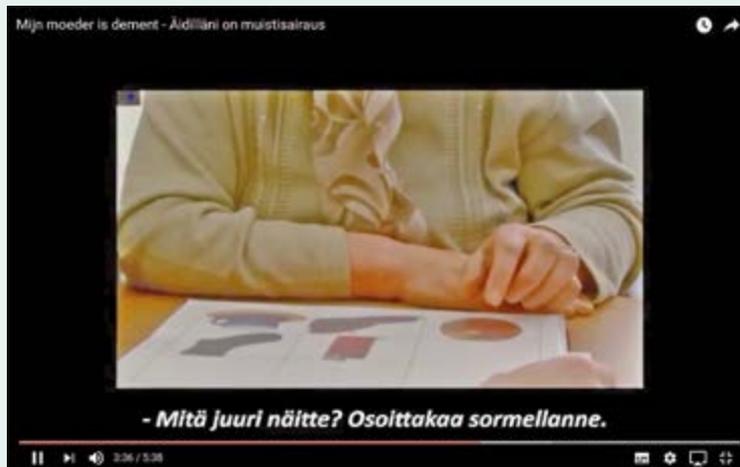


Clock drawn by a 75 year-old Roma woman who took part in the ETNIMU-project. According to her own words, she has assisted civic school but has never worked. The group leader, however, told us that the lady had assisted school for one year. Analphabetism provokes shame within the Roma people's group and may therefore constitute a reason to conceal that the person has not been schooled.

We knew that neither of the two women who did the clock-drawing test had problems with their memory. However, if you assessed the clocks drawn by them you could draw another conclusion. Therefore, whenever you conduct the task with ethnic minority elderly, you should always adjust the results with the cultural and educational background of the individual you are assessing.

During ETNIMU-project, we observed that although the current memory instruments and assessment tests are good, they may not always be the best possible tool to work with ethnic minorities. More personalized assessment tests that take into consideration linguistic differences, educational backgrounds and different cultural factors would help with the diagnosis of ethnic minority individuals.

In the Netherlands, the same conclusion was reached by a group of researchers who had been working with ethnic minority elderly; they mentioned that general assessment tests were not reliable with this target group. As such, the team developed a memory assessment test with contents that are as neutral as possible: this means that, for example, the images used in the assessment tests are not culturally bound.



In the image a Dutch woman of ethnic minority background is taking a memory assessment test that minimises culture-bound contents and takes into consideration, for example, the educational background of the assessed (Suomen muistiasiantuntijat ry, 2017). You can watch the short documentary My Mother Has a Memory Disorder by Ireen van Ditshuyzen about the development work in the Netherlands and memory disorders on the YouTube channel of the Society for Memory Disorders Expertise in Finland (Suomen muistiasiantuntijat ry).

The carers for ethnic minority elderly with memory disorders

When memory disorders progress and the functional abilities of the person deteriorate, the memory disorder touches also the lives of the person's family members. Due to the disorder, the personality and behaviour of the person start to change (Balabenkova 2012, 21).

The relationships between ethnic minority elderly with memory disorders and their family members may also be additionally burdened because, due to limited language skills, the elderly person may be dependent upon her family members (Linderborg & Jaakkola, 2012). In the ETNIMU-pro-

ject's group of carers, we noticed that the carers needed a lot of support and concrete advice to help them cope. During the meetings, we observed that when we tried to speak about how the carers could improve their brain health, the participants inadvertently changed the subject into the well-being of the elderly with memory disorders. The carers put their family members first and they appeared not to have the time to think about their own well-being. The project meetings, however, provided important moments of support, during which the carers could get answers to questions that puzzled them. One carer, for instance, had concerns about in how bad a shape should her mother be for her to become the official carer.



The image has been captured from a video by the Society for Memory Disorders Expertise in Finland (Suomen muistiasiantuntijat ry). In the video a Russian-speaking woman, who is also the carer for her mother with a memory disorder, tells about her experiences in Finland. You can watch the interview on the Society for Memory Disorders Expertise in Finland's YouTube channel (Suomen muistiasiantuntijat ry, 2017).

Experiences of a Russian-speaking carer in Finland

As a part of ETNIMU-project, we conducted an interview with a Russian-speaker, who acted as carer for her elderly mother with a memory disorder. The carer told about her experiences as an ethnic minority, non-native carer in Finland. She told that she had not had information about memory disorders until she had had to move away from her neighbourhood as a consequence of the behavioural changes that her family member went through, and the problems that had emerged with them. Eventually she had turned to a friend for advice who suspected Alzheimer and encouraged her to contact a doctor. The woman who ended up being her mother's carer had known nothing about being a carer. She describes the situation like this:

"I want to point out something very important: if we talk about the work that carers do, in Finnish the term carer defines your identity, it turns you into a carer. But in Russian there is no such word. Why not? Because in Finland there have always been

people like this. But in our home country, there were just children who looked after their parents. That was just the way things were."

According to the carer, the biggest challenges among ethnic minorities result from limited information and language skills. There are plenty of Finnish language materials but these are difficult to understand. There is need for information in different languages and this information should be distributed in places that are frequented by ethnic minority individuals, e.g. concerts or different kinds of meetings. According to the carer an ethnic minority person of her age might often be shy or timid, and for her to take the first steps to contact the health care providers might feel intimidating. Approaching services should be made as easy as possible.

ETNIMU-project produced information about brain health, memory and memory disorders



One of the aims of ETNIMU-project was to generate easy-to-read materials about the improvement of brain health, memory and memory disorders for ethnic minority elderly and their family members in their native languages. As a result, a set of three guides was created: Exercises to Activate the Brain 1 and 2, and Improving Brain Health!. The guides have been published in Finnish, Estonian, Russian and Somali. They have been designed to be used as a set that forms a well-rounded package of easy-to-understand theory and contains motoric and cognitive exercises. The set of the three guides can also be used to lead activities with groups of elderly people of different ethnic backgrounds, since the materials have produced so that they include as little culture-bound information as possible.

EXERCISES TO ACTIVATE THE BRAIN 1 -exercise booklet contains 22 coordination and concentration activities that seek to improve brain health, by working both the brain and different muscle groups together. The exercises begin easy, but gain more difficulty as you progress. The difficulty level can be increased by directing the movements towards different directions, or by including different body parts to the movements, e.g. by combining arms with leg movements. Exercises can be conducted sitting down or standing up.

EXERCISES TO ACTIVATE THE BRAIN 2 -exercise booklet contains 26 solving puzzles that activate the brain. The exercises suit well to leading groups and they can be used to lead discussions about different topics, work out word puzzles, or do activities by hands (e.g. colouring), or simply to add new types of activities to the group.

IMPROVING BRAIN HEALTH! -guide covers the essential topics about memory in a clear and easy-to-understand way. The guide is based on the course meetings that were designed and delivered through ETNIMU-project in 2015 and 2016.

Cultural sensitivity as a way of work

In ETNIMU-project, cultural sensitivity as a way of work was built upon the notion of acknowledging each individual's background and specific needs. The approach consisted of three steps: 1) reach out to the ethnic minority elderly, 2) engage with the elderly, and 3) build a relationship based on trust. In order for us to engage and to build trust with the ethnic minority elderly groups, we first had to find them and reach out to them. Cultural-sensitivity was, furthermore, supported by constant auto-reflection of our own work.

Reach out to the participants

Reaching out to the ethnic minority elderly is not easy, because given their backgrounds the people can easily be in a vulnerable position. Creating networks, forming contacts and collaborating with partners play a central role in the process of reaching out. Indeed, the biggest challenges during ETNIMU-project had to do with reaching out. The challenges included lack of mutual language, our unfamiliarity with the target cultures and the ethnic minority elderly's limited knowledge of services. Analphabetism also proved a challenge: for example, part of the Roma and Somali elderly participants in ETNIMU-project were analphabet. In addition, Finnish language contains many words and terminology that are not easily translated. Estonian and Russian, for instance, do not have corresponding words to express memory disorder [muistihäiriö] or engagement [kohtaaminen]. The fact that such concepts were foreign created a barrier for us during the process of reaching out, as the elderly we targeted did not necessarily realize that the subject matter had to do with them.

Easily understandable information about available services plays a key role in reaching out to ethnic minority elderly. Reaching out, however, may be challenging exactly because the ethnic minority elderly do not have sufficiently concrete information about the Finnish social and health care system, for example, which cases require medical attention and when (Törmä et al. 2014, 114). Also, the frequently used terminology in the Finnish health care system may be foreign to many. The concept of health promotion, for example, was foreign among

the Somali elderly women in ETNIMU-project, because in their country of origin they had been accustomed to physical work and to travelling from one place to another by foot, both of which had also kept their weight under control. During their time in Finland, many of them had noticed that their weight had risen because they had started to use public transport and consequently the amount of everyday exercise had reduced. When they learned that health promotion was a concept on its own, they had hard time understanding what was meant by it. In their culture of origin, healthy lifestyle had been built into many different activities and thereby required no special attention.

Moreover, mutually known figures and personas played a central role during the process of reaching out. This was something we had realized already during our previous work experiences, however, when we started ETNIMU the importance of this became even clearer. Employees at other associations, group leaders and active members in cultural communities were key in the process of reaching out to the project's target groups. Because of this, we decided at the start of ETNIMU-project that course meetings would be delivered in groups of ethnic minority elderly that were already up and running. In Helsinki, the Estonian and Russian-speaking groups, as well as the Russian-speaking carers' group had been active for years, and could be incorporated thanks to the earlier work experience of one of us, the project coordinator. The Roma people's group, in turn, was reached through the Finnish Roma Association.

In ETNIMU-project, also gender proved to be central in the process of reaching out. When we were planning the project, we had assumed, for example, that the Somali-speaking group would have both male and female participants. Our partners at Käpyrinne ry's Jade project, however, let us know that in Somali culture it was customary for men and women to act separately. The group of Somali elderly women was selected because Jade was already working with this group.

Throughout the course meetings we realized how significant gender was in terms of reaching out overall. Only the Roma people and the Russian-speaking carers' groups had active male

participants. In the Somali women's group, men would not take part because of cultural reasons, but in the other groups there was no such rationale. In spite of this, men's participation in the project ended up being minimal. We determined that reaching out to male participants would have required a different approach. We had, however, not taken this into consideration during the planning stages of the project, and on the other hand, we did not have the resources to start separate groups for men later on.

In addition to the Helsinki-based groups, ETNIMU course meetings were organized in the town of Kotka, which had been selected because of its large Russian-speaking population. We had assumed that there would be an up-and-running group for Russian-speaking elderly, but when the project started, we had to set up a new group. We had to adjust our original working plans, and to start looking for Russian-speaking elderly in Kotka by ourselves. In this task the teachers and students at the Eduhouse Vocational School, as well as the Kymenlaakso regional memory worker at Muisti- luotsi proved extremely valuable.

The challenges with reaching out continued onto our last year of the project. In Spring 2017 we tried to organize information events for group leaders that work with ethnic minority groups in cities where we did not have existing nets of collaboration. Over the phone, the meetings went fine and people showed interest. But at the day of the event no participants showed up. We thought that this had happened because we did not have personal contacts with the specific target groups. Personal connections can be of great help when you are creating the basis for engagement with ethnic minority groups.

Engagement

Engaging with the customer involves always acts of balancing between the customer's culture and her personal traits, life situation and history. The process of engagement starts within ourselves: it has to do with how easily we sense what is going on in other people's lives, and how well can we respond to what we see. We cannot simply state that a certain culture does not go with us - rather it might be that we do not get along with certain individuals. In familiar settings it is easier for us to sense individual traits and differences, whilst in more unfamiliar settings, everyone might appear to be the same. This is when you rely on skills that



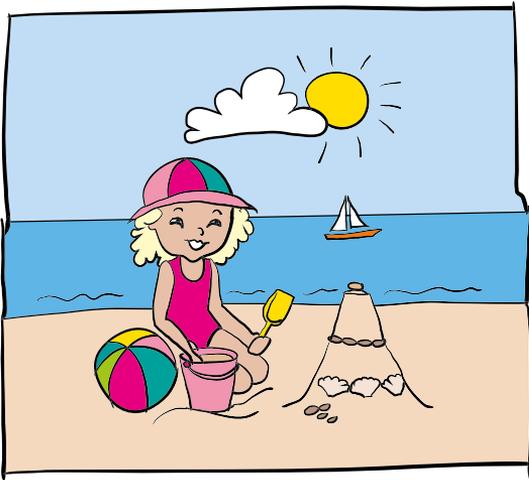
Above the original drawing that represents a Roma couple. On the right, the re-drawn image.

help you distinguish the person behind her group (Rönkkö, 2016).

During ETNIMU-project we realized that paying attention to different, even the seemingly small issues may play a big role when you engage with customers. For example, when the project started we had designed a project brochure that had drawings of couples of the different ethnic minority groups that would be involved in the project. The drawing that represented the Roma people portrayed a couple holding hands. The Roma group leader, however, told us that this would not be considered appropriate: too much intimacy would be linked with sexuality and shame. The image had to be re-drawn more culturally appropriate.

By engaging with the participants, we also learned about the importance of questions: by making questions in a respectful manner, we gained valuable insights into different cultures. We dedicated a lot of time to dialogue with the ethnic minority participants. We also paid a lot of attention to our tone of speech, gestures and expressions. The first meetings with the groups were a bit nerve wracking, however, because we were conscious of committing mistakes with cultural customs. For example, among the Roma people it is considered a taboo to talk about the body, and this was something that we had to take into consideration when planning the meetings. Before lunch, for example, it was not appropriate to refer to your stomach grumbling, as it would name a bodily function and a body part.

The guide booklets, generated as a result of the project, were designed and tested with the



The original image of one of the exercises that was going to be used in the group activities.

project participants. Doing so we received valuable feedback from different cultural minority groups about what was appropriate and what was not. For instance, one of the brain health exercises consisted of finding ten differences between images. The image showed a young girl playing at the beach. This image proved problematic; the Roma group leader told us that a girl in a bathing suit would be linked to sexuality and shame. The image had to be replaced in the Roma version of the booklet. To avert such cases, we delivered the course topics before each meeting to the group leaders, so that they could go through the materials and make comments in advance. Paying attention to details, asking for advice, and communicating openly proved great learning methods, as we could get information about the different cultures and avoid unintentional displays of disrespect.

Build trust

Trust is a significant factor for securing good outcomes and it is primarily built through interaction. If interaction and communication are rare, the sense of belonging and confidence suffer as a consequence (Vilkman, 2016). In ETNIMU-project, we started out with the group participants by collaborating with the group leaders - they were central in the process of building trust with the ethnic minority elderly. The group leaders provided a lot of important background information about differences between cultures, customs, religions and beliefs. For example, in many cultures it is

much more customary to show respect for elders than it is in Finland. With the Somali women's group also the interpreter was a valuable asset for us. The Somali interpreter could give us information about Somali beliefs, customs and other issues that we could learn only by interacting with Somali people.

In addition to the information you can receive from the group leaders, it might make sense to try to become familiar with the ethnic minority groups also through different routes. In some cases it might be important to know the history of different ethnic minority cultures. Some elderly people might have undergone trauma that should not be talked about. Being aware of such experiences in advance is important, so that you can make sure you will not hurt anyone unintentionally. However, you do not need to know everything about every culture in the world. Knowledge about customs, traditions and other issues is not at the core of cultural-sensitive work, but rather the willingness to ask and to engage with others. The work is about engaging with individuals with an open mind, not about working with or for a culture. Genuine interest is the foundation for relationships based on trust.

When you build trust with your customers, respect and time are fundamental. In ETNIMU-project, trust was built throughout the course meetings little by little, through listening, interaction and learning. When we learned new customs, we embraced them.

When you show respect, it is important to remember that you can and should always ask; there are no stupid questions! By asking about a person's background and culture, you also show interest in the other, and this helps in terms of building trust. When you do ask about the background and culture you should remember, however, to give the other person the option to choose whether or not, and when to answer - the other person has the right to decline if the question feels uncomfortable. It can also be polite to make this option explicit, for example, by phrasing your question with a simple "may I ask". The Somali women in ETNIMU-project, for example, encouraged us to make questions but they also said that although we could always ask, they might not answer. This demonstrates that we approached the Somali women with respect, and that they knew that they could choose to answer or to remain silent if they felt they could not confide in us.

The fact that we dedicated time to build relationships based on trust and respect paid off, in particular, with the Somali women and the Roma

people's groups when we wanted to take pictures during the course meetings. When trust increased, we were allowed to take pictures in these groups, but even then only when we confirmed individually with every participant. Some participants did not want to have their photographs taken, a wish we naturally respected.

In terms of trust, it is also important that you do not present yourself as superior to the group, but rather as equal with the participants. In one of the groups, the participants told us that they would not have stayed and listened to us and what we had to say, had our approach been more lecture-like. We also thought that the fact that both of us have our own migration experiences and are living in a foreign country helped to form trust. We both have moved from Estonia to Finland years ago. This formed shared ground for experiences and increased a sense of equity between us, the project workers, and the ethnic minority elderly, the project participants.

Auto-reflection

Auto-reflection proved to be another good working tool in ETNIMU-project. After every course meeting we would go through the meeting and write down the most important observations. We also took notes during the course meetings and wrote these down in an observation diary. This enabled us to analyze in retrospect what had happened in the groups, but also to reflect upon our own actions. So doing, we could also gain direct feedback from one another immediately after the meetings, which helped us to correct possible errors for the next time. It was also easier to come up with responses to the questions we had been made, as the events were still fresh in our minds. We also reflected upon our work with our other colleagues and the project's steering group. Collecting comments and thoughts from our project partners was particularly helpful especially in terms of our professional development.

Regular auto-reflection also helped us to become

How can you as an ethnic minority professional make the most of your background when engaging with customers?

- **LANGUAGE SKILLS.** Language skills help you communicate, but they also constitute a part of the feeling of belonging to the surrounding society.
- **SHARED HISTORY.** People who come originally, for example, from the ex-Soviet republics often share similar experiences. You can use these to look back to shared memories.
- **EXPERIENCE OF THE MIGRATION PROCESS.** Everyone has to go through the migration process in their new home countries. You can share experiences about this with others.

Because of shared traits and experiences it might be easier for you to identify with other ethnic minority individuals than with the majority population, even if the cultural backgrounds between you might be different. Two people who both belong to a minority group share at least the experience of coming from a different background than the majority population.

aware of certain challenges that we had with the groups. We noticed after a few course meetings, for example, that in some of the groups the group leaders had very strong roles. In the beginning, it was not clear for them what their roles would be in ETNIMU-project. We could remedy the situation easily by providing better instructions. Directing the ethnic minority elderly groups was also challenging from time to time: for example, in some groups we noticed while conducting motoric exercises that the participants had difficulties distinguishing the left hand from the right. We had to replace the terms left and right with other terms, such as, the window-side hand and the door-side hand. This change did not occur to us immediately, but rather we continued to refer to the left hand and the right hand even after several meetings. Conducting the same mistake over and over again, however, is not a sign of failure; changing the way you think is a learning and development process that does not happen overnight. Fortunately, conducting the course meetings over a longer period gave us the chance to improve our work methods, interaction and thought processes.

The importance of making questions became even more evident as some of our prior assumptions about the different customs were proven incorrect. This was something we realized as the courses progressed and we had our own auto-reflection meetings after the groups. The group meetings included an exercise in which the participants had to move newspapers from one participant to another using only their feet. We had been prepared that in the Roma people's group this exercise could pose some challenges due to reasons of hygiene (if something falls on the ground, it is considered dirty). Our assumption was proved wrong: the exercise entailed no problems in the Roma people's group. On the contrary, we had assumed that it would not entail any problems with the Russian-speaking groups. Some participants, however, declined to take part in the exercise because the newspapers happened to have a picture of the President. Having the newspaper on the ground and stumping upon it was considered degrading. Through mutual reflection, we concluded that although we might think we are familiar and understand the customs of some culture, we would always have to be ready to improvise and to question our beliefs.

A third important observation we reached through auto-reflection had to do with ethnic background and the ways in which it influences how



An image used on a slide show. We thought that the image would represent wellness and positive spirits.

people understand and interpret materials. This is something that should be taken into consideration when you are drafting the contents and designing the materials, as you should be prepared to adapt the materials to the needs of each group according to your abilities and resources. When we talked about well-being in the groups, we used an image of a dog on our slide show that we had chosen to express joy and well-being. Like us, the Roma people, and the Estonian and Russian-speaking elderly interpreted the emotion of the dog as something positive. In the Somali-speaking women's group, in turn, the dog was considered sad and agitated. This means that the backgrounds of both the professionals as well as the participants should be taken into consideration when you draft and deliver your contents. This has to do not only with your working materials, but with your approach, situations and interaction overall; people may interpret the same issue in different ways.

We considered auto-reflection to be a good tool in ETNIMU-project, as it enabled us to improve our work in the long run. If you only lead one course meeting, engaging in similar auto-reflection may prove too elaborate, but with activities that are realized over the course of ten meetings, for instance, already provide the opportunities for you to examine your own development in cultural-sensitive memory work.

The attitudes among professionals

Ethnic sensibility and awareness of your own ethnicity and prejudices

Being aware of your own ethnicity may prove challenging in settings in which you feel part of the masses. Regardless, every Finnish person has an ethnic background even when living in Finland.

A person who is not aware of different ethnicities and their traits might be ethnically blind. Such a person may not be aware that she too represents a specific ethnic group: it is an easy mistake to confuse ethnic groups with minority groups and to consider the majority population as “normal”. If so, the majority is thought to constitute the norm, and the minorities the exception. In Finland being Finnish is considered “normal” and thereby it might be something of which we are not aware. Often we become aware of own ethnicity only when we move abroad and notice that we are a part of an ethnic minority group. The Finns living in Sweden or Spain, for example, form ethnic minority groups who are aware of their ethnicity and have identities of an ethnic minority group. They identify within their group and also others define them as its integrants (Sarvimäki, 2015).

When we want to reduce prejudices it is critical that we first become aware of our own prejudices, because everyone has some. Becoming aware of your prejudices can be done, for instance, by taking part in reflective conversations within your work community, and/or by exposing yourself to experiences in which you are faced with difference. Prejudices can crumble also when people work together as a group towards a shared goal: establishing genuine, close contact with people you have prejudices about can be helpful. The settings in which you engage, however, should be positive and based on mutual respect and collaboration, not competition. In addition, you should have the chance to meet personally with the people you have prejudices about (Wahlström 1997, 102).

Social and health care professionals are often faced with customers from other cultures, and so they also have to face their own attitudes and prejudices. Sometimes also customers might have prej-

udices about the care staff (Oroza 2007, 441-443). The issue of prejudices came up through the ETNIMU-project meetings, as we noticed that we held prejudices about the different ethnic minority elderly. We had assumed, for example, that we could work with the Somali-speaking women in English, although none of the ladies spoke it. We had also assumed that the Somali-speaking women would have only little information about their health and the Finnish health care system. Our assumptions proved wrong, as the women knew a lot about both topics. On the other hand, we expected that working with Estonian speakers would be easy given our mutual backgrounds. We expected the participants to think the way we do about life in Finland. This proved not to be the case.

An ethnically sensitive employee is aware of her own emotions and feelings that may have to do with prejudices and fears. Such a person understands that she too has an ethnic background which affects the ways in which she perceives the world, what she considers as good or bad, and how she feels about others. Her value set has been built upon the culture in which she has grown up and lived her life. Ethnic sensibility is something that helps you understand how you and others behave as a part of your cultures. Cultural background, however, does not give special entitlements and we should not be expected to accept everything. Rather, behaviour should be adapted within the laws and regulations of the country (Sarvimäki, 2015).

Neither does ethnic sensibility mean that you should know your way around every possible culture or that every ethnic minority group should have their own system of care. Instead, it should give us the abilities to engage with elderly from different ethnic backgrounds. This means that you are aware of the ways in which ethnicity can shape different situations and you have the abilities to react to these. Ethnic sensibility requires some knowledge and an open attitude towards the world (Sarvimäki, 2015).

Respect and knowledge as work tools

According to an expert interview in a report by the Ministry of the Interior the health care system is focused on dealing with sickness and rather than approaching humans in a holistic manner its first and foremost interest is in diagnosis (Törmä et al. 2014, 218). The core principle of health promotion, however, emphasizes respect for human dignity, which in turn means giving time, being honest and present, and listening. It is also important that we do not simply pay lip service to the needs and wishes of our customers, but that we offer the customer the chance to influence her care. Critical for listening is the attitude: the professional should want to hear what the customer has to say and be able to acknowledge that the good of the customer is a central tenet of good professional care. Putting the plans and charts aside from time to time can help you hear what your customer has to say (Pietilä 2012, 245).

When you are working with ethnic minorities, all too often you also have to deal with discrimination. In order to eliminate discrimination, it would be important to share professional practices across the board. According to a research conducted by the Ministry of the Interior social and health care professionals would need more information about the different minority groups and their special traits and needs. Such special traits and needs include, for example, the fact that ethnic minorities may not have sufficient knowledge about available services, how different services work, and to what rights minorities are entitled (Törmä et al. 2014, 196-197). Often discrimination has also to do with poor sensitivity towards diversity. Normativities tend to govern the way we think, and so we assume that everyone has the same abilities. In the research by the Ministry of the Interior this became evident, in particular, in relation with the diffusion of information about care and services, and with service guidance: services are often designed so that they meet the needs of fully abled people. On a similar note, immigrants and ethnic minorities suffer as a consequence of the fact the Finnish majority culture is the reference for all services. Other cultures are barely considered (Törmä et al. 2014, 218).

From a professional point of view, however, it is important that we realize that culture-specific facts are not critical for successful care outcomes.

Professionals do not need know about customer's culture specifically, but rather have the understanding that the customer has a different perception of the Finnish culture and habits. When you, as a professional working with ethnic minorities, realize this you can provide the time and the space for your customer and adjust your approach to match your customer's knowledge and background.

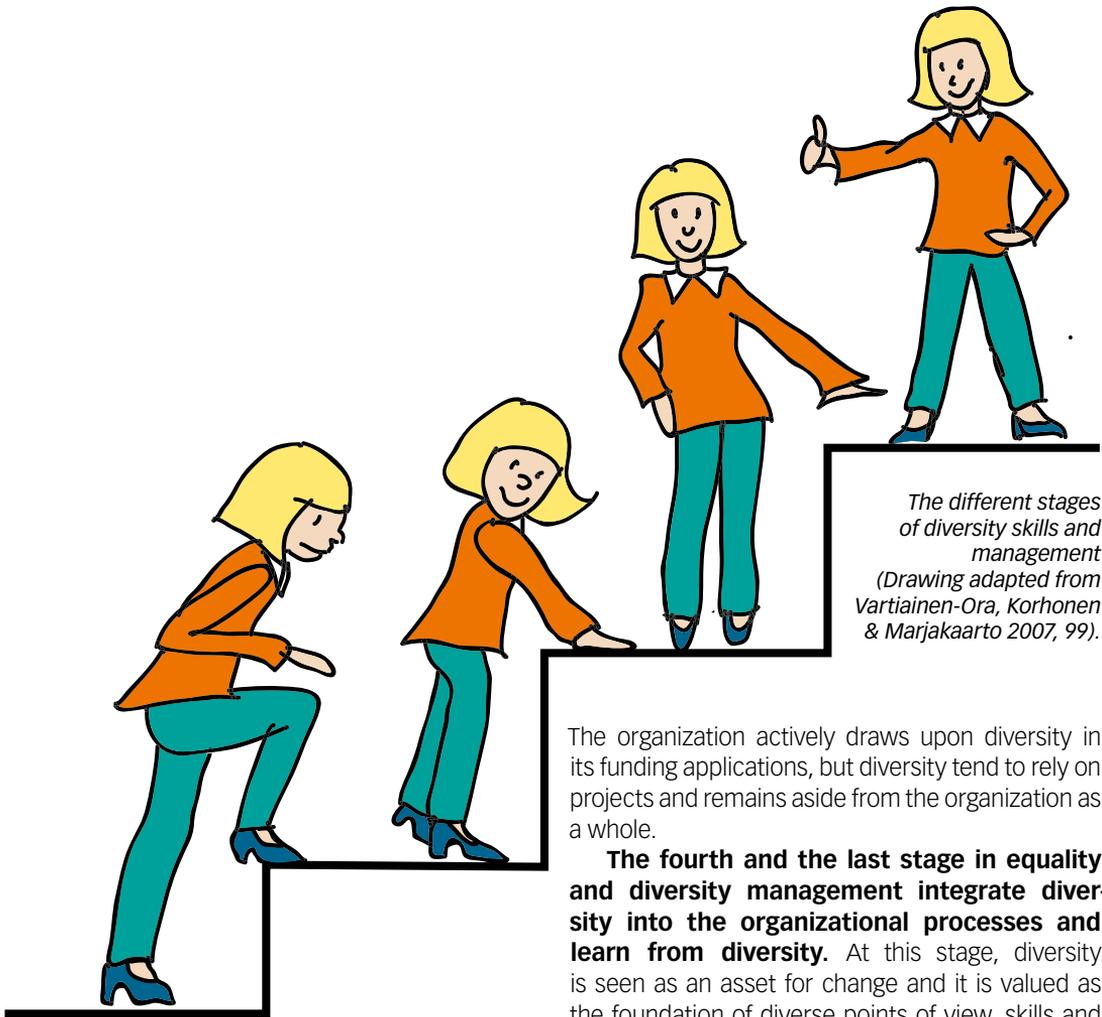
Diversity skills and management

Successful engagement with diversity and difference relies on ethnic sensibility from the part of the care workers, as well as from the managers and planners of elderly care services (Sarvimäki, 2015). They promote and enable the changes, and can so secure that the entire organization be committed to equality and diversity.

Equality and diversity management is a continuum that can be thought to consist of four stages. By examining these we can evaluate where our organization stands: what are we doing well, and where should we put more efforts.

The development of equality and diversity often starts in a situation, where people are against diversity. In the early stages of the process the majority tends to view minority support systems as unfair, and they fear that they could lose their own status. Diversity may be viewed as a threat to the organizational culture or simply as unnecessary. By standing against diversity, the organization may avoid the challenges that have to do with diversity but in so doing, it also loses out on the opportunities (Visti & Härkönen 2005, 13). In practice, at this stage Non-Discrimination Act is not followed and the organization has no diversity strategy. Multiculturalism may be mentioned in the documents as a term, but plays no role in reality. When dealing with challenges, the problems are placed where the customers, not in the organization's own actions.

The second stage in equality and diversity management has to do with the promotion of the legally required acts. In such cases the organization focuses on treating everyone the same and takes the diversity of its employees into consideration. The aim of equal treatment is to simply comply with the law. Differences are tolerated, but the majority still sets the norm. Different people are seen as representatives of a specific group rather



than as unique individuals; stereotypes get in the way of valuing individuality (Visti & Härkönen 2005, 13-14). At this stage, diversity is approached from the perspective of the organization. Diversity plan is at place, but old routines are kept alive. Diversity has not been addressed in the work communities and there is no monitoring or evaluation of the diversity plan.

The third stage in equality and diversity management has to do with taking advantage of diversity. Equality and diversity skills are used for marketing, sales and customer services, but different points of view, skills and experiences are not included in the work processes or aims (Visti & Härkönen 2005, 14). The organization values diversity as something important and it seeks to increase its services and activities for different minority groups. The minorities, however, are the targets rather than active actors in the process.

The organization actively draws upon diversity in its funding applications, but diversity tend to rely on projects and remains aside from the organization as a whole.

The fourth and the last stage in equality and diversity management integrate diversity into the organizational processes and learn from diversity. At this stage, diversity is seen as an asset for change and it is valued as the foundation of diverse points of view, skills and experiences. The organization learns from diversity, and it enables the organization to question its existing patterns of behaviour and thought processes (Visti & Härkönen 2005, 14). At the last stage the organization has clear strategies that are monitored and evaluated. Employees are trained to deal with diversity and develop cultural sensitivity skills. The standard activities serve the majority and minorities, and new opportunities are explored. The organization values the skills of its ethnic and other minority employees, and the recruitment criteria includes diversity. The organization is also in contact with different diversity networks.

When you start diversity and equality work in your organization you should notice that work communities may contain conflicts of interest, fears and other difficult emotions. These are humane and part of the deal, and denying them makes it more difficult for you to start out discussions and to tackle the issues at hand. Indeed, the biggest

challenges for equality and diversity are attitudes. When we speak about equality the first reaction may be, for example, that we don't have problems with the subject matter. Acknowledging the fact that there might be problems may be perceived as threatening, for example, because of fear of change. By offering information about equality and diversity you can start the discussion and increase awareness of the situation. The situation in your organization can also be evaluated through discussions or in the light of data that can help you identify what the developmental needs are (Visti & Härkönen 2005, 38-39).

Suggestions to support cultural sensitivity in work

Once you have figured out the developmental needs, concrete tools and instruments that help you change the situation are invaluable. The Ministry of the Interior has gathered a comprehensive list of suggested improvements for the social and health care services. The list of improvements is based on the research upon experiences of discrimination that different minority groups have enclosed, but they can be generalized also more broadly to cultural sensitivity in work.

The first suggestion for improvements states that the implementation of the Elderly Care Act should be monitored. Specifically, in the implementation and monitoring of the Elderly Care Act, attention should be paid to the diversity and equality of the elderly population, to the equality of services, as well as to the status and non-discrimination of different minority groups (Törmä et al. 2014, 225). If the official law is followed, also the quality of care and its criteria are ensured.

The suggestions also mention building more customer-centric social and health care services,

dialogue, customer participation, care plans for customer work, diversity plans, and simple feedback systems (Törmä et al. 2014, 225). The suggestions above are already quite detailed procedures and enable organizations to choose one that they can adapt the best they see fit. The underlying idea is that the customers are heard and listened to already during the planning stages.

The basic and complementary education in social and health care should also cover contents about different minority groups, including information about interpretation services, different cultures, disabilities, and sexual and gender minorities. The essential point is not about increasing the level of facts, but rather increasing information about which sources can help you get further information and where can you look for help (Törmä et al. 2014, 225). Using people who have personal experiences as experts and trainers can also be used as methods to increase awareness about different cultures and minority groups. Expert visits could be included in education, as it helps students to create links with different minorities also after they have left studies and started work life. Acknowledging diversity and seeing people in a holistic manner would be important in social as well as in the healthcare sector (Törmä et al. 2014, 196-197). As a part of ETNIMU-project we collaborated with Metropolia University of Applied Sciences where the project manager gave lectures about memory work with ethnic minorities.

Also media and individual actors have the responsibility to increase factual information about minorities and to address cases of discrimination (Törmä et al. 2014, 196-197). Similarly other actors who operate with public funds, such as NGOs and other organizations that generate materials for different target groups, can be considered responsible for increasing factual information.

Final words

An ethnic minority elderly person with a memory disorder is in some ways similar whilst in others, she differs from a customer from the majority population. Memory disorders progress the same way, regardless of the cultural background of the person, whereas, the perception of the disorder, how it is talked about, and how it is treated may differ greatly between cultures. During your appointment with an ethnic minority elderly person you will encounter challenges that should be considered, such as the customer's cultural background, language, the cultural-bounded nature of the assessment tests and the customer's educational background. All of these should be considered when you interpret the assessment tests' results.

Cultural sensitivity in memory work with ethnic minority elderly includes some core steps that consist of reaching out, engagement, dialogue, building a relationship based on trust, and constant reflection of your own work. Such an approach is always built upon empathy. The attitudes among social and health care professionals are essential to secure positive care outcomes - cultural sensitivity is needed both at the practical, as well as at the management level. Moreover, for you to become aware of your own prejudices and be able to develop your attitudes, knowledge and respect

for human dignity are fundamental.

On a more general note, you should also notice that cultural sensitivity cannot be hastened - time is what an ethnic minority elderly person mostly needs. As social and health care professionals we should try to find patience and pause for a moment.

Another core tenet of cultural sensitivity in memory work is that it cannot be done alone. Finding key people and partners in whom you can confide plays an extremely important role. Collaboration may stop and trust that was once built may break down if you do not have those key people.

A third matter worth reminding is that the observations and experiences we have shared here are based on our experiences with ETNIMU-project and the groups that took part in it. As such, the observations should not be used to generalize minority groups overall: the project participants do not represent their entire groups, countries or nationalities.

When cultures meet, you do not have to know as much as possible about every different culture, but rather you should be open to making questions and listening. A lot depends on your attitude and in your disposition to do long-term groundwork to build trust with the ethnic minority elderly individuals.



Finally, it is important to remember that although we too had drafted careful plans for the course meetings, we also committed mistakes. You should not be afraid of mistakes but rather try to remember to be forgiving with yourself. Paraphrasing the words of encouragement that the Roma people gave to us: "be brave and go ahead!"

Our deepest gratitudes

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